Right Place, Right Time

IMPROVING ACCESS TO HEALTH CARE INFORMATION FOR VULNERABLE PATIENTS

Consumer Perspectives

ALTARUM INSTITUTE
SYSTEMS RESEARCH FOR BETTER HEALTH

OLIVER WYMAN

Robert Wood Johnson Foundation

RIGHT PLACE, RIGHT TIME

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For more information about Right Place, Right Time, visit: www.altarum.org/RightPlaceRightTime

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EXECUTIVE SUMMARY

When and where do consumers seek out health care information?

What special barriers do vulnerable consumers face seeking health care information?

How can health care information be made more accessible and useful?

Consumers have an increasing responsibility for understanding their own health care, but health care information is often complex and difficult to understand. **The Right Place, Right Time project investigates how vulnerable consumers search for and use health care information, and how that information can be made more useful and accessible.** This report focuses on the needs of lower-income consumers, Medicaid beneficiaries, the uninsured, caregivers, and Spanish speakers, and **how health care information can be delivered at the right place and right time to maximize consumer value.** A complementary report* explores similar issues from the perspectives of payers, providers, and other health care marketplace organizations.

Our survey results find that most consumers seek health care information from providers, friends and family, and online searches. Of all information types, **consumers are most dissatisfied with health care cost information.** This is especially true for lower-income and uninsured consumers. Consumers believe **online booking, easy comparisons of procedures and facilities, and plain language explanations** would be especially useful improvements to their health care experiences. Consumers' views on health care information differ significantly based on income level, insurance status, and caregiver status; these differences can guide future decision-making on how best to provide vulnerable consumers with the information that they need. This report includes detailed results by consumer demographic group and by different patient decisions, such as how consumers seek information when deciding if care is needed, or when deciding where to seek care, choosing a doctor, or using online resources.

METHODOLOGY

Altarum Institute conducted this research with support from the Robert Wood Johnson Foundation and Oliver Wyman. **Altarum Institute conducted interviews and focus groups with 65 consumers and a nationally representative mail and web survey of 4,068 consumers**, fielded in June through August, 2016. Results are weighted to be nationally representative based on US census demographic characteristics. Detailed methodology, including specific survey questions, responses, and definitions, is available at the end of this report. The anonymized dataset from the Right Place, Right Time survey is available online at www.altarum.org/RightPlaceRightTime

* Right Place, Right Time: Health information and vulnerable populations, Oliver Wyman http://www.oliverwyman.com/our-expertise/insights/2016/jun/oliver-wyman-_-altarum-institute-study.htm

SUMMARY OF RESULTS

KEY FINDINGS

Key Finding 1: Consumers demand cost information and mobile-friendly websites

- About 50% of consumers are not satisfied with the availability of health care cost information. Lower-income consumers are significantly more dissatisfied than middle-income consumers.
- 94% of consumers under the age of 40 use their mobile phones for internet access most days or every day, and for many, mobile phones are their primary source of internet access. Consumers report that mobile-friendly websites are more accessible than mobile apps.
- Across all health care information types (e.g. cost, quality, treatment information), frequently consulted sources include asking providers, searching online, visiting specific health websites, and asking friends and family.
- Lower-income patients are less likely to consult all types of health information.

Key Finding 2: Consumers prioritize improvements to information about cost of care, accessibility, and comparisons

- Consumers' top priorities for improving their health care experiences overall are having the ability to easily see costs before a visit, and having more doctors covered by their insurance.
- The uninsured especially prioritize seeing costs before a visit (71%), while Medicaid beneficiaries and Spanish speakers prioritize more doctors being accepted by their insurance (64%) and (59%).
- Consumers report that services they would find especially useful are easy online booking; easy comparisons of procedures and facilities, including price and quality; and plain language explanations.

Key Finding 3: Caregivers use the most health care information but struggle to find resources to help themselves

- Caregivers, especially of children with complex medical needs, are superusers of health care information tools. They rely on information resources at double to triple the rate of non-caregivers.
- Caregivers feel overburdened and stressed; 16% of caregivers of adults rate their stress as "10 out of 10" while 24% of caregivers of children with complex medical needs rate their stress as "10 out of 10." This is double and triple the rate for non-caregivers, respectively.
- Lower-income caregivers find information about caregiver resources much more difficult to access than middle-income caregivers. Information on financial support is 67% more difficult to find for lower-income caregivers.

Key Finding 4: The uninsured report greater difficulty accessing health care information

- The uninsured are the least satisfied (70% dissatisfied) with cost of care information.
- The uninsured are less likely to search for all types of health information, including general information on managing health.
- The uninsured's top sources of information on insurance are friends and family, followed by healthcare.gov.

Key Finding 5: Spanish speakers struggle with language barriers, and rely on friends and family to offer advice and remedies

- Language, education, and culture can be barriers to receiving medical care. Spanish speakers may be new to American health care concepts as well as the English language.
- Feelings of shame may prevent some Spanish speakers from requesting Spanish language resources. Making Spanish language information available without requiring a request can make information more accessible.
- For Spanish speakers, friends and family are especially important sources of health care information, and are considered to be as accurate as medical websites like WebMD or Mayo Clinic. Spanish speakers are twice as likely to believe in the accuracy of friends and family (42%) as English speakers (22%).
- Spanish speakers often have relatively high trust in health care information, including information from doctors, insurers, friends and family, employers, documentaries, social media, and may be more receptive to health information through advertisements, social media, or television. Trust in accuracy for Spanish speakers is often twice as high as for English speakers.

Key Finding 6: Patients who feel disrespected by providers are less likely to trust health care information or follow medical advice

- Many consumers feel disrespected by providers, especially the uninsured (32% feel disrespected), those who are in poorer health (22% feel disrespected), and those with lower incomes (18% feel disrespected).
- 35% of lower-income consumers who are in poorer health with private insurance feel disrespected by providers.
- Consumers who feel disrespected by providers are three times more likely to not believe doctors are accurate sources of information than consumers who do feel respected.
- Consumers who feel disrespected by providers are twice as likely to not be adherent to their medication protocols. Diabetics who do not feel respected are one third more likely to have poorly controlled diabetes than diabetics who do feel respected by providers.

CONSUMER DECISIONS

When and where to seek care

- When deciding *whether* to seek care, consumers most commonly seek information from the internet. When deciding *where* to seek care, friends and family are the most commonly used source of information.
- When choosing between urgent care clinics, consumers place little value on information compared to when they are choosing between primary care physicians, retail clinics, telemedicine services, or emergency departments. Consumers may not view urgent care clinics as being meaningfully different from each other.
- Across all health care visit types, consumers value cost information the most when researching retail clinics. Additionally, when seeking information about retail clinics, consumers place little value on insurance acceptance. This suggests consumers may see retail clinics as more of an economic transaction than other care types.
- When deciding where to seek care, lower-income consumers are especially likely to value cost information. Middle-income consumers place more value on quality information.

Choosing a doctor

- Referrals from friends, family, and providers are the most important sources of information when choosing a new doctor, followed by online patient reviews.
- Consumers are more likely to value patient reviews of providers rather than reviews of facilities.
- Lower-income consumers are more likely to find reviews unintentionally while searching for other information on the internet. Middle-income consumers are more likely to intentionally search for patient reviews.
- While only 42% of consumers overall say they have used online patient reviews of doctors, of those that did, 83% say it influenced their choice of doctor. This suggests reviews will become more influential as more consumers use them.
- More than half of middle-income patients under the age of 50 use online reviews to choose doctors.
- When choosing a doctor, consumers consider provider respect and shared decision making to be just as important as a doctor's professional skill, but say information on respect and shared decision making is especially difficult to find.

Comparing treatment options and staying healthy

- When looking for information about treatment options and staying healthy, consumers tend to search online and ask their providers more than asking friends and family.
- Consumers consult pharmacists for general health information as frequently as they consult nurse hotlines.
- Lower-income consumers are slower to consult all health information resources once a health issue arises compared to those with middle incomes.
- Lower-income consumers are more likely to look for information about how to know if a condition is getting worse and to look for cost information than middle-income consumers.
- Consumers are mostly unaware of cost and quality comparisons of procedures or facilities and rarely search for them, but indicate these comparisons would be very useful.

Online consumer resources: patient portals and online appointment booking

- Consumer satisfaction with patient portals is relatively low, with only 29% being extremely satisfied.
- The patient portal features consumers value most include lab and imaging results, visit summaries with instructions, visit notes from an appointment, prescription refill requests, billing details, and online booking.
- Many consumers are not aware of the ability to book appointments online.
- Demand for online booking is high, especially among younger and middle-income patients.

IMPLICATIONS

Financial transparency is a top patient priority

Consumers consistently rank clearer patient cost information as their top priority for improving health care overall. This is especially true for lower-income and uninsured consumers. **Providing greater patient cost transparency should be a top priority for all health care stakeholders, including payers and providers.**

Consumers want simpler, more direct health care language

Many consumers are frustrated with the complexity of health care information, both medical and administrative. Information must be presented simply to be accessible. **To give patients control over their health care choices, provide simple explanations alongside more complex information.**

Consumers want mobile-friendly information

Many consumers rely on mobile phones for internet access, especially if they are lower-income, young, or racial minorities. **Make web resources mobile-friendly to ensure maximum accessibility. Consumers find mobile-friendly websites more accessible than apps, which they use infrequently.**

Consumers want quality information, but aren't using comparison tools

Consumers rarely search for formal quality comparisons, but they do seek out informal quality information through online patient reviews and referrals from family, friends, or providers. **Consumers are rarely aware of official quality comparisons, such as safety or patient satisfaction ratings.** This is especially true for lower-income consumers. **Stakeholders can better provide comparisons at the right place and right time to support patient decisions. For example, a health plan could send quality comparisons of providers and facilities to a patient before an upcoming procedure.**

Caregivers are superusers of health technology, but need more support

Caregivers, especially caregivers of children with serious medical needs, make heavy use of portals, apps, and other information resources, but struggle to find resources for themselves as caregivers, and are at risk of unsustainably high levels of stress. **Help caregivers by including information about caregiver resources, tools, and support in the clinical workflow.**

Friends and family are key health care information sources

Among some consumers, friends and family are go-to sources of health information. The uninsured use friends and family to learn about insurance, and Spanish speakers rate friends and family to be just as accurate as medical websites. **To reach the uninsured, Spanish speakers, and other groups, payers and providers should communicate directly through social networks and community organizations, such as schools, churches, and employers.**

Spanish speakers are reluctant to ask for resources in their language

Some consumers who do not speak English as their primary language may be hesitant to make a special request for resources in their language. If not offered outright, these consumers may seek out a different care provider who supports their language more directly. **Payers and providers can make health information more accessible by providing alternate language resources without requiring Spanish-speaking consumers to specially request them.**

Patient-provider relationships are paramount in health care

Uninsured, sick, and lower-income patients are much more likely to feel disrespected by doctors than their peers. Good patient-provider relationships are not just part of good bedside manner; perceived respect has a strong correlation with whether patients trust doctors to be accurate and whether patients are adherent to their medications. **Positive patient-provider relationships should be considered a medical priority, and should be encouraged through training, education and, potentially, compensation changes.**

Patients seek clues to provider warmth through online patient reviews and provider pictures

Patients value providers treating them with respect, but information about provider respect can be difficult to find. When personal referrals are not available, many patients turn to online reviews and pictures of providers to gauge a provider's bedside manner. **Ensure provider descriptions, pictures, and videos communicate warmth and respect.**

These implications can have a significant impact on how healthcare stakeholders should think about engaging all consumers, and especially vulnerable consumers. Specific implications and recommendations are included throughout this report and in summary at the end of the report.

Key Findings

KEY FINDING 1

Consumers demand cost information and mobile-friendly websites

HIGHLIGHTS

- In general, **lower-income, uninsured, and sicker consumers** are **less satisfied with health care information**, and **consult fewer sources of information** compared to middle-income, insured, and healthier consumers.
- When considering the availability of many health care information types, **consumers are most dissatisfied with cost information**, especially lower-income consumers.
- For many lower-income consumers, **mobile devices are the primary source of internet access**, but many health care websites are not mobile-friendly.
- **The top sources for health care information are providers, web searches, clinical websites, and friends and family.**

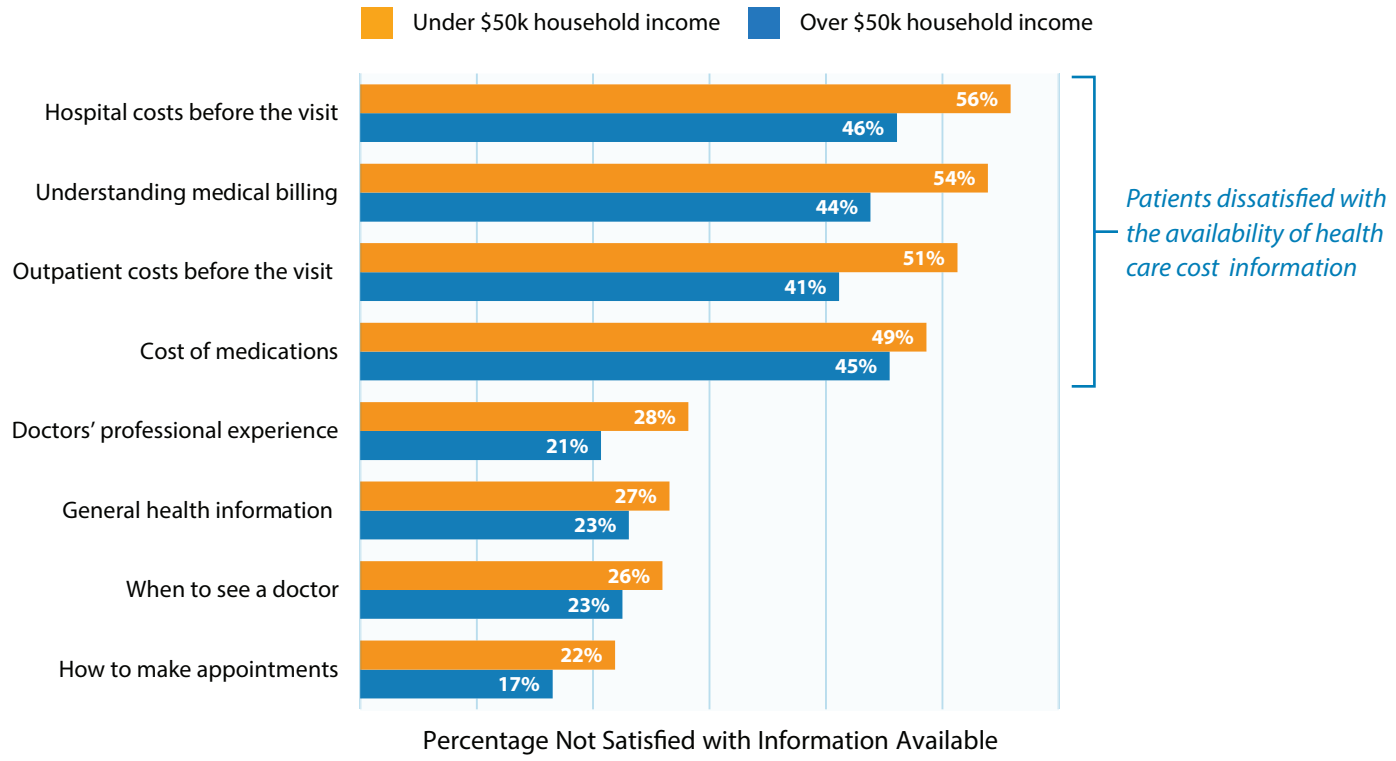
BY FAR, PATIENTS LEAST SATISFIED WITH AVAILABILITY OF COST OF CARE INFORMATION.

In our interviews, many consumers expressed their frustration with different aspects of the health care system, and with seeking out health information. To better understand national consumer sentiment, we surveyed consumers about their satisfaction in accessing nineteen types of information. **Overwhelmingly, consumers of all types are most dissatisfied with the lack of transparency for health care cost information.** This includes medical billing information (53% not satisfied), hospital costs before a visit (49% not satisfied), cost of medications (46% not satisfied), and outpatient costs before the visit (45% not satisfied). **Lower-income consumers are even less satisfied with the availability of health care cost information** than middle-income consumers.

Consumers are generally satisfied with the availability of many other types of health care information, such as information about how to make appointments (only 19% not satisfied), when to see a doctor (24% not satisfied), a doctor's professional experience (24% not satisfied), whether insurance is accepted by a doctor (25% not satisfied), and general health management information (25% not satisfied).

FIGURE 1.

Consumers Most Dissatisfied with Availability of Cost Information



NOTE: 95% Confidence interval is ± 2–3%. Variables include Q12_* by xLowIncome.

CONSUMER VIEWPOINT ON COST OF CARE INFORMATION

"Nobody told me [about the cost of care.] I don't know specific information on what they cover, what they don't cover. I also found out they didn't cover the anesthesia, the gas that I wanted, they only covered the shot so I had to pay out of pocket for that, which was fine, but I would have been more prepared if I knew before I came in this is what they cover and this is what they don't."

— Lower-income mixed-race woman in her 20s, Medicaid, Michigan

IMPLICATION

Confusion about cost of care is often the greatest source of consumer frustration. Making costs clear and accessible before they are incurred may promote patient satisfaction.

MOBILE IS KING.

Recent surveys by Pew[1] indicate that for a growing segment of the population, mobile phones are becoming the primary source of internet access, with 24% of lower-income smartphone owners relying on their phone as their primary source of internet access. Pew found this trend especially prevalent for people who are young, belong to a racial minority, and/or are lower income. Interview participants emphasized the importance of mobile internet access; **many young lower-income consumers estimated 90% to 95% of their internet access occurred through a mobile device rather than a computer**. However, mobile internet usage is less common with older consumers. While 94% of consumers under 40 report using mobile internet almost every day, only 36% of those over 75 use mobile internet regularly. **Making health care information mobile-friendly is essential to reaching consumers under 50.** Notably, Pew[2] also reports that 13% of Americans do not use the internet at all. This group tends to be lower income and over the age of 65. Offline resources are needed to reach this segment of consumers.

