

# **Consumer Perspectives on Health Care Decision-Making**

## Quality, Cost and Access to Information

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# EXECUTIVE SUMMARY

Increased access to health care data, growing concerns regarding cost, and shifts to greater patient responsibility for medical expenditures have catalyzed attention to “transparency,” to give patients access to health care information that they can use to assess—and make decisions on—the cost and quality of care. New York State (NYS) is in the process of creating an All Payer Database (APD) that will enable new levels of data transparency. This study examined consumer perspectives on health care quality and cost information to inform the development of an online consumer transparency tool.

Focus groups were convened in 2015 in three New York State cities: Buffalo, Albany and New York City. Eligibility criteria included having private insurance, regular health care use, and prior use of publicly available health care data. Individuals with high deductibles were prioritized. Discussion topics included perspectives and preferences regarding quality and cost related indicators and sources, as well as the format for dissemination of information.

Focus group findings include the following:

- Participants infrequently described using quality indicators commonly utilized by health care professionals, such as procedure volume or infection rate, to make decisions about health care providers. Instead, participants focused on provider communication skills, convenience and credentials.
- Participants were often unsure where to go for reliable, objective information about provider quality and cost. Personal recommendations and internet research—most often through sites such as Google and Yelp—were common sources of information. However, internet results were considered inconsistent and required excessive time and patience to navigate.
- Cost was important to participants, but many said they did not seek this information before choosing a provider. Additionally, accurate cost information was often viewed as difficult to obtain.
- Participants identified a need for increased access to objective data and felt a simple, web-based, interactive resource including information on multiple domains was best. Suggested content included information regarding access (e.g., location, hours, wait time), provider training and experience, interpersonal skills, volume and outcomes data, as well as patient reviews.

*If [the data were] somewhere and I knew to go there and put in a doctor's name and have statistics pop up as opposed to me having to figure out what those statistics are, I'd probably look at them and consider them. (Albany focus group participant)*

Findings suggest consumers are not proficient users of health care information and would benefit from increased access to quality and cost data for health care decision-making. However, efforts to provide such information to consumers should recognize the need to ensure individuals have the knowledge, motivation, and sense of empowerment to effectively utilize such data.

# BACKGROUND

Increased access to health care data, growing concerns regarding cost containment, and shifts to greater patient responsibility for health care expenditures have catalyzed expanded interest and attention to health care “transparency,” whereby patients, their advocates and others have access to health care information that can be used to assess—and make decisions on—cost and quality of medical services.<sup>1</sup> Many stakeholders have been involved in these efforts, including, non-profit organizations, insurers,<sup>2</sup> states<sup>3</sup> and the federal government.<sup>1</sup>

In 2011, New York State (NYS) passed legislation enabling the development of an All Payer Database (APD), combining encounter and payment data across payers.<sup>3</sup> Recognizing the APD’s potential to contribute to health care transparency and decision-making among NYS residents, the New York State Department of Health (NYSDOH) and the Department of Financial Services (DFS) are planning a platform for dissemination of cost and quality information to NYS consumers, building on lessons from other states and patient advocate organizations, as well as direct input from NYS residents. Although several public, private and non-profit models exist, use generally remains suboptimal<sup>4</sup>—suggesting the need for expanded consumer input during the development phase. NYSDOH and DFS recognized this need and contracted with the Center for Evaluation and Applied Research at The New York Academy of Medicine to carry out a series of consumer focus groups regarding health care priorities and decision-making. The groups focused on domains, data elements, indicators and dissemination modalities, eliciting information on experience, as well as recommendations, to inform the development of a product or products. This report provides findings from the focus groups.

