Right Place, Right Time

IMPROVING ACCESS TO HEALTH CARE INFORMATION
FOR VULNERABLE PATIENTS

Consumer Perspectives
Executive Summary

RIGHT PLACE, RIGHT TIME

JANUARY 2017

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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 in the full report at www.altarum.org/RightPlaceRightTime. The anonymized dataset from the Right Place, Right Time survey is also available online.

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*   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.

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

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.

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

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.

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

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.

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

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.

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

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 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

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.

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

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.

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

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.

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

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.

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

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.**

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.

- 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.

FURTHER READING

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RELATED PUBLICATIONS FOR RIGHT PLACE, RIGHT TIME

- Right Place, Right Time: Health information and vulnerable populations,
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- Overcoming lower-income patients' concerns about trust and respect from providers,
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