CONSUMER VIEWPOINT ON MOBILE INTERNET USE

Interviewer: *Thinking of friends and family, what proportion of their online searches do you think are on a phone versus a computer?*

Participant 1: *Like 90%.*

Participant 2: *I would say 95%.*

Participant 1: *Nobody uses their computer anymore. [Laughter]*

Participant 3: *[Nodding]*

—Lower-income Black women in their 20s and 30s, Medicaid/Uninsured, Michigan

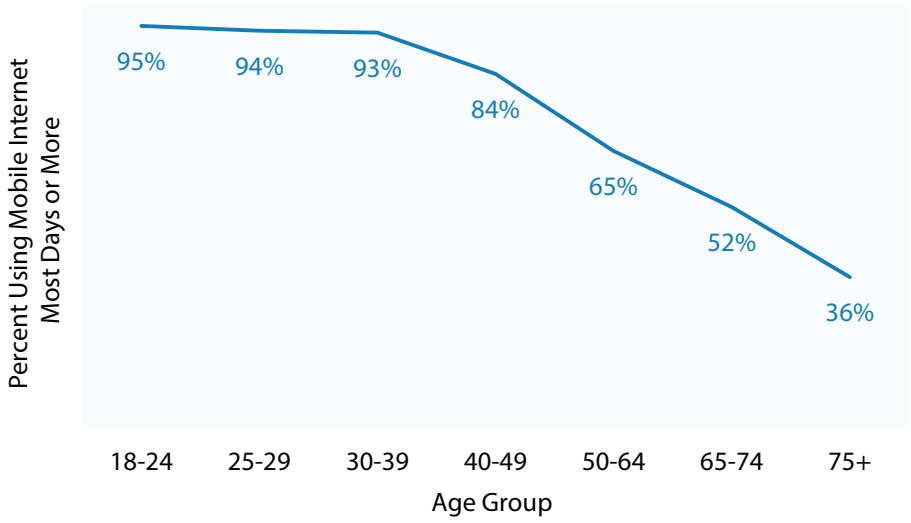
CONSUMER VIEWPOINT ON MOBILE INTERNET USE

"I don't even have a computer for real. I have my phone like a computer."

—Lower-income White man in his 20s, Uninsured, Washington, DC

FIGURE 2.

Mobile Internet Use Almost Universal for Consumers Under 40



NOTE: First three age groups are not significantly different (ages 18-39).
All other comparisons are significantly different, $p < .001$. Variables include Q7 by xAge7.

When websites or online tools are not formatted to mobile devices, they can become inaccessible to many consumers. Several focus group and interview participants were frustrated with websites that were not mobile-optimized. In these cases, many participants would either give up searching for information or call a phone number to find the information. Because of this, **mobile-incompatible websites can generate unnecessary phone call volume** when consumers are unable to find the information they need online.

CONSUMER VIEWPOINT ON MOBILE ACCESSIBLE WEBSITES

"One of the things on the Medicaid website, it's not formatted to fit your screen, so every time you enter a letter, it pushes over to one side of the screen, you've got to keep scrolling. So I just got frustrated and called and got the same information."

—Lower-income mixed-race woman in her 20s, Medicaid, Michigan

IMPLICATION

To better reach consumers, ensure online information is mobile-friendly. Mobile-friendly websites are much more accessible than apps, which require specific devices and must be downloaded and updated.

MOST FREQUENTLY USED HEALTH CARE INFORMATION SOURCES ARE PROVIDERS, THE INTERNET, AND FRIENDS AND FAMILY.

For different health care decision types, such as understanding how to manage general health or comparing specific treatment options, consumers rely on a few primary information sources: **providers, general web searches, specific health websites, and friends and family**. Consumers consult these sources first, consult them most frequently, and rate them as their most important sources. Information sources that consumers consult less often include government websites, insurers, advertisements, employers, apps, and social media. There are some exceptions to this broad trend; for example, www.healthcare.gov is rated as a frequently checked source of information about insurance for the uninsured. The exact results for each health care decision type are described in later sections of this report.

HEALTH CARE INFORMATION SOURCES

MOST USED

1. Providers
2. Searching online
3. Specific health websites
4. Friends and family
5. Government websites
6. Insurers
7. Employers
8. Advertisements
9. Apps
10. Social Media

LESS USED

CONSUMER VIEWPOINT ON WEB SEARCHES

"I think Google is a good venue for you to go to for information. It gives you questions that you can bring to your provider that she normally probably wouldn't give for the 15 minutes you'll have alone with your provider. I think that it does give you questions to bring to them because you don't know. It arms you with information for you to know yourself and you can get a second opinion or whatever about that information. You'll know more about the medication, you'll know more about the side effects, and you know more options."

—Lower-income White caregiver in her 50s, Medicaid, Illinois

CONSUMER VIEWPOINT ON CLINICAL WEBSITES

"When I'm sick, I go to WebMD to get some ideas. They give you a lot of different options for your symptoms, but I try to narrow it down. If I do that, then I'll see the doctor."

—Lower-income White man in his 20s, private insurance, Virginia

CONSUMER VIEWPOINT ON FINDING INFORMATION ABOUT DOCTORS

"I'm asking friends and then asking around, 'Who do you go to?' Word of mouth, that's got a lot to pull. 'So and so is like this and they're really good, they try to get to know you.' "

—Lower-income White woman in her 50s, Medicaid, Michigan

SUMMARY

- In general, **lower-income, uninsured, and sicker consumers are less satisfied with health care information** and **consult fewer sources of health information** compared to middle-income, insured, and healthier consumers.
- Consumer **cost information is the least accessible information type**, especially for lower-income or sick patients.
- Mobile devices are the primary source of internet access for many individuals, but are not as common for patients over 50.
- **Most frequently used health care information sources include providers, internet searching, and friends and family.**

Further Reading: US Smartphone use in 2015, Pew Research Center
http://www.pewinternet.org/2015/04/01/us-smartphone-use-in-2015/

KEY FINDING 2

Consumers prioritize improvements to information about cost of care, accessibility, and comparisons

HIGHLIGHTS

- **Consumers' number one priority for the health care system overall is greater cost transparency.** Other top choices include having more doctors covered by insurance and providers placing a greater focus on overall patient wellbeing.
- When given the choice for how to improve existing health care *information*, **consumer's top priorities are to improve information about doctors' professional experience, information about cost, and insurance acceptance.**
- Consumers would like **easy online booking options, easy procedure comparisons, and plain language explanations.**

THE MOST IN-DEMAND IMPROVEMENTS IN HEALTH CARE: COST INFORMATION, ONLINE BOOKING, AND WIDER INSURANCE ACCEPTANCE.

We asked survey respondents about eleven overall improvements to the health care system, which were selected based on patient input during earlier interviews and focus groups. Importantly, these improvements cover all aspects of health care, and not just health care information. Above all, our results find consumers prioritize the **ability to see costs before a visit**, selected by 58% of respondents. **Costs are especially important to the uninsured**, selected by 71%. **Medicaid beneficiaries and Spanish speakers' top priority is having more doctors accepted by their insurance** (64% and 59%). **Updates to clinic buildings, which are often cited as a competing expenditure by providers, are among the lowest-priority improvements**, recommended by only 25% of respondents.

Other high priority improvements include easy online booking and more providers that accept a patient's insurance. Consumers earning more than $50k annually per household are more likely to prioritize online booking (52%), and patients earning less than $50k per household are more likely to prioritize more providers accepting their insurance (60%). **Patients who are in poorer health prioritize doctors focusing on overall well-being, rather than treating a specific condition** (60%). Consumers earning less than $50k also prioritize a focus on overall well-being (54%). **Among those who speak Spanish as their primary language, 45% rank resources in their language as a top priority.** Figure 3 shows the overall top three consumer priorities for improving health care and how different types of consumers value these improvements. Scores for all 11 consumer priorities are shown in greater detail on page 80.

CONSUMER VIEWPOINT ON COST TRANSPARENCY AND EASY COMPARISONS

"Why isn't there a list of what different hospitals charge for a hip replacement, and you can just choose which one you go to? Why does that not exist? Why is it such a mystery?"

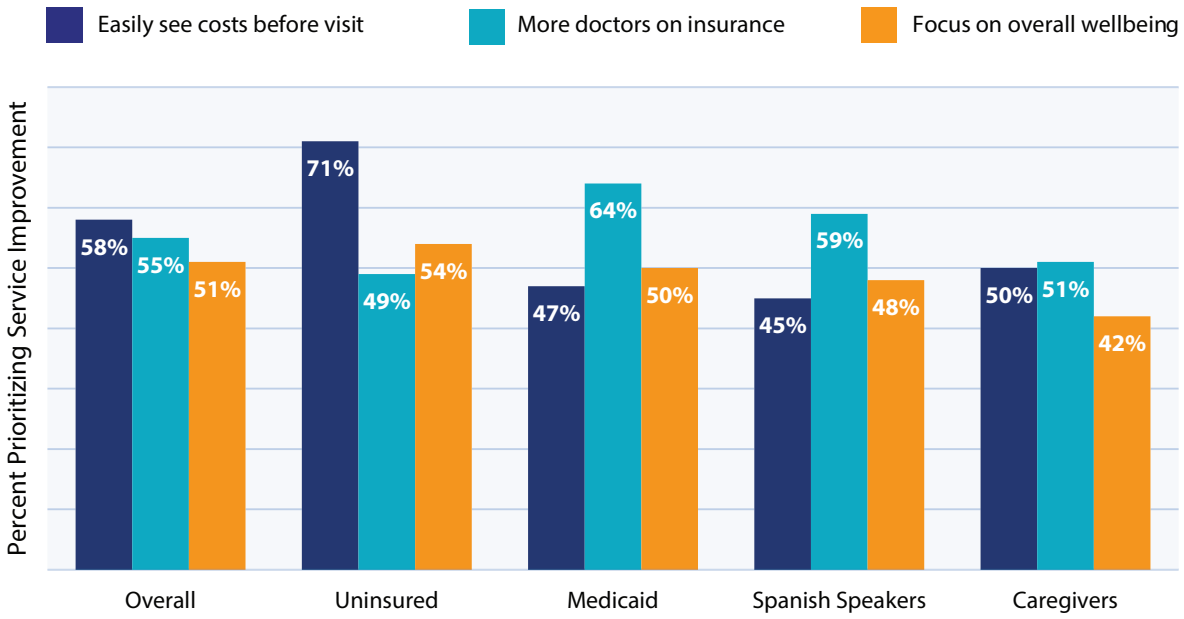
—Middle-income White caregiver in her 30s, private insurance, Illinois

IMPLICATION

Patients who are in poorer health are especially likely to value being treated as a whole person instead of as a condition. Providers should talk to patients about their overall priorities and goals, and how their treatment plan can help them meet those goals.

FIGURE 3.

Uninsured prioritize cost information;
Medicaid and Spanish speakers prioritize access to doctors



NOTE: 95% Confidence interval is ± 2% for overall, ±6% for uninsured, ±5% for Medicaid, ±5% for Spanish speakers, and ±4% for caregivers. Variables include Q14_* by xInsurance, xEnglish, and xCaregiver.

PATIENTS WANT CLARITY REGARDING COST OF CARE INFORMATION, AND INFORMATION ABOUT DOCTORS' PROFESSIONAL EXPERIENCE.

Survey respondents were asked to select their top five priorities for improving the understandability and accessibility of nineteen types of health care information. The top three consumer priorities are the ability to **see costs before a visit, know more about what insurance covers, and understand physicians' professional experience.** Lower-income respondents (less than $50k per household) are especially likely to want more accessible cost and insurance information.

IMPLICATION

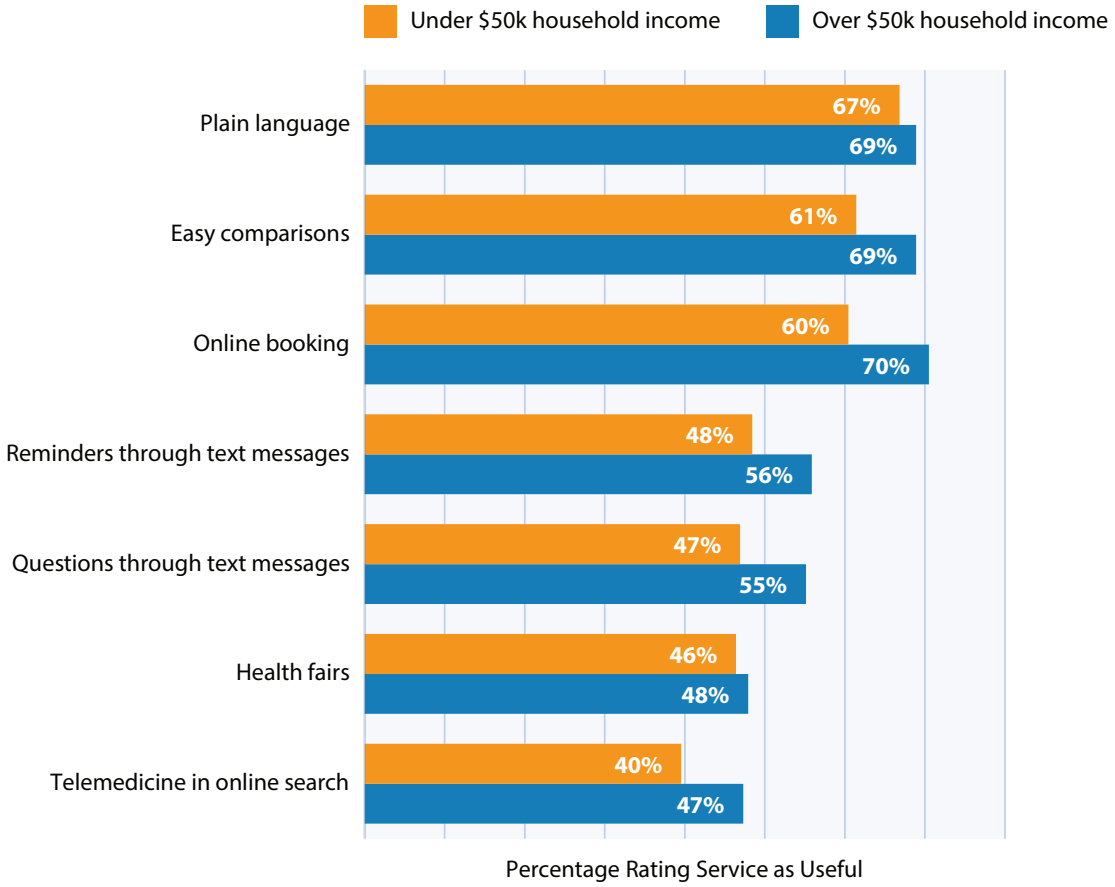
Health care organizations that make cost and physician experience information easily accessible and understandable will likely increase patient/member satisfaction.

PEOPLE WOULD FIND ONLINE APPOINTMENT-BOOKING, EASY PROCEDURE COMPARISONS, AND PLAIN LANGUAGE EXPLANATIONS TO BE USEFUL.

Survey respondents were asked to evaluate the usefulness of seven hypothetical health care information services. These seven services were selected based on participant feedback in the interviews and focus groups. By far, **the services rated as most useful include explanations of medical and insurance details in plain language (67% rate as useful), easy comparisons of procedure costs, patient reviews, facility safety and quality scores embedded into search results (65%), and easy online booking (65%).**

FIGURE 4.

Online Booking, Easy Comparisons of Procedures and Facilities, and Plain Language Explanations are Most Useful Services



NOTE: 95% Confidence interval is ± 2%. Variables include Q19–Q25 by xLowIncome.

IMPLICATION

To be accessible to all patients, written information should include an explanation at no higher than a fourth grade level (about 1 in 5 US adults struggle to read above a fifth grade reading level[3]). When a procedure is upcoming, provide patients with straightforward comparisons of cost and quality. Promote online booking where it is available and consider adding it where it is not yet available.

CONSUMER VIEWPOINT ON PLAIN LANGUAGE

"Once your tests are done by the doctors, you can go in and check what your results are but they don't explain what it means. It's just vocabulary —the verbiage belongs to the doctors, not to us. It's online so now not only am I on MyChart figuring out what I was diagnosed with, I have to find a search engine to actually place the word in there and see what I really have. I would change that. Just write it so that I can read it or understand it basically."

—Lower-income Hispanic woman in her 40s, private insurance, Illinois

SUMMARY

- Consumers' **number one priority** for improving health care overall is having the ability to **see costs before a visit.**
- For those who are in poorer health, the number one health care improvement priority is having providers **focus on overall wellbeing**, rather than focus on treating their condition(s).
- For several patient groups—including Medicaid beneficiaries, the uninsured, Spanish Speakers, and Caregivers—**having more doctors that accept their insurance** is a top health care improvement priority.
- Consumers want improved (more easily accessible and understandable) *information* about **doctors' professional experience, their insurance details, and health care costs.**
- Out of several hypothetical healthcare services, those rated as most useful to consumers include **simpler explanations of medical and insurance information, easy comparisons of procedures and provider embedded in web search results, and easy online booking.**

Further Reading: Plain Language, CDC
http://www.cdc.gov/healthliteracy/developmaterials/plainlanguage.html

KEY FINDING 3

Caregivers use the most health care information but struggle to find resources to help themselves

HIGHLIGHTS

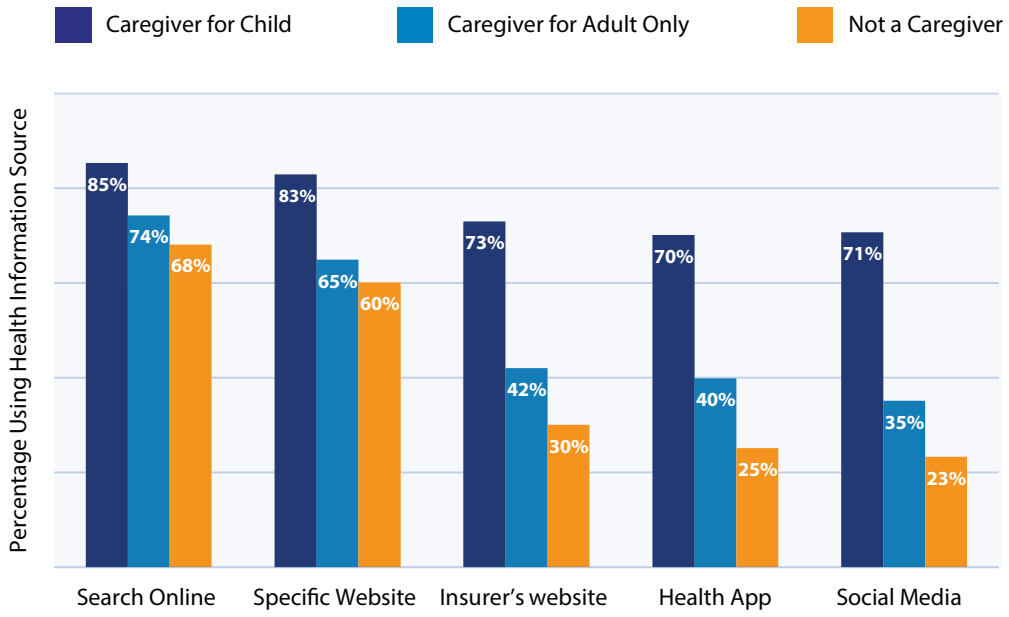
- **Caregivers use far more information sources and tools** than noncaregivers.
- **Caregivers have high daily stress levels**, especially when caring for children with complex medical needs.
- **Caregivers**, especially lower-income caregivers, **struggle to find caregiver support resources.**

CAREGIVERS ARE SUPERUSERS OF ONLINE HEALTH CARE RESOURCES.