# METHODS

Between August and December 2015, eight focus groups were convened involving 80 participants: four groups were convened in New York City (45 participants), two groups were convened in Albany (19 participants) and two groups were convened in Buffalo (16 participants). Focus groups were facilitated by two Academy staff. A semi-structured guide was used for the focus groups (see Appendix P36): topics included quality and cost related factors used by consumers in health care decision-making; current sources of consumer quality and cost information; and consumer preferences regarding quality indicators, source, presentation format and methods for promotion and dissemination of products. Focus group participants were asked to complete a brief questionnaire in order to gather basic background on sociodemographics, health care use, and health care decision-making processes. (see Appendix P36)

The size of the focus groups ranged from seven to twelve participants. Recruitment was conducted primarily through a *Craigslist* advertisement, with additional outreach conducted through local community-based organizations. Potential participants were screened via an online survey (see appendix), with a phone follow-up if responses were unclear. Participation was limited to individuals age 18 or older and privately insured. In addition, over the last year, participants had to be regular utilizers of health care (defined as having seen a doctor two or more times in the last year) and had to have used publicly available data to make health care decisions. Individuals with a high deductible ( $\geq$  \$1,000) were prioritized for participation.<sup>a</sup> The research protocol was approved by The New York Academy of Medicine Institutional Review Board and participants were provided with an information sheet describing the research and their rights and protections as study participants. Participant incentives were \$50.

<sup>a</sup> At the start of the study, participation was limited to individuals with a high deductible. The eligibility criteria were loosened due to recruitment challenges and an interest in learning about data use and quality concerns, as well as cost information.

## **Data Management and Analysis**

Focus groups were recorded and professionally transcribed. Transcripts were stored and coded using NVivo, a software package for the management and analysis of qualitative data. A preliminary codebook was developed, including code definitions, and then tested by four members of the research team, each of whom coded a particular transcript independently. Coding issues, including inconsistencies and redundancies, were reviewed and adaptations to the codebook were made. One member of the research team coded all transcripts using the finalized codebook. Coded data, as well as the full transcripts, were used by the research team to systematically examine pre-identified themes (e.g., quality indicators) and themes emerging from the data themselves (e.g., provider interpersonal skills and behavior).

## **Sample Characteristics**

As shown in Table 1, the majority of participants in this study were under age 62, college educated, female, employed full time, and with an annual household income above \$50,000. Just over half of participants were white, 22.5% were African American and 15% were Latino. Approximately 70% had a deductible of \$1,000 or more. Sixty percent (60%) of participants said they spent \$500 or less on out-of-pocket health care costs in the past year.

**TABLE 1. FOCUS GROUP PARTICIPANT CHARACTERISTICS**

	<b>N</b>	<b>%</b>
<b>AGE*</b>		
18 - 35	26	32.5%
36 - 45	22	27.5%
46 - 55	13	16.3%
56 - 64	16	20.0%
65 and older	2	2.5%
<b>EDUCATION</b>		
Less than HS Graduate	1	1.3%
HS Graduate or GED	8	10.0%
Some College but no Degree	15	18.8%
College Degree or Higher	56	70.0%
<b>GENDER</b>		
Male	28	35.0%
Female	52	65.0%
<b>RACE/ETHNICITY**</b>		
White	44	55.0%
Black or African American	18	22.5%
Hispanic/Latino	12	15.0%
Asian/Asian American	7	8.8%
American Indian/Native American	4	5.0%
Other	3	3.8%
<b>WORK STATUS</b>		
Employed full time	55	68.8%
Employed part time	13	16.3%
Not working	12	15.0%

(continued on P9)

<b>ANNUAL HOUSEHOLD INCOME*</b>		
Less than \$10,000	6	7.5%
\$10,000 to \$49,000	21	26.3%
\$50,000 to \$89,000	29	36.3%
\$90,000 to \$119,000	8	10.0%
\$120,000 or more	12	15.0%
<b>HEALTH INSURANCE DEDUCTIBLE*</b>		
Less than \$1,000	25	31.3%
\$1,000 – \$2,000	29	36.3%
\$2,001 – \$5,000	17	21.3%
Greater than \$5,000	7	8.8%
<b>OUT OF POCKET HEALTH CARE COSTS IN PAST YEAR*</b>		
\$0 to \$500	48	60.0%
\$501 to \$1,000	8	10.0%
\$1,001 to \$2,500	9	11.3%
Greater than \$2,500	10	12.5%
<b>USED PUBLICLY AVAILABLE INFO IN PAST YEAR*</b>		
Never	2	2.5%
1-2 times	35	43.8%
More than 2 times	42	52.5%
<b>SAW DOCTOR/VISITED HOSPITAL IN PAST YEAR*</b>		
0-1 time	1	1.3%
2 times or more	78	97.5%

*\*Percentages do not add to 100 due to missing data*

*\*\*Multiple responses permitted*

# FINDINGS

In the sections that follow, we describe participant perspectives on health care quality and its significance to health care decision-making, how quality is determined, and information sources used. Following that, we describe participant perspectives on the relevance of health care costs to their decisions, as well as the information sources used to determine—or predict—costs. The final sections describe participant recommendations regarding products that might be developed to facilitate more informed decision-making. Recommendations cover the actual data elements, format, platform, information source, and methods for the dissemination of information to promote use of the product or products developed.

## Participant Perspectives

### Defining Health Care Quality

Participants described a broad range of attributes that they use to define quality. Most commonly cited were interpersonal skills, including an evident interest in patient well-being and being generally personable, as well as willingness to listen to patients and to take the time needed for diagnosis and treatment. Although some participants phrased their concern in general terms (e.g., “*Somebody that’s compassionate as a doctor*”), others emphasized the contribution quality communication plays in good care. Examples of the range of responses include:

*I felt she was competent and thorough, but what made the difference to me or what stood out, because I’m sure there are a lot of competent physicians in the area, is just that she had a very good bedside manner. She was very compassionate, very caring and it felt like a personal touch, combined with the expertise. (Albany focus group participant)*

*I’m very greedy for information. So I would rather have a doctor that will answer every single question and concern that I have, even if I do personally think they could stand to be a little more warm. That’s not as important to me. I just want to know that all of my concerns that day will be answered. (New York City focus group participant)*

Competency, though not referred to as frequently as interpersonal skills, was another important quality attribute. Descriptions of competency varied, and the concept remained vague for some participants. It generally included diagnostic and treatment capabilities, as well as relevant medical knowledge and skills, including being current in their practice. A subset of participants also noted that it was important that providers were not overzealous in providing unnecessary care, including excessive tests, medications, and procedures. Additionally, patients who suffered from less common conditions felt that training and experience relevant to that condition was critical.

*I guess somebody that...understands or is aware of new diseases or new genetic issues ... they're not necessarily old school. They're not diagnosing you with something brand new and the disease of the week, but they're also not telling you to stick a leech on it. (Buffalo focus group participant)*

*From the first appointment, you can tell if the doctor's smart enough or not. Sometimes the doctor understands your issue and knows a lot of ways to treat your situation, and other doctors are just following general rules. They aren't very flexible, they can't accommodate your specific issue. Like, I have a good experience with dental health care providers. So like, one doctor says, "Oh, you have to pull this tooth," and another one could say, "Oh, we can still save it if you do this, this, and this." (Albany focus group participant)*

Characteristics related to wait times and the office environment were often closely associated with quality. Participants felt long wait times were indicative of a provider who sacrifices quality in favor of higher patient volume—and a higher income. Long wait times on the day of a visit were described as frustrating and disrespectful *vis a vis* their time and other responsibilities. In addition to wait time, the characteristics of a provider's office environment, including cleanliness and the behavior of staff, were considered important by several participants and were thought to reflect the provider's quality of care.

*With the quality ... sometimes it's clear that [if you have to wait too long], it's a money mill, that they're ... overbooking and you're not getting the care that you need. (Albany focus group participant)*

*I honestly think you can tell more about a doctor—like if you just go in the waiting room and sit there for like 20 minutes, you can pretty much tell how the visit is gonna be. ... If they got young girls sitting at the desk playing on their phones, joking around with each other. You can sort of tell the kind of place that you're in. (Buffalo focus group participant)*

A small number felt location was an indicator of quality. Specifically, providers located in higher income neighborhoods were perceived as better than those in lower income neighborhoods.