Caregivers are defined as those who care for someone with special health needs without being paid. Survey results show **caregivers frequently use a wide variety of health care information sources**, much more so than non-caregivers. **Caregivers are especially likely to use online resources such as patient portals or apps.** Caregivers also report relying on social media more frequently to connect with others in similar situations. In this research, caregivers were categorized as those who care for children with complex medical needs, and those who care for adults only. Caregivers of children tend to be health care "superusers" and access far more health care information than caregivers of adults or non-caregivers.

FIGURE 5.

Caregivers of Children are Superusers of Health Care Information



NOTE: 95% Confidence interval is ±2% for non-caregivers, ±6% for caregivers of adults, and ±5% for caregivers of children. Variables include Q44_* by xCaregiver.

IMPLICATION

Caregivers represent an outsized share of portal and health care app users, and as such, are especially good audiences for new resources and tools. They may also be especially helpful in providing user feedback and insight.

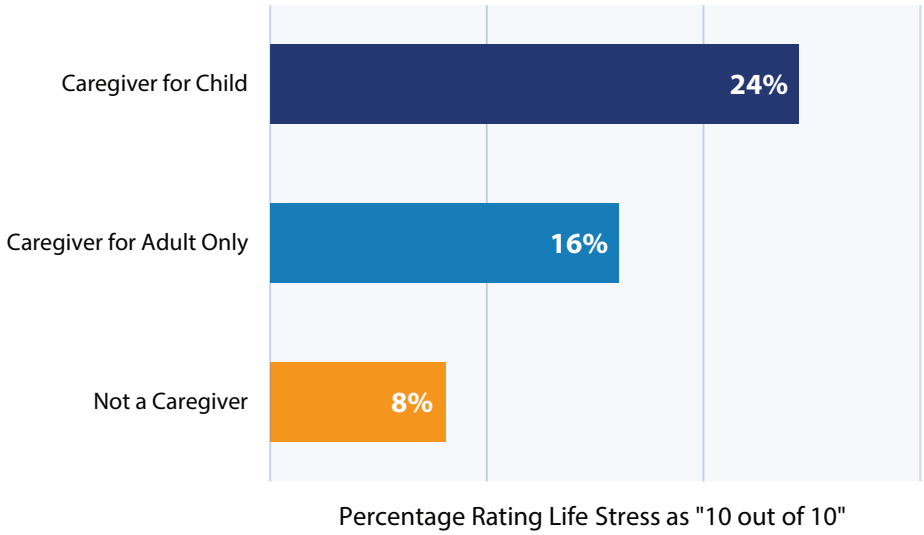
CONSUMER VIEWPOINT ON PATIENT PORTALS FOR CAREGIVERS

"I use the portal a lot because I share the responsibility of taking my son to the doctor because I work full-time. So his dad will take him but that's how I find out exactly what happened and what was there in the medications and things like that. So I like the portal."

—Middle-income Black caregiver in her 40s, private insurance, Illinois

FIGURE 6.

Caregivers, Especially of Children, Face High Levels of Stress



Caregivers of adults report **double** the level of stress of non-caregivers, and caregivers of children report **triple** the level of stress of non-caregivers

NOTE: All three groups are significantly different, $p < .05$. Variables include Q74 by xCaregiver.

CAREGIVERS FACE OVERWHELMING LEVELS OF STRESS

Our survey results find that caregivers report much higher levels of stress on average than non- caregivers. **Caregivers of adults are twice as likely as non-caregivers to rate their life stress as "10 out of 10." Caregivers of children are three times as likely to rate their life stress as "10 out of 10."**

IMPLICATION

Caregivers are especially likely to value services and tools that can reduce their stress. Because of their strong social networks with other caregivers, they are likely to recommend these services and tools to others.

CONSUMER VIEWPOINT ON STRESS AND RESPITE CARE

"My grandson's been kicked out of every single daycare within a reasonable radius of me, so I wanted some respite care because I was feeling burnt out. Even talking about it, I feel angry and bitter, all the stuff. I'm sorry if it shows. They have respite care for everybody except the emotionally disturbed."

—Lower-income White caregiver in her 50s, Medicaid, Illinois

CAREGIVERS STRUGGLE TO FIND RESOURCES NEEDED TO CARE FOR THEMSELVES.

While caregivers tend to be experienced at using health care information resources, they are not as successful at finding resources to support their own needs. Caregiver support can be limited, and difficult to find where it is available. Caregivers we interviewed reported that providers rarely, if ever, directed them to support for caregivers, and they spent substantial time looking for caregiver support. This was particularly the case for caregivers of children who struggled with long-term care requirements. Survey results show **caregivers have the most difficulty finding out how to get financial support, respite care, and government assistance.** This is especially difficult for lower-income caregivers**. Lower-income caregivers are 67% more likely to have difficulty finding information on financial support for caregivers** compared to middle-income caregivers. Interviewees recommended social workers and online support groups as helpful caregiver resources.

IMPLICATION

Caregivers are especially likely to value services and tools that can reduce their stress. Because of their strong social networks with other caregivers, they are likely to recommend these services and tools to others.

CONSUMER VIEWPOINTS ON ASSISTANCE FOR CAREGIVERS

Interviewer: *Where have you found the most useful information for programs or assistance specifically for caregivers?*

Caregiver 1: *There are none.*

Caregiver 2: *There really aren't.*

Caregiver 3: *I was going to say the same but I was going to let somebody else say it.*

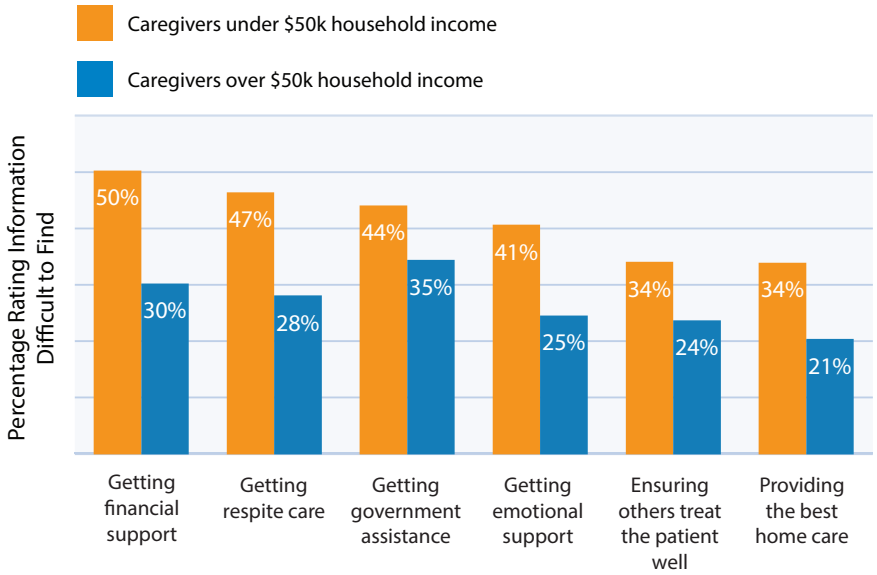
—Lower-income caregiver 1, White woman in her 50s, Medicaid, Illinois

—Lower-income caregiver 2, Black woman in her 40s, Medicaid, Illinois

—Lower-income caregiver 3, White man in his 30s, Medicaid, Illinois

FIGURE 7.

Caregivers Report Financial Resources Most Difficult to Find, Especially Lower-income Caregivers



NOTE: 95% CI is ±6% for caregivers of adults, and ±5% for caregivers of children.
Variables include Q65_* by xCaregiver and xLowIncome

SUMMARY

- **Caregivers, especially of children with serious medical needs, are superusers of online health resources** and technologies such as patient-portals or smart phone apps.
- Many caregivers feel high levels of stress. **Caregivers, especially of children with serious medical needs, report much higher stress levels than non-caregivers.**
- **Caregivers often struggle to find resources for caregiver support.** Information about financial assistance or respite care is particularly difficult for caregivers to locate. Lower-income caregivers face even more challenges finding caregiver information.

Further Reading: Caregiving in the US, 2015, National Alliance for Caregiving
http://www.caregiving.org/caregiving2015/

KEY FINDING 4

The uninsured report greater difficulty accessing health care Information

HIGHLIGHTS

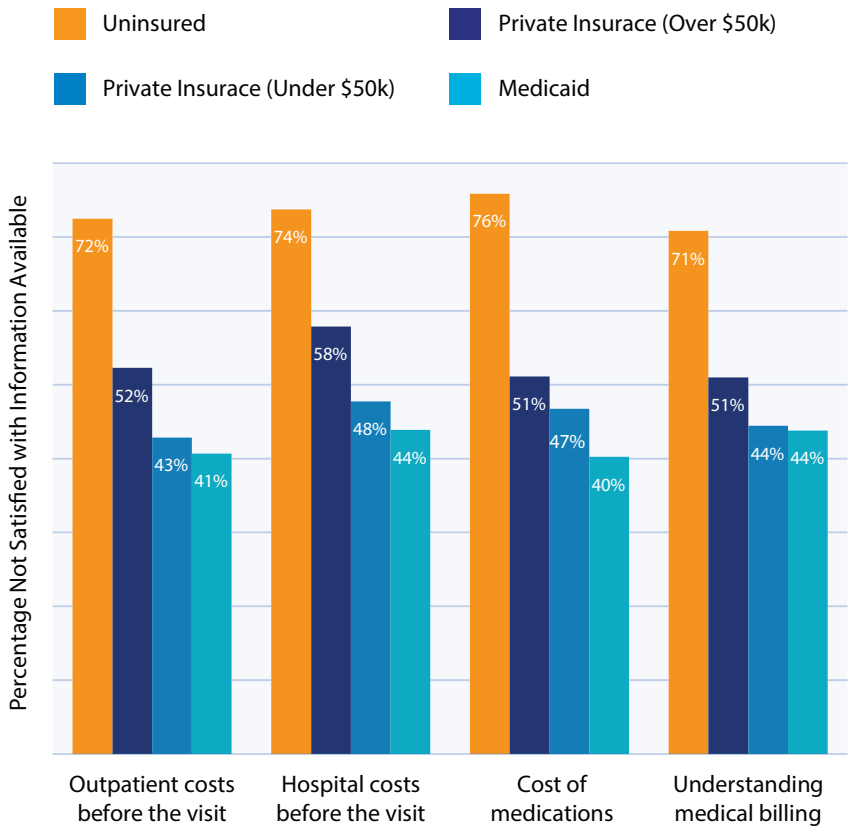
- **More than 70% of the uninsured are dissatisfied with the availability of cost of care information**, which is higher than any other group of patients.
- **The uninsured are less likely to search for general health information.**
- **The uninsured's primary sources of information about health insurance are friends and family and www.healthcare.gov**

THE UNINSURED HAVE THE MOST DIFFICULTY FINDING HEALTH CARE COSTS.

Many survey respondents report difficulty finding information about cost, particularly the cost of services before a hospital procedure or office visit. This is especially true of the uninsured, who rate health care cost information as the most difficult to access relative to other types of information. Those with no insurance also have more difficulty finding cost information compared to those with private insurance or Medicaid. **Compared to insured consumers, the uninsured are half as likely to be satisfied with cost of care information.** For example, only 24% of the uninsured are satisfied with information they are able to find about medication costs, compared to 49% of lower-income privately insured individuals.

FIGURE 8.

Uninsured Most Dissatisfied with Availability of Cost Information



NOTE: 95% Confidence interval is ±5% for uninsured, ±4% for Medicaid, ±4% for lower-income private, and ±3% for middle-income private.

CONSUMER VIEWPOINT ON OVERWHELMING NATURE OF INSURANCE INFORMATION

"The whole reason I haven't had any type of insurance for the last six, seven years is because it was overwhelming. You see commercials on TV, they're sending you stuff in the mail—it was too overwhelming so I was like, 'I'm not about to even dive into it because it was too much.'"

—Lower-income Black woman in her 20s, Uninsured, Michigan

CONSUMER VIEWPOINT ON OVERLY COMPLICATED INFORMATION

"It does feel like they're trying to make [insurance and patient costs] complicated for no reason. It's a long, drawn out story when you can really just break it down to what all I need to know and that's it."

—Lower-income Black woman in her 30s, Uninsured, Michigan

IMPLICATION

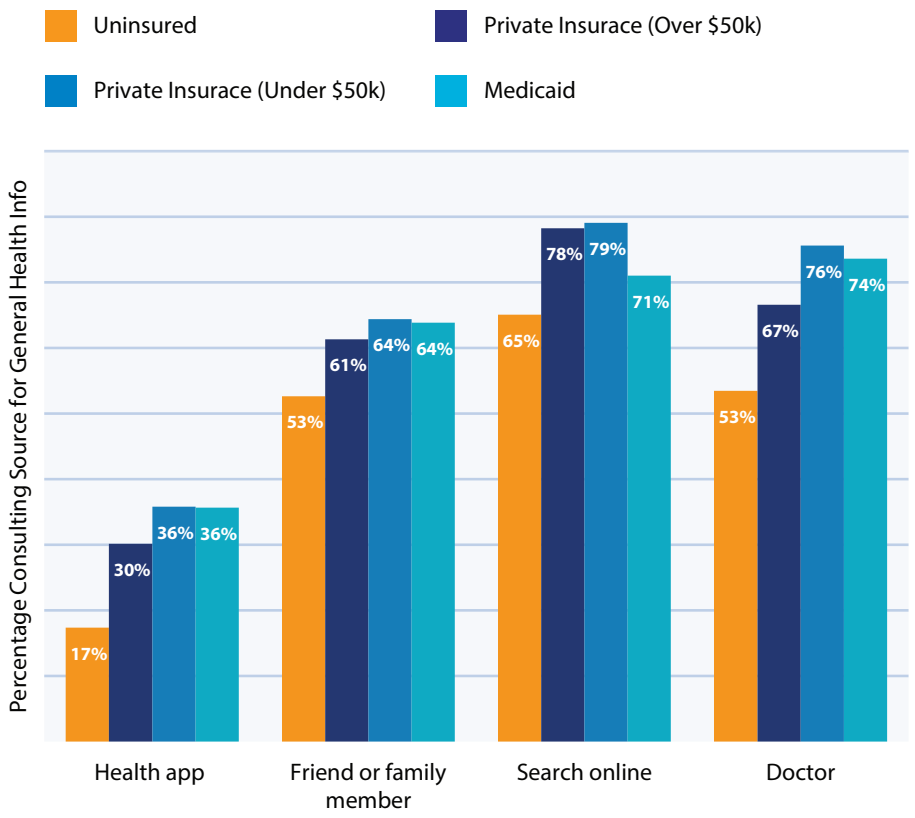
Providers who prioritize cost transparency may gain business from uninsured patients paying in cash, such as at retail clinics.

THE UNINSURED ARE LEAST LIKELY TO SEEK HEALTH INFORMATION.

Challenges that uninsured consumers face in seeking or finding cost information may be one component of a more general disengagement with health and health information. Several uninsured interviewees were reluctant to seek advice or help from mainstream medical sources. They often preferred to self-treat, relying heavily on information they obtain themselves or through the advice of friends or family members. Survey respondents who were uninsured are less likely to seek health information across all sources compared to those with private insurance or Medicaid. **The uninsured's primary source for health information is the internet, and the uninsured are just as likely to seek health advice from friends and family as they are to consult a physician for information.**

FIGURE 9.

Uninsured Less Likely to Look for Information on Managing Health



NOTE: 95% Confidence interval is ±5% for uninsured, ±4% for Medicaid, ±4% for lower-income private, and ±3% for middle-income private. Variables include Q44_* by xInsurance.

THE UNINSURED RELY ON FRIENDS AND FAMILY FOR INFORMATION THE MOST.

Our survey also asked uninsured respondents to indicate the sources they consulted for information about acquiring health insurance. The top source is friends and family, followed closely by www.healthcare.gov. Less frequently consulted sources include providers, employers, insurers, advertisements, and health fairs.

IMPLICATION

Many uninsured patients are less likely to seek health information from conventional sources. Special effort may be needed to reach uninsured patients in the communities where they live, such as outreach campaigns in drug stores, grocery stores, or community organizations. One existing example includes a health risk assessments offered at Walmart in collaboration with InComm and Pursuant Health[4].

CONSUMER VIEWPOINT ON FINDING HEALTH INSURANCE INFORMATION

"Usually I ask the people I work with [about health insurance]. But, nobody [14 people] has insurance there. Everybody pays at the end of the year."