*It's kind of sad to admit, but I found out that going out in the suburbs, I get immediate care and I get my attention addressed immediately because ... they're more competent. They're not on a time schedule, like you said, "Let's see how long it takes me to diagnose this person, write a prescription, and send them out the door." (Buffalo focus group participant)*

*I would [not] choose [a location] in my area, it would be in another area. Because I feel that in my area sometimes you get a lot of interns, or uptown you're considered guinea pigs. So we get a lot of practice doctors on us, "Oh yeah, send them to Harlem." (New York City focus group participant)*

## **Measuring Health Care Quality**

When asked how they assess provider quality prior to seeking care, few participants described—or were familiar with—indicators and predictors of quality used by the medical field (e.g., high volume with respect to a particular procedure). Instead, most participants cited credentials and experience that suggested quality, such as education and/or affiliation at a prestigious institution, years practicing, licensing and certification. In addition to positive attributes, “red flags” such as medical malpractice claims, were considered important by many participants.

*I would want to know the education of the doctor, and how many years in his field. (Albany focus group participant)*

*Before I even go see my doctor, I would try to find out background information: how long he had his residency, what's his specialty, because I need to know if something happens to me, this doctor is able to handle my case. And what surrounding doctors or hospitals he's affiliated with that he could refer [me] to for services. [New York City focus group participant]*

*Say I want to switch my car insurance; I get rated on how many accidents I had, how many this, how many that. So a doctor—how many malpractice that you had, how many times you been sued—why can't they get rated, too? [Buffalo focus group participant]*

Participants who had surgery or a particular procedure were most likely to identify and prioritize specific clinical quality indicators, such as volume and outcomes. One participant described the challenge of identifying similar metrics for care of chronic conditions.

*I recently had a knee surgery and I wanted to choose somebody that actually performed the procedure more often than not, [more often] than somebody that was more focused in another area of the type of surgery. Because I had a torn patellar tendon, which is the tendon that connects the quad and also the knee cap. So I wanted to find a doctor who was very fluent in that type of procedure. [Albany focus group participant]*

*I think it's kind of hard to quantify exactly what you would be looking for in instances where it's not like a procedure that you're getting done—if you have a chronic illness like diabetes or high cholesterol. I don't know what I would look for in a doctor to help me with the treatment, my diabetes, because I don't know how you would quantify that. Like, "How many patients did you see that had diabetes?" [Buffalo focus group participant]*

Not surprisingly, participants felt provider competency was particularly important in cases where specialized or critical care was required. They contrasted this concern to a more casual approach to primary care, which they could more easily change and they assumed carried less risk.

*I'm kind of a special case, because I have late stage Lyme and a lot of people don't believe that it even exists. So for me that's one of the important things that I have to look for first: someone who believes that it exists and understands how it affects my body so that they can actually treat me properly. (Albany focus group participant)*

*I think it really also depends on what you're getting done and what type of doctor you're seeing. Like I said, for me it's usually my yearly check-ups or regular gynecologist or eye doctor. It's pretty standard. I know if I was having something a lot more serious or if I had a pre-existing medical condition, I would do a lot more research. But honestly, when it boils down to it, I go on ZocDoc, I see who's available like 8:00 AM or 5:30 PM, so I can go before or after work; whether it's near my apartment or near my office, and that's pretty much what I end up doing. And if I like that doctor I stay with them, but I'm kind of not doing this crazy research for three hours for something that's really basic. If it was more involved then definitely I would be. (New York City focus group participant)*

### **Information Sources for Quality**

As shown in table 2, according to results from the brief participant surveys, almost three-quarters (73.8%) of participants reported asking for recommendations from family members or friends when making decisions about health care providers, 66.3% said they looked for information on the internet, and 62.5% used information available from their insurance company. Participants more often searched for quality information (83.8%) than information on cost (76.3%) or service availability (73.8%).

**TABLE 2. INFORMATION FOR HEALTH CARE DECISION-MAKING**

	<b>N</b>	<b>%</b>
<b>SOURCES</b>		
Friends/Family Members	59	73.8%
Internet	53	66.3%
Insurer	50	62.5%
Health Care Provider	49	61.3%
CBO	8	10.0%
Other	4	5.0%
<b>DOMAINS</b>		
Quality of services	67	83.8%
Cost of services	61	76.3%
Availability of services	59	73.8%
Other	18	22.5%

Qualitative findings were consistent with survey results. Participants reported they were often unsure of where to look for information about provider quality and said they most often depend on personal (e.g., family and friends) and professional recommendations to make choices about where to go for care—the latter (recommendations from a trusted health care professional) being the most commonly mentioned and trusted in focus group discussions. Although a small number of participants were concerned that providers basically recommend their friends, these recommendations were generally described as the most accessible and most reliable sources of information regarding the quality of a potential health care provider.

*If I wanted to pick a doctor based on the number of patients or the kind of procedure, I wouldn't even think that information was anywhere. I would just go more by personal referrals as opposed to data. (Albany focus group participant)*

*It's like I don't know where to look because, like I was saying, I feel like it's not a wide database of information. [The] only [resources are] some of your friends, like she was saying, and recommendations from other doctors that you might trust. (Buffalo focus group participant)*

*Word of mouth for me. My mom worked in a hospital and she has a friend that's a nurse, you take it on faith, but that seems to work out pretty well... you just talk to lots of doctors. Different types of doctors refer other types of doctors and it seems to work well. ... Because of friends in the health care industry, we take their word for it because we know them. (New York City focus group participant)*

When asked about publicly available data, participants most often described Google searches, as well as searches on popular commercial sites, such as Yelp and ZocDoc. Participants indicated that web searches connected them to provider websites, which contain important biographical detail about doctors, as well as ratings and other basic information about a provider.

*I usually do a Google search, and Google gives you a lot of different websites. ... And then, I don't know, I just look at cost, how far from my house, and reviews, and I just compare a few and then pick one. So yeah, some people have stars. Some people just have testimonials. I definitely read [them]. (Albany focus group participant)*

*I go on [the practice] site...and they have bios of all their doctors and they'll tell you what their background is and where they went to medical school. ... The doctor I'm seeing right now [worked] in Africa, helping out there. So you do get to see what your doctor's about. And I mean, it's all about going to the right sites when you Google it. (Albany focus group participant)*

Participants reported that online patient reviews were carefully considered as they made their health care decisions. Descriptions of personal experiences with a provider, even if that individual was an anonymous stranger, were valued and sought after by many participants. Most recognized that reviews were not necessarily reliable—noting that everyone has different needs and preferences by which they judge providers and that postings are not vetted for veracity or conflict of interest. However, they reported having some ability to distinguish useful from non-useful information.

*I found my dentist on the internet, based on reviews. And actually, I'm really liking her and she's done a good job, very patient. ... I saw the reviews come up, and I just did one of those, "Okay, that's the one." If I didn't like [her], I wouldn't go back. (Albany focus group participant)*

*I'll just do, like I said, any sort of Google search. Or just put the name out there and just go through and see what people are saying. Of course you're gonna get the people that are family members and you're gonna get the people that are competitors, so you get rid of those, like a Yelp review; but I go through that. (New York City focus group participant)*

Participants who reported trying to make very informed decisions regarding health care choices described spending considerable time searching across multiple sources of varying quality; they did not always feel satisfied with the information they found. Although a few participants with backgrounds in health care knew of specific governmental and/or institutional websites to use in their search, most could not recall, or were uncertain of, the sources they had used to retrieve quality information.

*I think it's very telling that we've been talking about so many review sites and so many reviews—like a number of us have mentioned doing hours of research on these things and it's like if these were good sources of clear information we wouldn't have this. We'd be like, "Oh yeah, we go here and we spend ten minutes." Definitely my experience has been that I go and look and I look and I look and I feel like I haven't gotten anywhere and I'm just kind of having to like, "Okay, well this sort of looks good I guess," and then interacting with the doctor I can make an actual judgment. (New York City focus group participant)*

*Like, when I was looking for a pediatrician for my son ... I think it was just a Google search of the doctor's name. (Albany focus group participant)*

*There is also a website. I forget what it was. But it's a disciplinary board where you can check your doctor's name against it to see if they have a past history. (New York City focus group participant)*

In the end, participants' own first hand experiences were consistently considered the most important indicators of quality.