—Lower-income Spanish-speaking Hispanic woman in her 50s, Uninsured, originally from Mexico, living in Texas

SUMMARY

- **The uninsured are highly dissatisfied with the availability of cost of care information**, much more so than others, including lower-income insured patients.
- **The uninsured are less likely to look up general health information** from a variety of sources than their insured peers.
- **The uninsured's primary sources of information about health insurance are friends and family, followed by www.healthcare.gov**

Further Reading: Key Facts about the Uninsured Population, Kaiser Family Foundation
http://kff.org/uninsured/fact-sheet/key-facts-about-the-uninsured-population/

KEY FINDING 5

Spanish speakers struggle with language barriers when accessing health care, and rely on friends and family to offer advice and remedies

HIGHLIGHTS

- **Language, education, and culture can be barriers to seeking medical care.**
- **Even when Spanish language resources are available they are not always used because of fear of stigmatization.**
- Spanish speakers are more likely than English speakers to rely on **friends and family members as important sources of health information.**
- Spanish speakers often **have overall higher trust in most health care information sources.**

LANGUAGE, EDUCATION, AND CULTURE MAY PREVENT SPANISH SPEAKERS FROM ACCESSING CARE.

Spanish-speaking survey respondents report their **lack of English proficiency is the biggest barrier to understanding health care cost information.** In addition to difficulty understanding costs, just under half of Spanish-speaking survey respondents also say that **language issues present a barrier when communicating with doctors or reading printed materials**, such as forms. During our interviews, several Spanish speakers noted that **even when translators or Spanish language versions of forms are available, patients may be reluctant to ask for or use these resources.** Some felt they would be stigmatized as immigrants if they requested Spanish language resources.

CONSUMER VIEWPOINT ON THE STIGMA OF ASKING FOR SPANISH LANGUAGE MATERIALS

"I'd have to go to the doctor, and I wouldn't want to go because I would get all these forms that I didn't understand. I was ashamed, so I didn't ask for a Spanish version because of the stigma that would come with it like, 'Here comes another one that doesn't speak English that shouldn't be here.' Nobody really wants to be seen that way."

—Spanish-speaking Hispanic woman in her 20s, private insurance, originally from Mexico, living in California

In addition to language barriers, Spanish speakers may not have the familiarity or cultural experiences required to easily understand the American health care system. For example, very few residents in Mexico have private health insurance, using publicly funded health care instead. **When Spanish speakers come to the US, many are learning new concepts about American health care as well as new vocabulary.**

CONSUMER VIEWPOINT ON HEALTH CARE EDUCATION AMONG SPANISH SPEAKERS

"Spanish speakers don't know what some terms mean even when you translate them, especially when applying for insurance. I think people just don't have the background to understand what that means."

—Spanish-speaking Hispanic medical social worker in her 20s, private insurance, originally from Mexico, living in Texas

Spanish speakers are also less likely to utilize health care at all. According to research by the US Census Bureau[5], **Hispanics are the least likely of all racial and ethnic groups to see a doctor**, with 42% not seeing any providers and 72% of Hispanics never using prescription drugs in 2010. Although this can be related to insurance coverage, some interviewees also explained that culturally, Spanish speakers are more likely to delay care.

CONSUMER VIEWPOINT ON SPANISH SPEAKERS' USE OF HEALTH CARE

"I was watching this TV show about Latinos, and the grandmother was sick, she refused to go to the doctor because she only had that one problem. Her rule was that she was supposed to go to the doctor once she had three problems, and it was a big joke because everybody thought, 'Yeah, that's how it is,' but in reality, it's not all that funny."

—Spanish-speaking Hispanic woman in her 20s, private insurance, originally from Mexico, living in California

IMPLICATION

Providing Spanish language materials without requiring them to be requested can increase information accessibility. Education may be required in addition to translation, including plain language explanations of billing, insurance, and treatment plans.

SPANISH SPEAKERS RELY ON FRIENDS AND FAMILY FOR HEALTH INFORMATION.

Spanish speakers are often part of tight knit communities both in their home countries and in the United States. They are more likely than English speakers to place a great deal of value on social relationships and social supports[6], and seek medical advice from friends and family. Our survey results show that **Spanish speakers frequently consult a friend or relative about their medical concerns**, second only to seeking health information from a physician directly. In contrast, **English speakers are more likely to use clinical website**s than Spanish speakers. **Spanish speakers are also more likely to consult pharmacists.**

SPANISH SPEAKERS' TOP HEALTH INFO SOURCES	ENGLISH SPEAKERS' TOP HEALTH INFO SOURCES
1. Doctors	1. Doctors
2. Friends and family	2. Searching online
3. Search online	3. Specific health websites
4. Pharmacists	4. Friends and family

CONSUMER VIEWPOINT ON IMPORTANCE OF FRIENDS AND FAMILY FOR RECOMMENDING DOCTORS

"They [Spanish speakers] usually ask their friends, 'Where do you go that they speak Spanish?' and that's where they'll go. They didn't do any research about how good the doctor is or anything like that. It's just, 'That's where my friend went, so that's where I'm going to go.'"

—Spanish-speaking Hispanic woman in her 20s, private insurance, originally from Mexico, living in California

CONSUMER VIEWPOINT ON IMPORTANCE OF FRIENDS AND FAMILY AS SOURCES OF MEDICAL ADVICE

"Let's say I go to my brother or sister and they say, 'Yes, this remedy will work.' I have that bond with them. There's that relationship that they do care about what I'm doing to my body, therefore I will trust them."

—Lower-income Spanish-speaking Hispanic man in his 30s, private insurance, originally from Mexico, living in Illinois

IMPLICATION

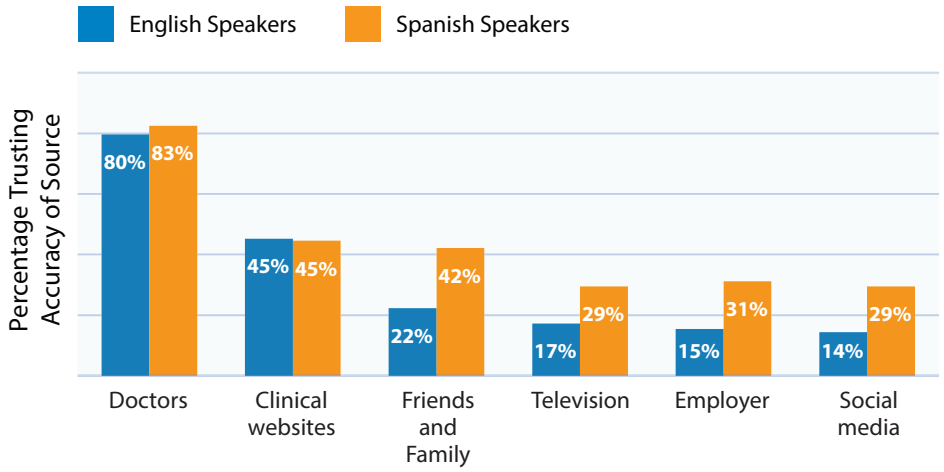
Word of mouth referrals may be especially effective among Spanish speakers. Successful outreach to Spanish speakers will leverage existing social networks, such as schools, churches, and employers.

SPANISH SPEAKERS ARE MORE TRUSTING OF SEVERAL HEALTH INFORMATION SOURCES THAN THE GENERAL PUBLIC.

Spanish speakers are relatively more trusting in the accuracy of several different sources of health care information. Like English speakers, Spanish speakers rate doctors as the most accurate sources of health care information. But **Spanish speakers view friends and family as equally accurate as clinical websites like WebMD or Mayo Clinic. Spanish speakers are twice as likely to perceive television documentaries, employers, and social media as accurate sources of health information compared to English speakers**, though trust is still relatively low for these sources. Notably, **employers are some of the least trusted sources for both English and Spanish speakers.**

FIGURE 10.

Spanish Speakers are More Trusting of Most Health Care Info Sources



NOTE: 95% margin of error = ±2% for English speakers and ±6% for Spanish speakers. Variables include Q78_* by xEnglish.

IMPLICATION

Spanish speakers are more likely to trust friends and family, television, employers, and social media, which are relatively distrusted as health information sources by English speakers. Payers, providers, and others may have more success reaching Spanish-speaking members through these channels than with their English-speaking members.

CONSUMER VIEWPOINT ON TRUST OF HEALTH CARE PROVIDERS BY SPANISH SPEAKERS

"I do think the Hispanic community, Spanish-speaking community does trust the doctors to get information and, of course, the hospitals because that's their last resources. It's always whatever the doctor says, that's what is right."

—Spanish-speaking medical social worker in her 20s, originally from Mexico, living in Texas

SUMMARY

- **Language, education, and culture can be barriers to Spanish speakers seeking medical care.**
- **Friends and family members are especially important sources of information** for Spanish speakers, and are considered equally as accurate as clinical websites.
- **Even when Spanish language resources are available they are not always requested because of fear of stigmatization.**

Further Reading: Culture Insights Communicating with Hispanic/Latinos, CDC
http://www.cdc.gov/healthcommunication/pdf/audience/audienceinsight_culturalinsights.pdf

KEY FINDING 6

Patients who feel disrespected by providers are less likely to trust health care information or follow medical advice

HIGHLIGHTS

- **Many patients say they are not respected by doctors**, especially the uninsured, lower-income, and the sick.
- **When patients feel disrespected, they are more likely to mistrust doctors as sources of accurate or well-intentioned information.**
- **When patients feel disrespected, they are less likely to take their medications.**

LOWER-INCOME AND SICKER PATIENTS MOST LIKELY TO FEEL DISRESPECTED.

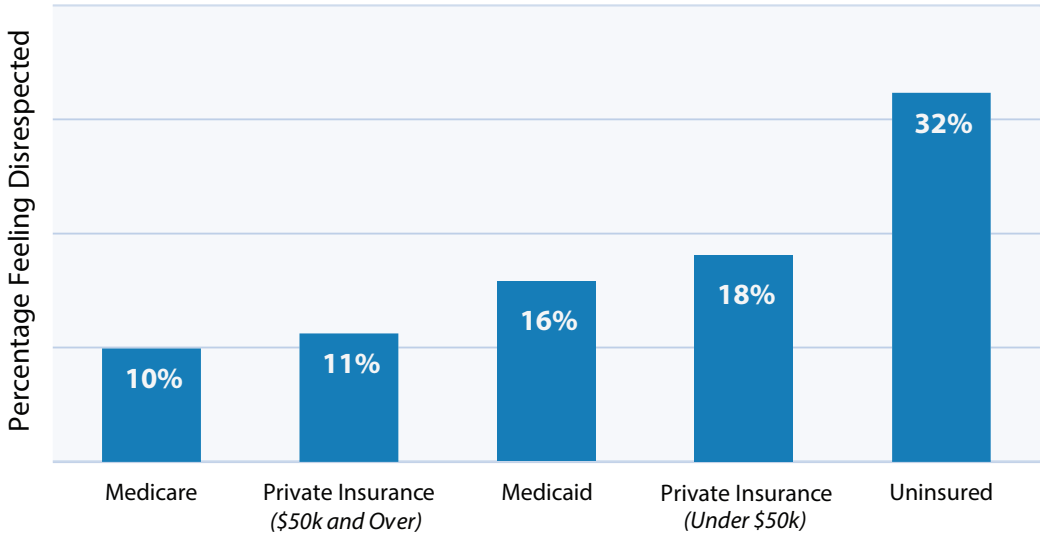
Patient groups differed widely in how likely they were to feel disrespected by their doctors. **The three types of groups most likely to feel disrespected include the uninsured**, and to a lesser extent, those with **Medicaid**, those with **lower-incomes**, and those in **poorer health**. By far, uninsured patients are the most likely to feel disrespected, where 32% feel they are "Never", "Rarely", or "Sometimes" treated with respect by doctors. In contrast, only 13% of privately insured patients feel disrespected.

Among patients who are privately insured, those earning less than $50k per household are more likely to feel disrespected (18%) than those earning more than $50k per household (11%), which though small in number is statistically significant. Medicare patients feel the most respected overall, with only 10% feeling disrespected by doctors.

Women are slightly more likely to feel disrespected by doctors; 16% of women feel disrespected, while 14% of men feel disrespected, which again though small, was statistically significant. Black (14%), White (14%), and Hispanic (12%) respondents feel similar levels of disrespect (no statistically significant differences), while 19% of Asian respondents feel disrespected, which is marginally significantly higher than for White respondents. Overall, patients over 65 feel much more respected (7% disrespected) than under 65 (16% disrespected).

FIGURE 11.

Lower-income and Uninsured Most Likely to Feel Disrespected

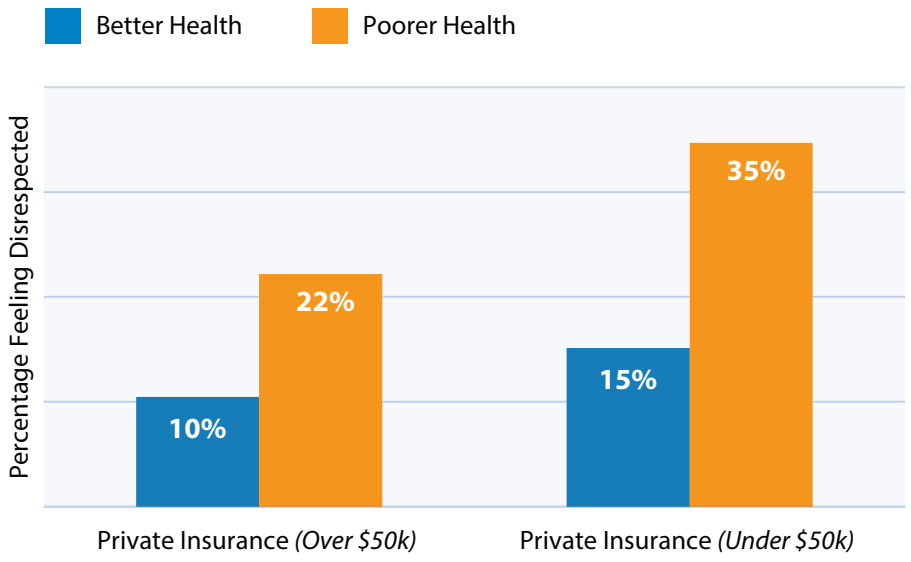


NOTE: 95% margin of error = ±3% for Medicare, ±3% for private insurance ($50k and over), ±5% for private insurance (under $50k), ±4% for Medicaid, and ±6% for uninsured. Private insurance (under $50k) and Medicaid feel significantly more disrespected than Medicare or private insurance (over $50k). The uninsured feel significantly more disrespected than any other group. Variables include Q80 by xInsurance.

Patients in poor health are much more likely to feel disrespected than those in good health. Among those who rate their health as "Excellent" or "Very Good" (grouped as "Better Health"), only 13% feel disrespected. In contrast, among those who rate their health as "Good," "Fair," or "Poor" (grouped as "Poorer Health"), 22% feel disrespected, which is a significant difference. However, health status and income interact together; **lower-income patients in poorer health feel the most disrespected by far**. In other words, the disrespect gap between lower-income and middle-income patients exists mostly with those in poorer health.

FIGURE 12.

Patients who are Both Lower-income and Sick Most Likely to Feel Disrespected



NOTE: Differences between those in "Better Health" are not significant. All other comparisons are significant, $p < .001$. Variables include Q80 by xInsurance and xPoorHealth.

CONSUMER VIEWPOINT ON JUDGMENT FROM PROVIDERS

"He would talk about how he didn't want to be there if he had a Medicaid patient, that he just felt like they're complaining. The way he talked about his patients, it was clear. It changed my view. That type of judgment—that really scared me. It scared me to go back on Medicaid, especially pregnant, because I feel that there are judgments made on people who have Medicaid."

—Lower-income White woman in her 30s, Medicaid, Michigan

CONSUMER VIEWPOINT ON PATIENT PROVIDER INTERACTIONS

"My primary care doctor sucks. I go in there and it's about 10 minutes, in and out. I'm like, 'Yes, this is going on, this is going on, and this is going on.' She's like, 'Okay. I'll prescribe you this,' and boom out of the door. So they don't really care. It's not like they're really there to care about you. They just want to sell what you need and that's it. They're gone. You're out the door and they get paid."

—Lower-income White caregiver in his 30s, Medicaid, Illinois

IMPLICATION

Patients who are uninsured, on Medicaid, have lower incomes, or are in poorer health are more likely to have had negative interactions with providers, and may be sensitive to perceived disrespect. Basics like making eye contact, smiling, and asking how a patient is doing can set the tone for a positive patient-provider interaction.

PATIENTS WHO FEEL DISRESPECTED ARE LESS TRUSTING OF DOCTORS.

Many interviewees who felt disrespected were also skeptical of doctors' medical advice and questioned whether doctors have good intentions for their patients. Often, patients who feel disrespected mistrust doctors as information sources, and are concerned about doctors' financial motivations to provide more or less care than is medically appropriate. **Our survey results find strong support that patients who feel disrespected by doctors are far less likely to trust doctors overall.** Of those who feel respected, about 84% believe doctors to be accurate and well-intentioned. Of those who feel disrespected, only half believe doctors are accurate or well-intentioned.

Taken together, these results show that patients who are uninsured or who have lower incomes and health concerns are far more likely to feel disrespected by physicians, and patients that feel disrespected are more likely to be medically non-adherent and less trusting of doctors. This does not prove causality; but these results do statistically control for age, gender, and income. These results suggest a strong association between feeling respected and patient outcomes, though the influence of patient-provider relationships on health is still not fully understood.