*You almost have to interact with them, be in their office, and just kind of the feeling you get from them. You've gotta feel comfortable. (New York City focus group participant)*

*I can look online all day long, but that doesn't mean when I get to the doctors it's [not] a different thing. He might act completely different than what the paperwork on the computer's saying. (Buffalo focus group participant)*

## **Perspectives on Health Care Costs**

Although results from the brief participant survey indicate that 76% of participants have sought information on the cost of health care services, in focus group discussions many participants reported that they did not generally seek cost information prior to seeking medical care and that cost was less consistently considered compared to quality. Almost universally, cost concerns focused on out of pocket costs but participants felt that their options were largely mediated by health insurance. Therefore, cost-related decisions about health care often centered on accessing or avoiding care altogether and—most commonly—choosing in-network providers and checking that particular services would be covered by insurance. A limited number of participants also reported that they looked for information regarding co-pay or co-insurance prior to seeing a provider. Beyond information related directly to out of pocket payments, charge differentials appeared largely irrelevant to participants.

*I don't think most people pay attention to cost quite frankly. If you have insurance I don't think most people in this room are gonna get excited if the insurance company has to pay this much or that much. I was not insured until I was in my mid-30s, and I used to pay cash out of pocket for medical. Then I wanted to know what everything cost, everything. (New York City focus group participant)*

*For me, it's whether it's in network or out of network ... if there are any out of pocket expenses that I'm going to have to pay. So that's always a determining factor. (New York City focus group participant)*

A notable exception was a participant in NYC who reported investigating price differences in order to minimize the cost to her insurance company. She felt it was important to shop for a lower price, even if it did not directly affect her out-of-pocket costs, because of the direct relationship between payments made by insurance companies and premiums charged to patients.

*For procedures, like mammograms, any kind of MRIs, X-rays, even though my insurance company may pay more, I found that it offends me what some institutions, like [x medical center], charge for a mammogram, where I had it done for years. So I will do a comparative search until I find a radiology company that has good reviews and charges one-third—bills the insurance company—one-third to one-half as much money. Because I think most people think, when their service is paid for, it's like, "I don't care what it costs." But what the companies are billing insurance companies is what determines our rates. ... So for procedures, I am what you call a 'competitive shopper.'*  
(New York City focus group participant)

Among the majority who never or rarely sought cost information, several explanations emerged. Some explained that they do not seek this information because they feel making a decision about a particular provider based on cost is incompatible with seeking high quality health care. This perception was often described in general terms and was rarely backed up with specific examples or evidence that low cost and high quality are incompatible.

*I think it's a mental thing. If you find a doctor that's cheap, you're like, "What is—what are they doing wrong?" But it really might just be that they're cutting all the crap out that other doctors aren't, and they're just giving you the base, like, "This is what you pay." But, it's a mental game with yourself—you just see lower price then think of lower quality.* (Buffalo focus group participant)

Participants also felt it was difficult to investigate health care costs prior to seeking care in an emergency or if the need for health care was urgent, due to the importance of a quick decision. Others reported that it was uncomfortable or inappropriate to ask about cost during distressing moments brought on by poor health, or that it was less important to consider cost if the need for care was highly specialized or life threatening—given limited options. Concerns about the reliability of cost information were also mentioned.

*I had an emergency situation a couple of years back ... I just picked a hospital, didn't think about where my insurance would be taken, and I was hit with a very big bill that wasn't covered and that is still being paid month to month, now out of pocket. In case of emergency you don't think, "Where is my insurance going to be taken? Where can I get service for free?" You just go with the flow and try to get service. (Albany focus group participant)*

*Why don't they have a menu at the doctor's office? It's like, as tasteless as that sounds, I know it would make it a lot easier, because in moments like that, you're like, "I can't believe my husband or my wife or whatever has this going on and I'm really thinking about money right now." Like your—you almost feel guilty and you're saying, "I can't really have to ask this."*

(Buffalo focus group participant)

*I feel like if it's a major procedure then you may not care [about cost], if it's like life or death type of thing. ... The severity of your illness or health plays a factor in how well or how much you're gonna look at cost. (Buffalo focus group participant)*

Participants who did look for cost information did not necessarily use that information to make choices about providers. While some said that getting a high estimate for a visit prompted them to look for an alternative, others who sought cost information said they only did so in order to be able to anticipate the bill.