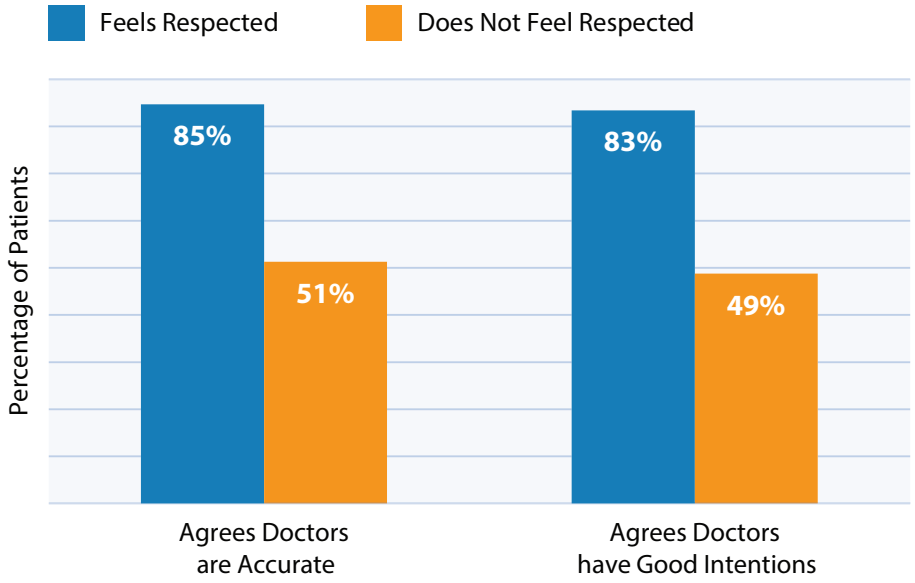
CONSUMER VIEWPOINT ON SUSPICION OF PROVIDERS' MOTIVES

"It's kind of scary. A dishonest mechanic is one thing telling you, 'You need this, this, and this,' but doing something with your body or your loved one's body, giving them unnecessary medication or the current promoted medicine? That's a lot worse."

—Lower-income White caregiver in her 50s, Medicaid, Illinois

FIGURE 13.

Feeling Disrespected Linked to Mistrusting Doctors as Information Sources



NOTE: Both comparisons are significant, $p < .001$. Both comparisons control for age, gender, and income. Variables include Q78_4 and Q79_4 by Q80.

IMPLICATION

Patient-provider relationships influence trust in medical advice. Feeling disrespected could lead patients to mistrust valuable medical advice. Creating a respectful environment and holding providers accountable to being respectful is essential to positive patient outcomes.

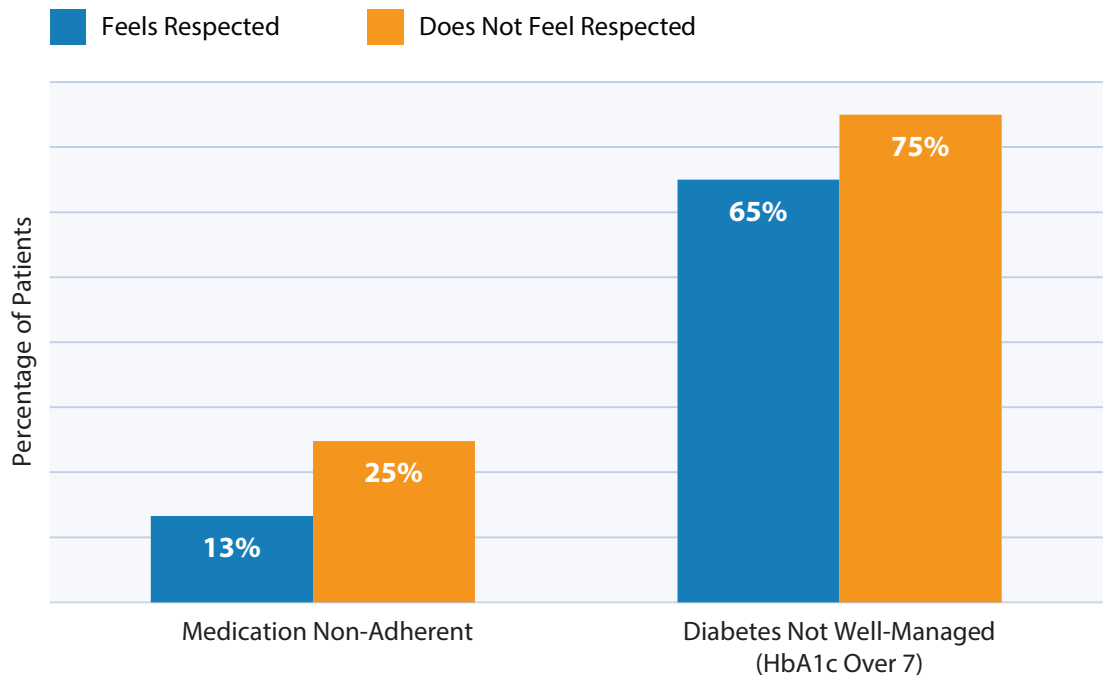
PATIENTS WHO FEEL DISRESPECTED ARE LESS LIKELY TO FOLLOW MEDICAL GUIDELINES.

Some consumers we interviewed said that **after a negative encounter with a provider, they would not follow the provider's medical advice.** In one case, a woman felt her doctor did not treat her well, and so she did not take her blood pressure medication. Unaware of this, the doctor wrote another prescription. She did not take that either, and remained untreated. This breakdown in the patient- provider relationship led her condition to worsen. This is consistent with research showing positive patient-provider relationships are associated with better health outcomes.[7]

A relationship between feeling respected and medication adherence also comes through in our survey results. Of those who feel respected, 13% report being non-adherent to their medications, while of those who feel disrespected, 25% are non-adherent. In other words, **patients who feel disrespected are about twice as likely to not take their prescription medications as directed.** Among diabetics, 35% of those who feel respected keep their HbA1c under 7, while 26% of those who feel disrespected keep their HbA1c under 7. In other words, **respected patients are 35% more likely to keep their HbA1c under 7 than disrespected patients.** These findings do not prove disrespect causes non-adherence; other factors may cause a patient to feel both disrespected and be non-adherent. These findings do suggest that feeling respected by providers can play an underappreciated role in patient health.

FIGURE 14.

Feeling Disrespected Linked to Medication Non-Adherence



NOTE: Medication non-adherence $p < .001$; HbA1c difference is not significant, but statistical power is limited by the small number of people in the disrespected diabetic group (n=53). Both comparisons control for age, gender, and income. Variables include Q73 and Q77 by Q80.

IMPLICATION

A positive patient-provider relationship is correlated with better medical outcomes. When providers make eye contact and listen carefully, or adopt other behaviors or practices that convey and promote respect, patient adherence may increase.

CONSUMER VIEWPOINT ON PATIENT-PROVIDER RELATIONSHIPS

"He [the doctor] doesn't look up at you, he don't [do] nothing. You want interaction with your doctor because if he's just writing some prescriptions and saying what he wants, did he really see you? He'd tell me I've got high blood pressure; he'd write me three different prescriptions, man. They just sit in my purse. You never even came over here and touched me, man, how can you tell me that's what I really need?"

—Lower-income Black woman in her 40s, Medicaid, Michigan

CONSUMER VIEWPOINT ON PATIENT-PROVIDER RELATIONSHIPS

"My son is obese and the doctors look down upon that. It pisses me off because they're not the ones who experience it. They're not the ones who deal with it and for you to look down upon me—I'm doing the best I can for what I can do. It pisses me off. It makes me want to rebel against them and do the same, do it more, do what they don't want me to do."

—Lower-income White woman in her 40s, Medicaid, Michigan

SUMMARY

- **About 15% of patients feel disrespected by doctors.** Feeling disrespected is much more common among **the uninsured, lower-income, and the sick.**
- Patients who feel disrespected are **less likely to trust information from doctors.**
- Patients who feel disrespected are **less likely to take their prescription medications.**

Further Reading: Overcoming Lower-Income Patients' Concerns About Trust and Respect From Providers, Health Affairs http://healthaffairs.org/blog/2016/08/11/overcoming-lower-income-patients-concerns-about-trust-and-respect-from-providers/

Consumer Health Care Decisions

CONSUMER HEALTH CARE DECISIONS

Whether and Where to Seek Care

When consumers seek medical care, they are choosing not just *whether* to seek care, but they are also choosing *where* to seek care, such as the type of facility and the services a facility provides. Primary care offices, urgent care clinics, retail clinics, and emergency departments all present distinct choices with respect to provider familiarity with patients, potential wait time, capacity to deal with emergencies, and price transparency. Our survey explored what, if any, health care information sources consumers consult when deciding whether to seek care. We also asked how consumers decide where to go once they determine they need care.

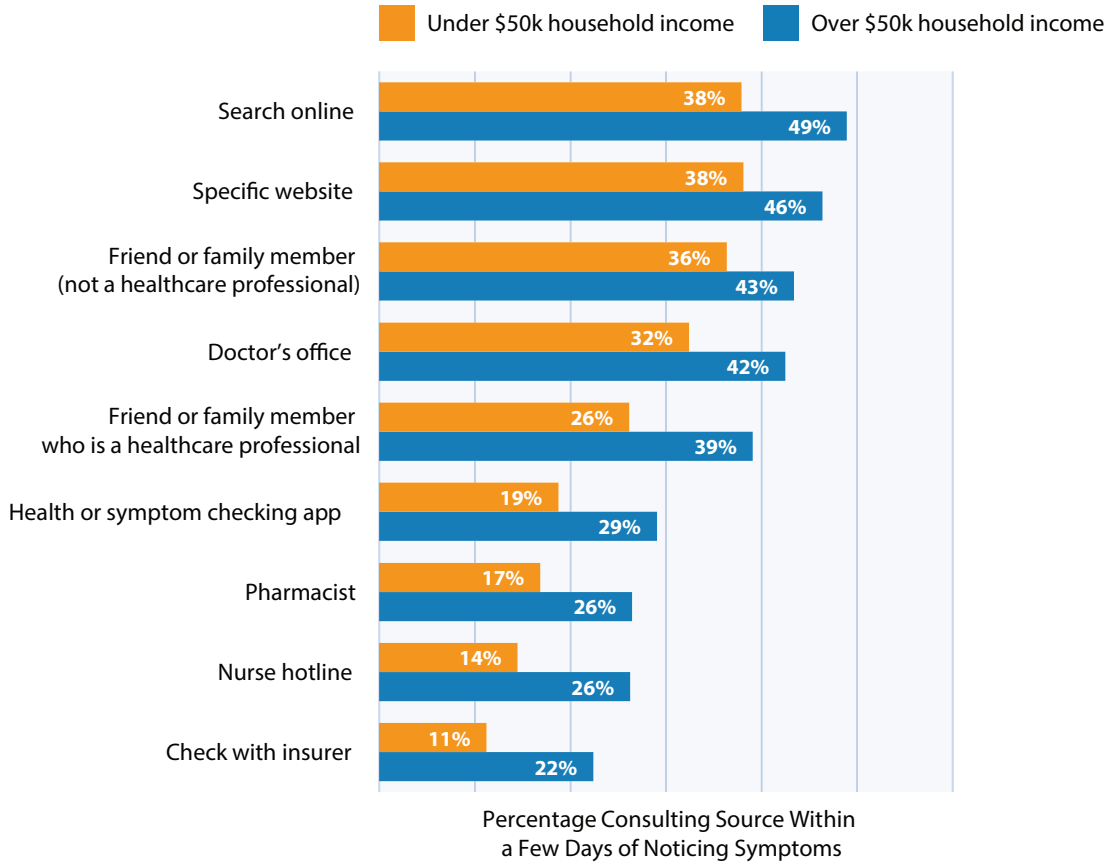
WHEN DECIDING *WHETHER TO SEEK CARE*, CONSUMERS MOST FREQUENTLY CONSULT THE WEB, FOLLOWED BY FRIENDS AND FAMILY.

Before deciding where to seek care, consumers must decide if care is needed at all. By far, **online searches (44%) and visiting a clinical website (42%) are the most common sources consulted when deciding whether to seek care, within a few days of a new medical issue.** Conferring with friends and family (40%) or calling a doctor's office (38%) are also common. Despite the recent proliferation of health apps, on average, relatively few consumers report using them to help them decide whether to seek care, with the exception of people under the age of 40. Out of all health information sources, consumers are least likely to check with their insurer or call a nurse hotline when deciding whether to seek care.

People under the age of 40 are most likely to use the web to decide whether they need care, and they also consult several other sources more often. **Consumers under 40 are twice as likely to use health apps, consult with pharmacists, call their insurer, or call a nurse hotline as older consumers when determining if they need care.**

FIGURE 15.

Web, Friends and Family are Top Sources in Deciding *Whether* to Seek Care



NOTE: 95% Margin of error = ±3%. Variables include Q27_* by xLowIncome.

CONSUMER VIEWPOINT ON SEARCHING THE WEB FOR CARE

"For me, when I was sick, I just did my Googles. I was like, 'I know I can Google this. It will help me right now.' So I just did that. I just did my Googles."

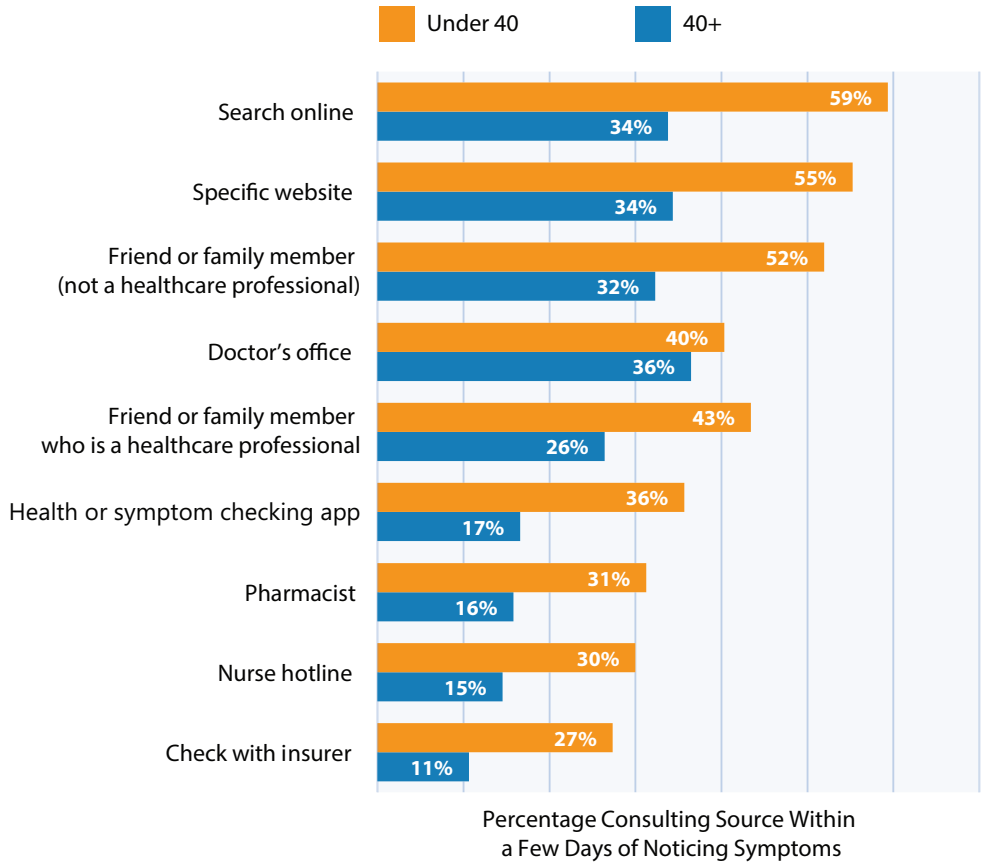
—Lower-income White man in his 20s, Uninsured, Washington, DC

IMPLICATION

To reach different consumer segments, health care information must be available through different channels. Apps and web resources may primarily reach younger consumers but not older consumers, who often prefer to call a doctor's office.

FIGURE 16.

Consumers Under 40 More Likely to Use All Information Sources in Deciding *Whether* to Seek Care



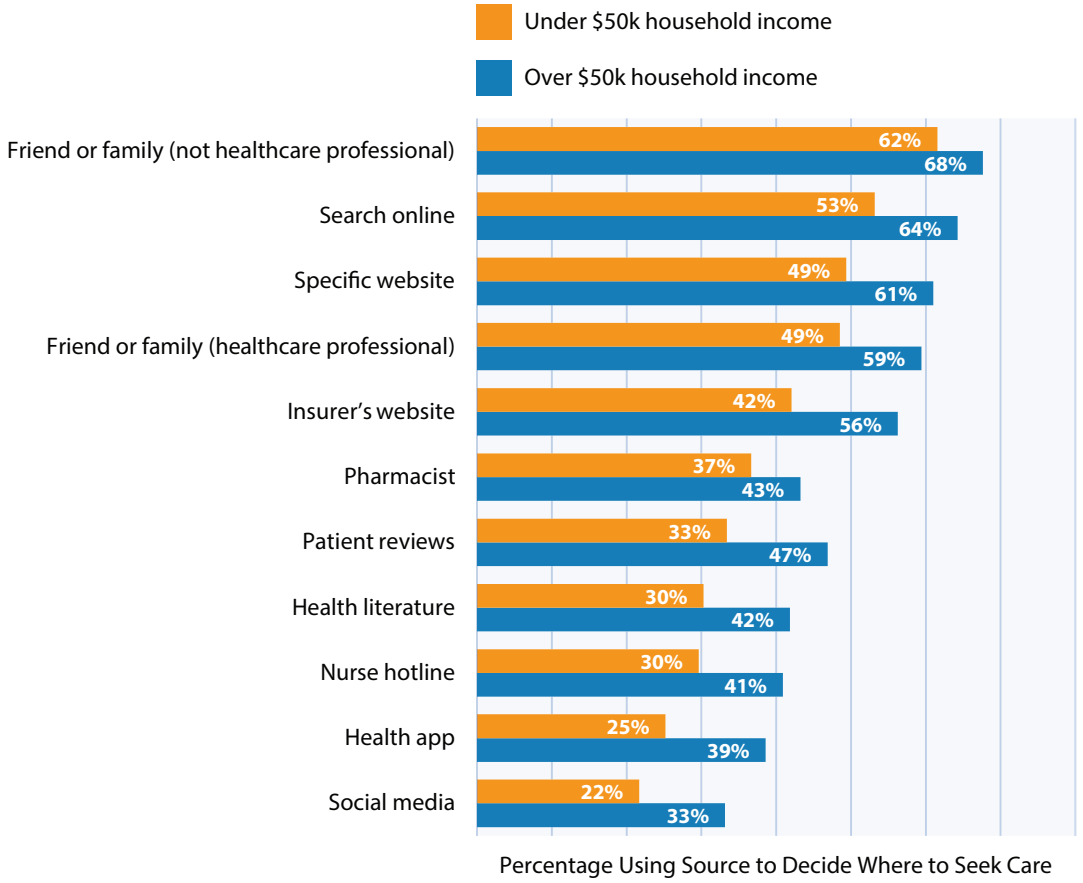
NOTE: 95% Margin of error = ±3%. Variables include Q27_* by xAge.

PERSONAL REFERRALS AND WEB SEARCHES ARE TOP SOURCES FOR DECIDING *WHERE TO GO* FOR CARE.

When deciding where to go for care, people most frequently consult friends and family (65%). Web searches (59%), specific websites (55%), friends and family who are health care professionals (54%), and insurer websites (49%) are also frequently used information sources. Trends between middle-income consumers and lower-income consumers are generally similar, but middle-income consumers consulted all sources more frequently. **Patient reviews are influential when choosing a specific physician, but less so in choosing a facility.** When deciding on a facility, only around one in ten consumers say they check reviews. However, **42% use reviews to select a doctor.**

FIGURE 17.

Friends and Family and Web are Top Sources in Deciding *Where* to Seek Care



NOTE: 95% Margin of error = ±3%. Variables include Q33_* by xLowIncome.

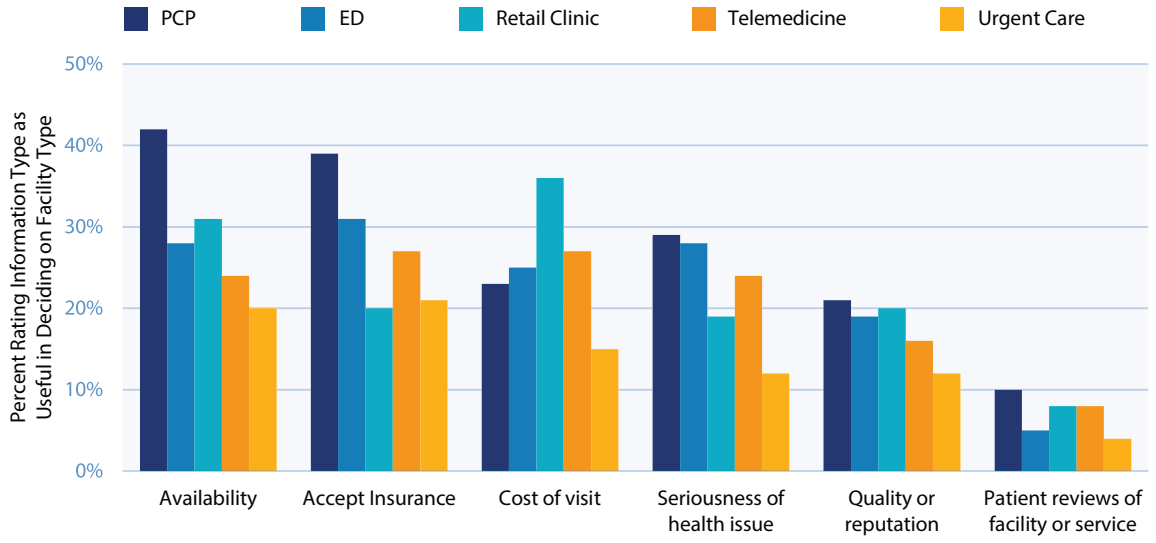
CONSUMERS VALUE DIFFERENT TYPES OF INFORMATION WHEN DECIDING WHETHER TO VISIT A PCP, URGENT CARE CENTER, RETAIL CLINIC, TELEMEDICINE, OR EMERGENCY DEPARTMENT.

When deciding where to go for care, consumers valued the most amount of information when deciding whether to see a primary care provider. **The most helpful considerations in seeing a PCP are availability for appointments (42%) and if the patient's insurance would be accepted (39%).** Quality information (21%) and facility reviews (10%) are viewed as less important considerations. In our consumer interviews, most people were interested in quality information, but were unaware if it was available. Information seeking behavior is similar for lower- and middle-income consumers.

Consumers rate all information types as unhelpful when deciding whether to visit an urgent care clinic. The information types consumers report as most helpful are insurance acceptance (21%) and availability (20%). Quality information (12%) and facility reviews (4%) are viewed as less important. Given how little information is sought in choosing or visiting an urgent care clinic, **consumers may not see urgent care clinics as differing from one another in important ways.**

FIGURE 18.

Consumers Value Different Information Types When Choosing a Facility for Care



NOTE: 95% Margin of error = ±2%. Variables include Q35A_*, Q36A_*, Q37B_*, Q39_*, and Q41_*.

When consumers consider a retail clinic, such as MinuteClinic, they value more information overall than when considering an urgent care clinic. The cost of the visit is the most valuable information when considering a retail clinic (36%), more so than local availability (31%) or insurance acceptance (20%), which are the most important information types when considering a PCP. Cost information is more valuable when considering retail clinics than for any other facility type, and insurance information is the least important of any facility type. This may indicate **patients are more likely to perceive a retail clinic visit as an economic transaction as compared to a visit to their PCP or other care facility.**

When considering telemedicine, consumers value several factors similarly, including availability (24%), acceptance of insurance (27%), cost of visit (27%), and seriousness of health issue (24%). Like all care types, quality information (16%) and patient reviews of services (8%) are not highly valued. **When considering telemedicine, consumers value more information than they do when considering urgent care.**

Consumers value more information in deciding whether to visit an emergency department than whether to visit an urgent care facility or retail clinic. Lower-income people are more likely to value insurance acceptance when deciding whether to visit an emergency department, while middle-income people are more likely to value quality information.

IMPLICATION

Insurance information, availability, and cost are top factors in choosing a facility. Make this information transparent to help attract consumers. Reviews are more valuable in selecting a provider than a facility.

SUMMARY

- **When deciding *whether* they need care, consumers most often tend to search for information online first, and then ask friends and family or call a doctor's office.**
- **When deciding *where to go* for care, consumers tend to ask friends and family for information first, and then search online.**
- **Lower-income people consult the fewest sources of information** to help them decide whether to seek care or where to go for care.
- **When people are choosing between different care facilities, they want information about insurance accepted and appointment availability.**
- Consumers consider the **most information when choosing a PCP.** They consider the **least information when choosing an urgent care center.**
- **Retail clinics may be viewed more as an economic transaction** than other care types.
- **Consumers value patient reviews of providers much more than reviews of facilities.**
- **Lower-income consumers are more likely to value cost information when making health care decisions, while middle-income people are more likely to value quality information.**

Further Reading: Deciding to visit the emergency department for non-urgent conditions: A systematic review of the literature, American Journal of Managed Care
https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4156292/

CONSUMER HEALTH CARE DECISIONS

Choosing a Doctor

While many consumers have become used to detailed comparison shopping, this approach can be more difficult when choosing a doctor, as information about doctors can be hard to find or even quantify. As a result, referrals and online reviews are consumers' top information sources when choosing a doctor. Consumers rely on others' personal experiences to learn about prospective physicians. **While reviews are influential when used, many consumers find online patient reviews unintentionally.** Many of the consumers we spoke with, particularly those with lower-incomes, had firsthand experience feeling disrespected by health care providers. Thus, a potential doctor's **bedside manner is a defining metric of quality**, alongside professional skill. However, this information can be difficult for health care consumers to find from traditional sources of quality information or outside of patient reviews.

WHEN CHOOSING A NEW DOCTOR, PATIENTS SEEK ADVICE FROM FRIENDS AND FAMILY, FROM PROVIDERS, AND FROM PATIENT REVIEWS.

Survey participants report that **referrals made by friends and family members or by providers are the most important sources of information they use when choosing a new doctor**, regardless of income. **Patient reviews** and **provider directories** are also rated highly.

MOST IMPORTANT SOURCES IN SELECTING A DOCTOR

1. Referral from friend or family
2. Referral from provider
3. Patient Reviews
4. Provider directory from insurer

PATIENT REVIEWS ARE HIGHLY INFLUENTIAL, BUT UNDERUTILIZED.

While only 42% of survey respondents had used patient reviews, of those that did, 83% say reviews influenced their choice of doctor. This suggests an expanding role for patient reviews in the future, as more people become aware of them and have a need to choose a new doctor. **More than half of middle-income patients under the age of 50 use patient reviews**, and usage is especially high (64%) for consumers 25 to 39 years old.

While reviews are generally influential across all consumer groups, **many consumers we interviewed said they found reviews unintentionally while searching for other information**. Consumers in poorer health are more likely to find reviews without intending to (43%) compared to those in better health (33%).

Once our interviewees found review sites, they often used them when looking for potential providers. Interview participants described taking a discerning approach to evaluating reviews, looking at date stamps, whether the reviewer was dissatisfied with aspects of the facility rather than the provider, whether the writing appeared authentic, and the number of reviews that were available. The consumers we interviewed evaluated these factors together to determine the usefulness of each review.

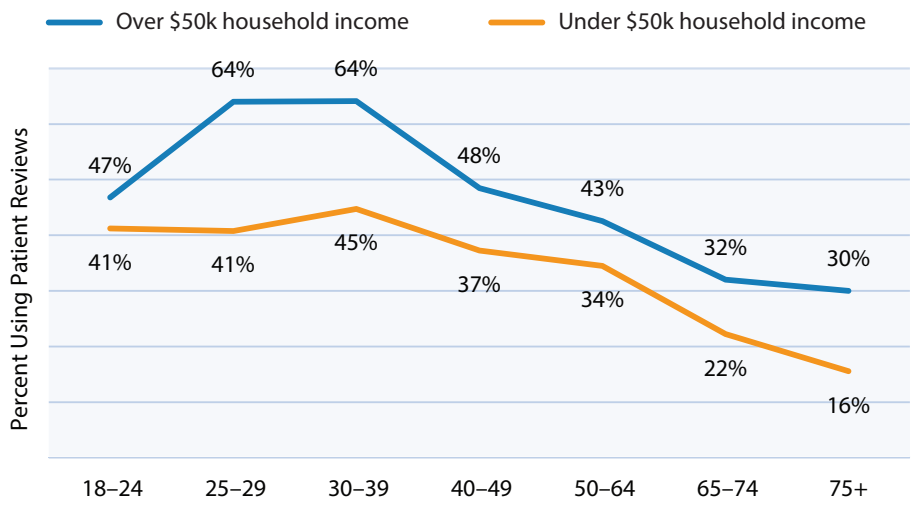
CONSUMER VIEWPOINT ON REVIEWS

"Seeing a few negative reviews is good because I assume that not all of them are paid for."

—Lower-income White man in his 30s, Medicaid, Washington, DC

FIGURE 19.

Lower-income and Older Consumers Less Likely to Use Patient Reviews



NOTE: 95% margin of error varies for each age and income group, ranging from ±5 to ±8%. Variables include Q17 by xAge7 and xLowIncome.

According to survey respondents, the most important content in patient reviews include self-reported information on whether insurance is accepted, whether the doctor treats patients with respect, a doctor's professional skill as a physician, and a doctor's use of shared decision-making. Consumer priorities are broadly similar across income levels. While consumers cite reviews as useful in making a first appointment, many also stress the importance of then having a positive personal experience in order to maintain a relationship with their provider. Lower-income consumers are less likely to use reviews (34%) compared to middle-income consumers (49%). Older consumers are also less likely to use reviews than younger consumers.

CONSUMER VIEWPOINT ON REVIEWS

"I do look at reviews and see what people say about that doctor. Even though I don't know those people, if there's 10 reviews and seven of them have bad things to say, naturally I would just cross that doctor off my list and go to look at a different one."

—Lower-income White caregiver in her 50s, Medicaid, Illinois

IMPLICATION

Patient reviews are highly influential, but also underutilized by older and lower-income consumers. Given the ability of patient reviews to inform provider choice, payers and providers should promote awareness of reviews when consumers may be looking for a doctor, as well as encourage patients to write reviews of their own.

MOST IMPORTANT INFORMATION IN CHOOSING A DOCTOR	LEVEL OF DIFFICULTY TO FIND
1. Treats patients with respect	**Difficult** to find *(5th most difficult out of 20)*
2. Accepts insurance	**Easier** to find *(15th most difficult out of 20)*
3. Shares in decision-making	**Difficult** to find *(4th most difficult out of 20)*
4. Is responsive to phone calls	**Difficult** to find *(6th most difficult out of 20*
5. Has adequate professional skill	**Somewhat difficult** to find *(11th most difficult out of 20)*

IMPORTANT PROVIDER INFORMATION CAN BE DIFFICULT TO FIND.

When choosing a new doctor, multiple pieces of information are rated as "important" by consumers. The most important information includes: whether a doctor 1) treats patients with respect, 2) accepts a patients' insurance, 3) shares in decision-making, 4) is responsive to phone calls, and 5) has adequate professional skills.

Consumers report the most difficult information to find relates to prior malpractice suits, whether a doctor can be seen "same day," sensitivity to patient feelings, and whether a doctor treats patients with respect or shares in decision making. **Both whether a doctor treats patients with respect and whether a doctor shares in decision-making are considered among the most important factors to weigh when choosing a new doctor, but are also ranked as the most difficult information to find.** Many interviewees describe looking at **physician photographs** to try to gauge provider warmth.

CONSUMER VIEWPOINT ON PROVIDER PHOTOGRAPHS

"When I look at a doctor's picture, I feel like I can tell how that person would be. 'Well, he looks like he would be mean.' 'Well, he looks like he doesn't care.' It's the expression on his face."

—Lower-income White caregiver in her 50s, Medicaid, Illinois

IMPLICATION

Patients seek out providers who are respectful. In addition to being the right thing to do, treating patients with respect and sensitivity can provide a competitive advantage. Payers and providers can demonstrate positive patient-provider relationships by promoting their patient reviews, patient satisfaction scores (such as CAHPS and H-CAHPS), and other indicators of good patient-provider relationships.

SUMMARY

- Consumers rely on referrals and reviews when choosing a new doctor, and **tend to rely on reviews of the doctor rather than the facility.**
- **While only 42% have used patient reviews, of those that did, 83% say it influenced their choice of doctor.**
- **Respect and sensitivity are among the most important qualities that people want in a physician**, on par with professional skill and accessibility.
- **Information about physician respect and sensitivity is often difficult to find.**
- **More than half of middle-income patients under the age of 50 use online reviews to choose doctors**

Further Reading: Finding quality doctors:
How Americans evaluate provider quality in the United States, AP/NORC
http://www.apnorc.org/projects/Pages/finding-quality-doctors-how-americans-evaluate-provider-quality-in-the-united-states.aspx

CONSUMER HEALTH CARE DECISIONS

Comparing Treatment Options and Staying Healthy

Consumers face a wide range of information sources when choosing between treatment options and learning how to stay healthy. When we asked interviewees to tell us about how they search for this kind of health information, most participants said they follow a similar course of action: they begin with an online search, especially when searching for information about how to be healthy. This was true of every group we interviewed, regardless of insurance status, income, race, or gender. However, when consumers want information about different medical procedures, they are also very likely to consult their physician in addition to searching online. Respondents with lower-incomes follow the same general trend when seeking information about staying healthy, but are slower to consult each source.

FOR DECIDING ON TREATMENTS AND MANAGING HEALTH, THE WEB, PROVIDERS, AND FRIENDS AND FAMILY ARE TOP INFORMATION SOURCES.

When consumers search for information on managing health, a web search is usually consumers' first course of action. General web searching (50%) using sites such as Google, is usually the initial step followed closely by visiting a specific website (43%) such as WebMD or Mayo Clinic. Physicians are also consulted early on when a health need arises, though their opinion is sought more when considering different treatment options (47%) than when learning about staying healthy (39%). Friends and family members are also consulted.

EARLIEST SOURCES SOUGHT FOR MANAGING HEALTH

1. Search online
2. Doctor
3. Specific website
4. Friends and family

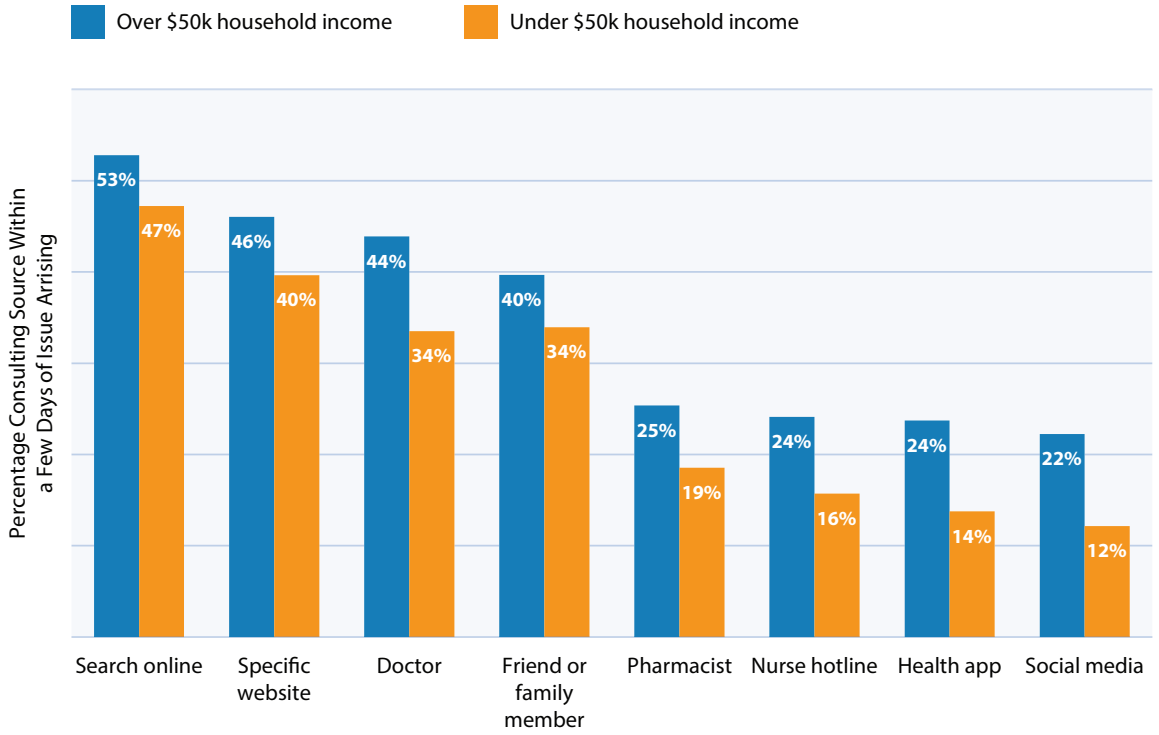
LOWER-INCOME CONSUMERS LESS LIKELY TO CONSULT ALL INFORMATION SOURCES WHEN A HEALTH ISSUE ARISES.

When experiencing a health issue, on average, **middle-income consumers consult all types of health information sources earlier than those with lower-incomes**. People with lower incomes may have many competing priorities for their time and resources. This was frequently voiced in interviews; consumers who did not know how they would pay their electric bill did not prioritize health care. Notably, although many health care organizations maintain a social media presence and offer mobile apps, **social media and apps are the least consulted source for both staying healthy and learning about treatment options.**

In our interviews, several consumers described pharmacists as surrogate providers, available for consultation without an appointment or out of pocket cost. Survey results show that **consumers ask pharmacists about health management as often as consumers use nurse hotlines.**

FIGURE 20.

Searching Online, Doctors, Health Websites, and Friends and Family are Earliest Sources Consulted for Health Management Information



NOTE: 95% margin of error = ±3%. Variables include Q43_* by xLowIncome.

LOWER-INCOME CONSUMERS MORE LIKELY TO SEARCH FOR HOW TO MANAGE SPECIFIC HEALTH CONDITIONS—INCLUDING WORSENING CONDITIONS.

We asked survey respondents about the kind of information they looked for when searching for general health information. When consumers seek information on general health, they look most for general healthy living advice (48%), how to eat well (46%), and how to diagnose a condition (45%). In general, **lower-income people are more likely to search for what to look for when a condition worsens** (38%) compared to middle-income people (32%). This may be because lower-income people are more likely to self-ration their doctor visits and seek medical advice only in severe circumstances.

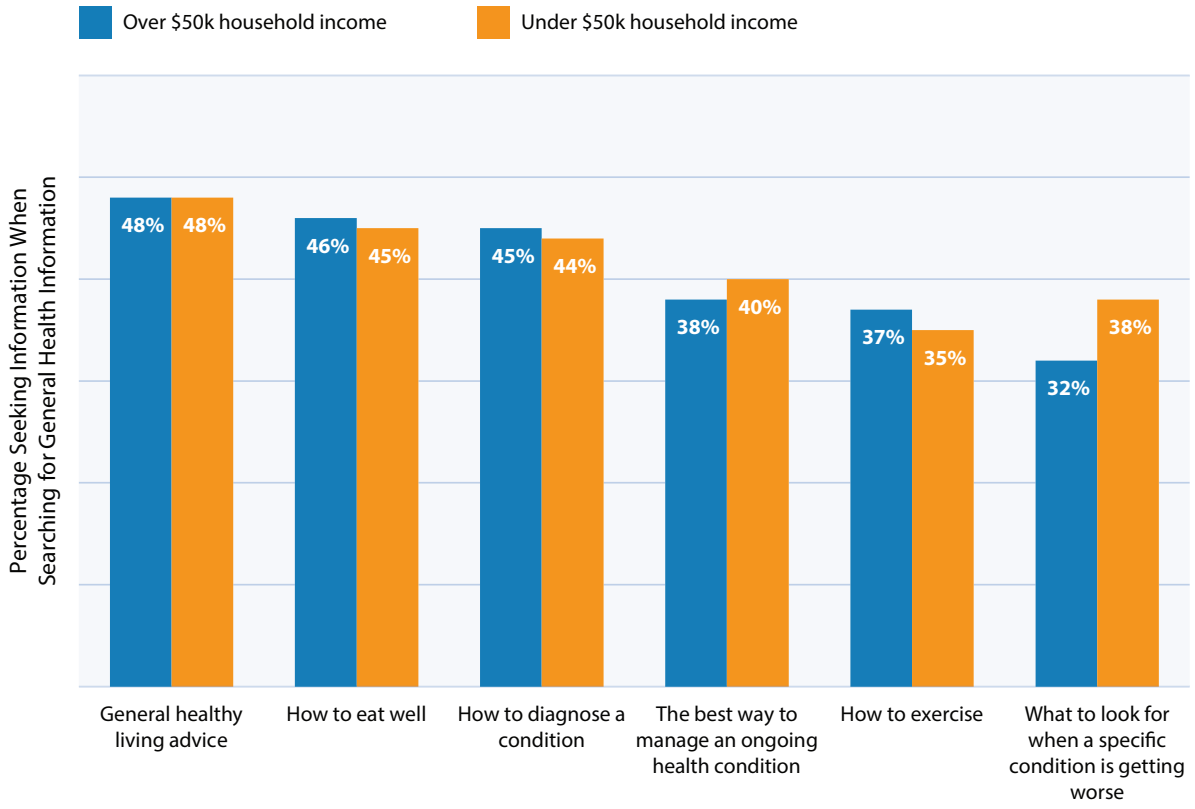
CONSUMER VIEWPOINT ON COMPETING PRIORITIES FOR LOWER-INCOME CONSUMERS

"I'm trying to figure out still why I got an $800.00 utility bill and then you want me to turn around and worry about health insurance? You got to worry about your immediate living first before you can worry about health insurance."

—Lower-income Black woman in her 30s, Uninsured, Michigan

FIGURE 21.

Lower-income Consumers More Likely to Search for How to Manage Specific Conditions



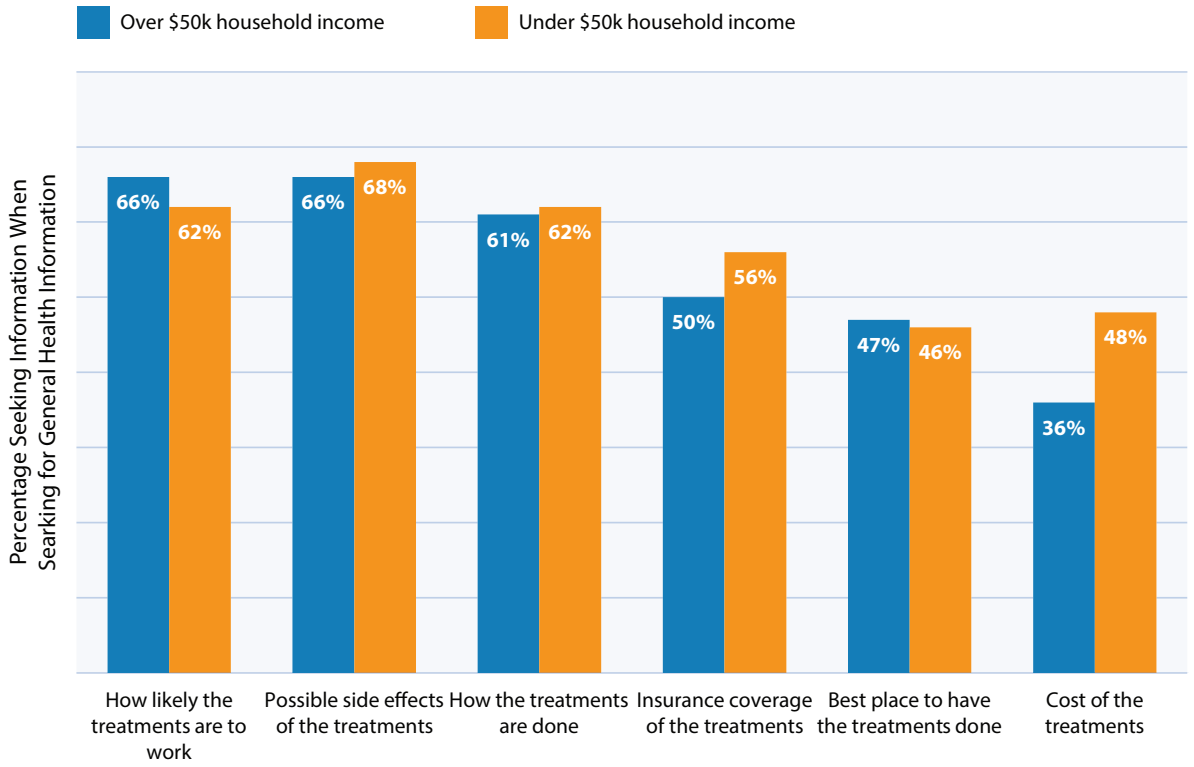
NOTE: 95% margin of error = ±3%. Variables include Q45_* by xLowIncome.

LOWER-INCOME CONSUMERS MORE LIKELY TO SEARCH FOR COST OF TREATMENT.

We also asked respondents about the kind of information they sought when considering their treatment options. When consumers seek information on treatment options, they look most for information about side effects (65%), likelihood of successful treatment (63%), and the treatment regimen (60%). **Lower-income consumers are more likely to seek out information about insurance coverage and cost of the treatments** compared to middle-income people.

FIGURE 22.

Lower-income Consumers More Likely to Search for Insurance Coverage, Cost of Treatments



NOTE: 95% margin of error = ±3%. Variables include Q48_* by xLowIncome.

OPPORTUNITIES REMAIN FOR PROCEDURE COMPARISONS.

During our interviews, **almost all consumers said they were unaware that cost and quality information was available for different medical procedures**, but most people indicated an interest in learning more. In support of this, **integrating comparisons of procedures by facility into generalized search results (e.g. via Google) is rated as one of the most useful possible health care information services** (Key Finding 2). Consumers desire cost and quality information, but have trouble finding it. Making comparison data available by default when consumer decisions are imminent, may help consumers make much more informed decisions.

IMPLICATION

Search engines such as Google can facilitate procedure comparisons by including comparison results with search results, similar to existing comparisons of restaurants. Payers can offer similar comparisons through mail or phone when a procedure is likely to be upcoming.

SUMMARY

- When looking for **general health information or treatment options, consumers tend to search online first and then ask their providers for advice.**
- **Lower-income consumers are slower to consult all health information resources when a health issue arises** compared to those with middle incomes.
- **Lower-income consumers** are more likely to look for information about how to know **if a condition is getting worse** and for **cost information about procedures.**
- Consumers are mostly **unaware of cost and quality comparisons** of procedures or facilities and rarely search for them, but indicate these **comparisons would be very useful.**

Further Reading: Treatment Options, AHRQ
http://www.ahrq.gov/patients-consumers/treatmentoptions/

CONSUMER HEALTH CARE DECISIONS

Online Consumer Resources: Patient Portals and Online Booking

Over the past 10 years, a wide range of new online health information tools have become available to consumers, including patient portals, patient reviews, and online booking platforms. While this proliferation has served to empower many consumers, the absence of dedicated or tailored platforms also risks vulnerable consumers being left behind. More vulnerable consumers may not be aware of new tools, their insurance may not be integrated with them, or they may have limited internet access or be less internet savvy. Online resources could be designed for wider accessibility.

PATIENT PORTALS: LAB RESULTS, VISIT SUMMARIES AND NOTES, REFILLS, BILLING, AND BOOKING ARE TOP FEATURES.

Patient portals allow patients to access their health information online and view recent visit summaries, communicate with providers, and request prescription refills. About half of survey respondents say they have used a patient portal (49%), but **portal usage is more common among middle-income patients (56%) than lower-income patients (40%)**. Portal usage rates are similar across gender and health status. **Caregivers of children with serious medical needs are far more likely to use portals (67%)** than caregivers of adults (51%) and non-caregivers (45%).

Satisfaction rates with patient portals are not especially high; only 29% of patients say they are "extremely satisfied" with their portal. However, another 47% report they are "satisfied" but not "extremely satisfied," suggesting portals are moderately satisfying with room for improvement.

Consumers say the most important feature for a portal is the ability to see lab and imaging results (86% rate as important). Other top features include seeing visit summaries with instructions (78%), seeing visit notes from an appointment (76%), the ability to request prescription refills (75%), seeing billing details (72%) and online booking (72%). Overall, lower and middle-income consumers have similar priorities for patient portals.

CONSUMER VIEWPOINT ON PATIENT PORTALS

"I just joined the portal a year ago and I love it. It's like a new discovery for me because I'll send her an email and within a day, she'll respond and she'll say 'Your script is at Walgreens' or 'How are your symptoms,' stuff like that. So I like it. I don't have to pay out the copay every time just to go see her."

—Caregiver White woman in her 40s, private insurance, Illinois

IMPLICATION

Patient portals should incorporate top features, such as lab and imaging results, visit summaries and notes, refill requests, billing details, and online booking. Caregivers and patients with chronic disease may benefit from links to resources and support groups. Portals have significant room for improvement.

ONLINE BOOKING: LESS COMMON, BUT POPULAR WITH YOUNGER PATIENTS.

Online booking for medical appointments is still relatively uncommon, and only **18% of survey respondents report using online booking**. Online booking is more common for middle-income consumers (26%) than for lower-income consumers (14%). People in better health (22%) are more likely to use online booking than those in poorer health (15%). Caregivers of children are far more likely to use online booking (43%) than caregivers of adults (23%) or non-caregivers (15%). Online booking is also less common for people older than 50 (10%) and most common for people in their 30s (33%). **Among users, 88% are "satisfied" or "extremely satisfied" or with online booking**, indicating a high level of user satisfaction.

Online is most popular with younger patients, though there are significant differences by patient income. **Nearly half of middle-income consumers ages 25 to 39 use online booking (43%), while only 19% of lower-income consumers in the same age group use online booking.** Among older consumers, the income gap in online booking diminishes.

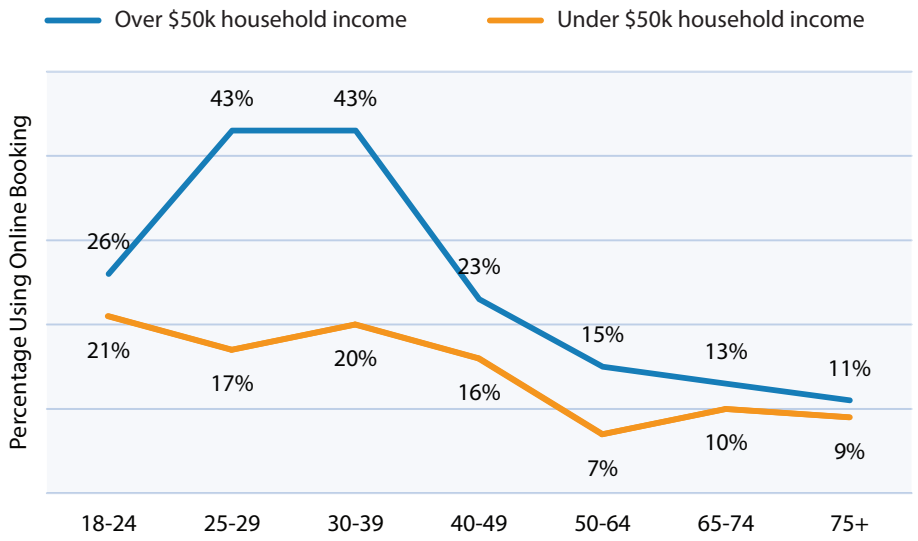
CONSUMER VIEWPOINT ON ONLINE BOOKING

"Booking online is just easier scheduling. For me, that's half the reason I sometimes don't call the doctor, because I don't want to deal with the phone conversation. I mean, I'm lazy, and if it's right on my phone and I can do it in 60 seconds, that would be a lot easier."

—Lower-income White man in his 20s, private insurance, Virginia

FIGURE 23.

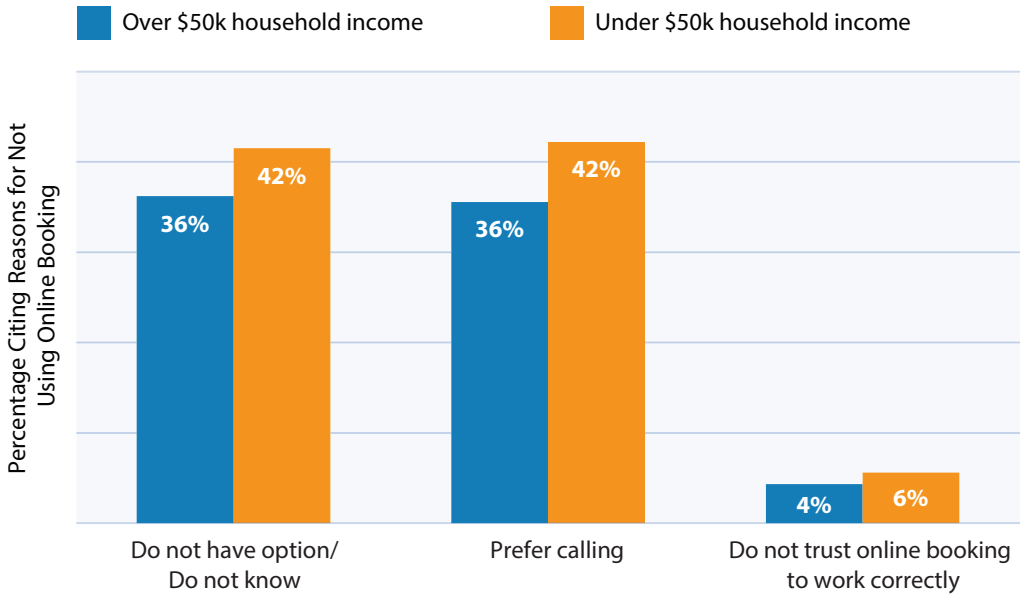
Young, Middle-income Consumers Most Commonly Use Online Booking



NOTE: 95% margin of error varies for each age and income group, ranging from ±5 to ±8%. Variables include Q43_2 by xLowIncome.

FIGURE 24.

Consumers Not Booking Online Split Between Lack of Availability/Awareness, Preference for Phone



NOTE: 95% margin of error = ±3%. Variables include Q34E_* by xLowIncome.

The most common reasons for not using online booking are that consumers either prefer to speak on the phone or are not aware of the option. In general, lower-income people are more likely to prefer calling and to not be aware of online booking. **Encountering difficulties when trying to use online booking is low, with fewer than 5% of consumers citing difficulty as a reason they do not use online booking.**

IMPLICATION

Many consumers would be open to online booking, but don't have or don't know about the option.

While online booking is selected as a top improvement as a health care information service (see Key Finding 2), consumers are also very satisfied with existing appointment booking options (see Key Finding 1), and some consumers may prefer phone booking. Online booking appears to be a highly desirable convenience for consumers for younger and middle-income consumers, but phone booking is also acceptable to most consumers.

SUMMARY

- **Only 29% of consumers are extremely satisfied with patient portals**, leaving room for improvement in patient satisfaction.
- For patient portals, the most high-demand features are **lab results, visit summaries with instructions, visit notes from an appointment, prescription refill requests, billing details, and online booking.**
- Many consumers are **open to online booking, but are not aware of the availability.**
- **There is increasing demand for online booking**, especially among younger and middle-income patients.

Further Reading: Lessons from more than a decade in patient portals, Health Affairs
http://healthaffairs.org/blog/2016/04/07/lessons-from-more-than-a-decade-in-patient-portals/

RECOMMENDATIONS

Based on findings from our research, Oliver Wyman and Altarum Institute propose several recommendations for those working to better serve vulnerable healthcare consumers. This section presents general recommendations for the healthcare marketplace as well as specific recommendations for providers, health plans, policymakers, and healthcare information organizations.

Provide information in the most accessible manner

Ensure that information is easy to find, optimized for general web searches (e.g. Google searches), mobile-friendly, and written at a fourth grade reading level. Proactively offer translated resources (e.g. Spanish, Chinese) rather than require that consumers request them on their own.

Prioritize greater cost transparency

Communicate costs and insurance coverage clearly, using a variety of different channels (e.g. print, online), before they are incurred. Utilize tools that are simple and easy for consumers to understand.

Focus on the community, not just the individual

Capitalize on existing social networks by conducting outreach in community settings (e.g. churches, markets and schools) rather than solely via traditional hospital, insurer, and government channels to connect with vulnerable consumers. This type of outreach may help dispel skepticism and ensure that trusted sources of information (family and friends) have the best and most accurate information to share with others in their community.

Engage caregivers more deeply

Promote and tailor resources and tools to caregivers. Develop caregiver-specific resources such as tools that can connect caregivers to respite care and financial assistance, and ensure caregivers are aware of them.

Rebuild trust and respect

Treat consumers with respect, regardless of coverage type or demographics. Maintain and promote a culturally sensitive atmosphere across all organizations. Consider developing and promoting measures that help denote whether patients feel respected by particular providers. Hold providers accountable for being respectful to patients.

Link efforts to higher-priority initiatives

Sustain momentum for health information improvement efforts by linking initiatives to broader organizational goals and by tracking outcome metrics (e.g. medication adherence rate increases in response to provider cultural sensitivity training, decrease in ER visits through better communication of visit costs, etc.).

RECOMMENDATIONS FOR PROVIDER ORGANIZATIONS TO CONSIDER

- Standardize healthcare vocabulary to ensure information is simple and clear for all reading levels.
- Incorporate costs into shared decision-making when discussing treatment regimens.
- Make health care prices and costs available to patients online.
- Build respect and trust with patients by investing in training for appropriate physician bedside manner and comprehensive care teams that are better suited for building patient relationships.
- Train providers to treat individuals equally, regardless of insurance status or income level.
- Ensure providers smile in their professional photos, as appearance is often a proxy for warmth and friendliness.
- Consider offering online booking services.
- Promote and encourage use of online patient reviews.
- Make alternative language resources available proactively, alongside English language materials.
- Build support for caregivers into the clinical workflow to ensure their personal needs are being met.
- Engage family members and caregivers throughout the care process to reach patients more effectively.
- Ensure that websites and any web tools are mobile-optimized.

POINTS FOR HEALTH PLANS TO CONSIDER

- Standardize healthcare vocabulary to ensure information is simple and clear for all reading levels.
- Ensure that cost transparency tools are mobile-friendly and intuitive, limiting complicated customization options and avoiding large price ranges.
- Leverage the power of relationships to motivate good health decisions by investing in online social support, peer competition, and provider review platforms.
- Motivate providers to treat their patients with respect through education and financial/cultural incentives.
- Build trust by hiring culturally sensitive staff that are familiar with the community.
- Make caregiver resources (e.g. respite care, financial assistance) available and easily accessible.
- Share information with physicians about the importance of smiling and appearing approachable in their provider directory photos.

Points for Health Plans to Consider, continued...

- Leverage community-based organizations like churches, grocery stores, and homeless shelters for sharing healthcare information.
- Ensure that websites and any web tools are mobile-optimized.
- When consumers are likely to be deciding on a procedure or other major medical decision, send relevant price and quality comparisons directly to the consumer.

POINTS FOR POLICYMAKERS TO CONSIDER

- Standardize healthcare vocabulary to ensure information is simple and clear for all reading levels.
- Share Medicaid claims data with health plans and providers to enable the development of cost and quality transparency resources.
- Partner with health plans and providers to connect consumers to existing public resources including food, financial assistance and other resources.
- Ensure any consumer-facing websites are mobile-optimized.

POINTS FOR HEALTH INFORMATION COMPANIES AND PLATFORMS TO CONSIDER

- Standardize healthcare vocabulary to ensure information is simple and clear for all reading levels.
- Develop resources for caregivers to access—both for care of their loved ones as well as for their own care.
- Proactively offer Spanish language (and other language translations based on customer base) to avoid the extra step of having to ask for the information.
- Ensure tools are mobile-friendly and not accessible only via apps.
- Collaborate with payers and providers to obtain the latest health care information.
- Develop means of providing real-time alerts on an as-needed or proactive basis such that consumers have the information they need at the right place, at the right time.
- When consumers appear to be approaching a medical decision, such as choice of doctor or procedure, proactively offer comparison information, such as cost and quality.

METHODOLOGY

SUMMARY

The Right Place, Right Time Consumer Perspectives report is based on three phases of research. The first phase involved semi-structured interviews of 14 vulnerable consumers to explore consumer experiences searching for and using health care information. From these interviews, we developed a focus group discussion guide and conducted 5 focus groups with 51 vulnerable consumers. We used the results of the interviews and focus groups to develop a mixed-mode nationally representative survey, completed by 4068 adults. The interviews, focus groups, and survey were conducted by Altarum Institute in collaboration with Oliver Wyman and the Robert Wood Johnson Foundation. This research was funded through a grant from Robert Wood Johnson Foundation.

Full survey results are included in a Topline Report available at:
www.altarum.org/RightPlaceRightTime

INTERVIEWS

In March and April 2016, we conducted interviews with 14 vulnerable consumers in Michigan, Illinois, Texas, and California, representing a diversity of ages, race, and gender. The interviewees included Medicaid beneficiaries, those without health insurance, family caregivers, and Spanish speakers. One Spanish speaker was a medical social worker who had become fluent in English, and spoke about her time as a former non-English speaker and as someone who works with a large volume of non-English-speaking patients. Participants were asked how and when they search for health care information, where they encounter barriers to information, and their views on possible improvements to health care information. Where possible, interviews were conducted in participants' homes. Interviews were recorded, transcribed, and analyzed for key content themes using a Grounded Theory approach.

FOCUS GROUPS

In April 2016, we conducted five focus groups with 51 vulnerable consumers to further explore content themes from the individual interviews. Focus group locations included three in Chicago (Lower-income Medicaid/Uninsured, Family Caregivers, and Spanish speakers), one in Battle Creek, Michigan (Lower-income Medicaid/Uninsured), and one in Washington, DC (Lower-income Medicaid/Uninsured). Focus group participants were balanced across age, race, and gender. All focus groups were moderated by trained researchers. The Spanish speakers' focus group was conducted in Spanish. All focus groups were video recorded, transcribed, and analyzed for key content themes. Consumer viewpoints used in this report were quotations from these interviews and focus groups. Some quotes were edited for length and clarity.

SURVEY

The survey used a multi-mode design, using a combined sample of address-based sampling and a census-balanced web panel. A total of 4068 consumer completed the survey, including 444 responses from the mail sample and 3624 from the web sample. All participants had the opportunity to complete the survey in Spanish, and participants recruited by mail had the option of completing the survey by mail or online. The online survey included some additional follow-up questions for low-prevalence groups, such as respondents who were uninsured, caregivers, or had a diagnoses of diabetes. These questions were only shown to eligible participants, as determined by their prior responses. The online survey was designed to be completely compatible with computers and mobile devices to allow input from participants without access to a computer.

MAIL SAMPLE

Mailed surveys were sent to a random address based sample (ABS) of 4000 US residential addresses. This sampling procedure excluded PO boxes and addresses flagged as commercial, educational, seasonal, or vacant. Participants received a cover letter explaining the purpose of the survey, a $2 cash pre-incentive, a survey booklet, and prepaid return envelope. Participants had the option of completing the survey booklet by mail or completing the survey online. A reminder letter was sent to non-participating invitees 3 weeks after the initial invitation. After completing the survey, participants were mailed $10 in cash as an incentive. Out of the sample of 4000 residential addresses, 519 were returned as postal non-deliverable, 8 invitees were deceased, and 388 completed the survey. Using the American Association of Public Opinion Research RR3 formula, this yields a response rate of 11.2%.

WEB PANEL SAMPLE

In addition to the address-based sample, we also used a non-probability web panel sample of 3680 participants provided by Scientific Sampling International (SSI). The panel demographic characteristics were designed to be US census balanced for adults ages 18 and over on age, gender, race, income, and use of Spanish as a first language.

WEIGHTING

The final dataset was weighted to adjust the sample characteristics to known population characteristics of the US adult population for gender, age, race and income. Population targets were derived from the US Census Bureau's Annual Estimates of the Resident Population for age, sex, and race (2015) and the US Census Bureau's American Community Survey for household income (2014), which in both cases was the most recent data available. Weighting was done through the WTADJUST procedure of SAS-callable SUDAAN release 11.0.1.

DATA

The anonymized survey data for Right Place, Right Time is available online at www.altarum.org/RightPlaceRightTime. Variable names from the Right Place, Right Time survey dataset are used in figure notes throughout this report.

OPERATIONAL DEFINITIONS OF SURVEY RESPONSES

Throughout this report, we have defined certain survey responses as falling into categories such as "better health" or "poorer health," "accurate" or "not accurate," and "useful" or "not useful." This section describes the operational definitions used to categorize each set of survey responses in this report. In some cases, several similar questions have the same response items and categorization rules. An example question is provided for each categorization. Full question text, response options and frequencies are available in the Topline Report.

SELF-RATED HEALTH Question	Response Options	Categorization
Q4. In general, how would you rate your overall health?	Poor Fair Good	Poorer Health
	Very good Excellent	Better Health

USES MOBILE INTERNET Question	Response Options	Categorization
Q7. How often do you use the internet on a phone or tablet?	Less than once a month At least once a month At least once a week	Does not use mobile most days
	Most days Every day	Uses mobile most days

SATISFACTION WITH INFORMATION TYPE Question	Response Options	Categorization
Q12. Are you satisfied with how easy it is to find and understand the following kinds of information?	Very dissatisfied Dissatisfied Neither satisfied nor dissatisfied	Not satisfied
	Satisfied Very satisfied	Satisfied

USEFULNESS OF INFORMATION SERVICE Question	Response Options	Categorization
Q19–Q24. Would you find [health care information service] to be useful to you?	Not at all useful A little useful Somewhat useful	Not useful
	Very useful Extremely useful	Useful

CONSULTS SOURCE FOR GENERAL HEALTH INFORMATION Question	Response Options	Categorization
Q27. When you are feeling unwell and deciding whether you need to seek medical care, when do you tend to look to each source to understand if you need medical care?	Rarely or never Only when symptoms become severe Several days after noticing symptoms	Does not consult source within a few days
	A few days after noticing symptoms Soon after noticing symptoms	Consults source within a few days

CONSULTS SOURCE FOR GENERAL HEALTH INFORMATION Question	Response Options	Categorization
Q44. When you want to know more about what you can do to stay healthy or self-treat a health condition, how often do you go to these sources for information?	Never Rarely Sometimes	Does not consult source regularly
	Usually Always	Consults source regularly

DIFFICULTY OF FINDING INFORMATION Question	Response Options	Categorization
Q65. How easy or difficult has it been to find out about these kinds of information?	Never tried	N/A
	Very difficult Difficult	Difficult
	Easy Very easy	Not difficult

MEDICATION ADHERENCE Question	Response Options	Categorization
Q77. How often do you take your prescription medications in the dosage and frequency as recommended by your doctor?	Never Rarely Sometimes	Not adherent
	Almost always Always	Adherent

ACCURACY OF INFORMATION SOURCE Question	Response Options	Categorization
Q78. Overall, how much do you believe the sources below to be accurate sources of healthcare information?	Not at all accurate Rarely accurate Somewhat accurate	Not accurate
	Very accurate Extremely accurate	Accurate

INTENTIONS OF INFORMATION SOURCE Question	Response Options	Categorization
Q79. Overall, how much do you think the sources below have the best intentions for you?	Not at all well-intentioned Rarely well-intentioned Somewhat well-intentioned	Not well-intentioned
	Very well-intentioned Extremely well-intentioned	Well-intentioned

FEELS RESPECTED BY DOCTORS Question	Response Options	Categorization
Q80. How often do you feel doctors treat you with respect?	Never Rarely Sometimes	Does not feel respected
	Almost Always Always	Feels respected

SAMPLE CHARACTERISTICS

Total	N	%
All survey respondents	4068	100

Gender	N	%
Male	1947	48
Female	2099	52
Refused	22	1

Age	N	%
18–24	480	12
25–29	352	9
30–39	683	17
40–49	640	16
50–64	1064	26
65–74	497	12
75+	327	8
Refused	25	1

Race and Ethnicity	N	%
White	2544	63
Black	467	11
Asian	211	5
Hispanic	617	15
Other	89	2
Refused	140	3

Annual Household Income	N	%
Under $20k	621	15
$20k–$29k	365	9
$30k–$39k	343	8
$40k–$49k	305	7
$50k–$59k	281	7
$60k–$74k	347	9
$75k–$99k	430	11
$100k–$149k	452	11
$150k+	345	8
Refused	579	14

Health Insurance Status	N	%
Private health insurance	1818	45
Medicare, including Medicare Advantage	951	23
Medicaid	478	12
Other government plan	248	6
No coverage of any type	253	6
State-sponsored health plan	120	3
Don't know	117	3
Refused	82	2

Primary Language	N	%
English	3731	92
Spanish	337	8

Caregiver Status	N	%
Non-Caregiver	3473	85
Caregiver for Adult Only	283	7
Caregiver for Child	300	7
Refused	11	0

TABLE OF CONSUMER PRIORITIES

Survey respondents were asked about their priorities for improving types of health care services overall (Q14). Respondents could select 5 out of 11 health care services to prioritize for improvement. The percentages below indicate the percentage of consumers that prioritized improving each health care service. The color of each table cell corresponds with the magnitude of the number.

FIGURE A.

Consumer Priorities for Improving Health Care Services Overall

	Overall	Over $50k income	Under $50k income	Uninsured	Medicaid	Poorer health	Spanish speakers	Caregivers
Easily see medical costs before visit	58%	58%	58%	71%	47%	55%	45%	50%
More providers who accept insurance	55%	51%	60%	49%	64%	60%	59%	51%
Focus on overall wellbeing	51%	48%	54%	54%	50%	60%	48%	42%
Easy online appointment booking	49%	52%	44%	39%	51%	43%	50%	49%
Expanded doctors' hours	48%	50%	47%	42%	52%	47%	45%	50%
Comprehensive patient portal	45%	47%	42%	43%	42%	44%	36%	44%
Easily see safety record for your doctor	41%	41%	40%	36%	42%	40%	36%	45%
More clinics near you	40%	36%	45%	55%	47%	41%	52%	47%
Get care through telemedicine	29%	33%	24%	28%	29%	22%	28%	39%
Updates to clinic buildings	25%	26%	24%	21%	30%	21%	25%	33%
Resources in my language	12%	10%	14%	22%	15%	11%	45%	13%

Survey respondents were also asked about their priorities for improving the accessibility and understandability of 19 types of health care information (Q13). Respondents could select 5 out of 19 information types to prioritize for improvement. The percentages below indicate the percentage of consumers that prioritized improving each information type. The color of each table cell corresponds with the magnitude of the number.

FIGURE B.

Consumer Priorities for Improving Health Care Information

	Overall	Over $50k income	Under $50k income	Uninsured	Medicaid	Poorer health	Spanish speakers	Caregivers
Doctors' professional experience	47%	49%	45%	43%	50%	45%	64%	54%
Insurance accepted by doctor	45%	43%	47%	39%	50%	45%	45%	44%
Costs before the visit	41%	40%	43%	62%	32%	37%	26%	35%
Insurance coverage details	40%	40%	41%	38%	34%	39%	46%	29%
Cost of medications	31%	29%	33%	40%	24%	37%	22%	20%
Official quality ratings of doctors	29%	32%	25%	24%	29%	26%	22%	37%
When to see a doctor	26%	25%	27%	19%	33%	24%	29%	30%
Doctor's availability for appointments	24%	23%	25%	17%	25%	26%	30%	23%
Patient reviews of doctors	23%	24%	23%	24%	30%	22%	22%	30%
Hospital costs before the visit	23%	23%	24%	31%	15%	23%	17%	15%
General health info	23%	23%	23%	21%	28%	18%	29%	28%
Your personal medical records	22%	22%	23%	22%	25%	26%	20%	19%
How to make appointments	19%	19%	19%	21%	24%	15%	33%	30%
Info about medical billing	18%	19%	17%	19%	11%	18%	9%	10%
Info about different procedures	16%	17%	14%	11%	12%	22%	9%	10%
Chronic disease management	15%	16%	15%	15%	17%	26%	19%	20%
Where to seek care	14%	13%	15%	16%	17%	10%	20%	17%
Official quality ratings of hospitals	13%	15%	10%	10%	11%	12%	10%	11%
Details about outpatient clinics	13%	13%	12%	17%	14%	6%	14%	23%

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