*A doctor was highly recommended to me. It's funny, I called three different people and they all came up with the same doctor's name. And I called the office and they said, "We do not accept that insurance." And it was going to be a \$40 fee versus a \$20. So I didn't go there, because—think about it: \$40—I could get two for one. So I said, "Man, I can't go there." (Albany focus group participant)*

*I call ahead sometimes, like, "Do you take so-and-so, and how much is this?" Just so I won't go in blindsided. (New York City focus group participant)*

The impact of high deductible plans on decision-making behavior was unclear. High deductibles were rarely mentioned as a motivator for seeking cost information prior to choosing a provider, and several participants had little understanding of "deductibles"

as distinct from other payment related terms, such as premiums. On the rare occasion that deductibles were discussed—mainly in one Buffalo focus group—participants presented differing views, as illustrated below.

*Now that I have a terrible, high deductible plan where I have to pay out of pocket, up until \$3,000 before anything kicks in, I'm always asking about cost ... I don't make that much, you know. I'm not making \$100,000 a year where I can just shell out \$200 for an office visit, so I definitely look at cost now as a deciding factor, unfortunately. (Buffalo focus group participant)*

*We've now gone to a high deductible plan and the idea behind that was to make us savvy consumers, but I get frustrated I guess, thinking "why should I have to be a consumer for my health care?" So, I've never done that, I've never researched that. I still just continue to go to the doctors that we've gone to, and who knows, maybe I could be getting a better deal somewhere else, but, I've not done that. (Buffalo focus group participant)*

## **Information and Access**

Not surprisingly, many participants found the health care payment system to be somewhat incomprehensible and difficult to maneuver within, which impacted their engagement with cost information.

Insurance companies were the most commonly mentioned source of cost information. Participants noted that they provided information regarding network membership, as well as insurance plan coverage for particular services. Providers were also consulted, though they were generally seen as less knowledgeable with respect to patient out of pocket costs than insurance companies, due to the number of payers and plans they deal with. Participants knew that health care payers negotiate prices and that out of pocket costs could differ by type of plan depending on co-pay, co-insurance and other charges.

*Basically, I could ask my doctors as many [payment] questions as I want but she's not going to have the answers. So, I will always have to go to my insurance company for that and get an idea like, "Yeah, we'll reimburse you minus 70 percent." (New York City focus group participant)*

*You go to a mechanic and get an estimate. But you can't go to somebody who's going to be feeling your body to get an estimate? It's absurd, the walls they can put up. [New York City focus group participant]*

*I'm not sure how possible that is [to find cost information] in most cases because I've had the experience of going to a place and then being like, "Oh, yeah insurance will cover that" and then, "No way," the insurance company decided not to do it after all. What do you do? And a lot of how this stuff is charged is depending on the relationship between the particular place and the insurance company and stuff like that. It would be amazing if we could have more information about costs, like definite costs. [New York City focus group participant]*

As exemplified above, a number of participants described unexpected and/or problematic charges that illuminated the lack of clarity in the health care delivery system and the financial implications thereof, from the perspective of patients. Examples of participants' complaints included medical bills that lacked proper documentation and charges for dental care, labs and prescription medications that seemed illogical or unnecessarily high. Participants generally felt that questioning these bills—or the practices they referred to—was difficult, time consuming, often non-productive.

*I've always ended up paying more, and even when I get double billed, I pay. It's too much of a hassle to get your money back with the hospital. I would like some sort of budget breakdown before you go in. Maybe say, "Hey, I don't wanna do this or do that." [New York focus group participant]*

*I went to [the dentist] for routine cleaning and they said, "Hey, let's do a fluoride treatment. Do you want that?" I'm like, "Is that part of my routine cleaning?" [The dentist replied] "Most people want it." I look at my bill later and \$100 for added fluoride that's not covered if you're over the age of 12 ... had I known that then: "Please don't offer it to me. I'm okay. It's in my daily toothpaste." [New York focus group participant]*

*A friend of mine, he had a leg injury and he went to the hospital and they gave him a brace and come to find out that he didn't even need the brace. ... And when he got a bill he realized that the insurance only covered a part of the cost for the brace, including the crutches as well, too. So it's kind of in the situations, could there be a way where they could pull up information or provide information and say, "Hey, this is what we feel you may need. This is what it's going to cost. And according to your insurance and their database, this is what may or may not be covered." (Albany focus group participant)*

Finally, although participants expressed great interest in having increased access to cost information, this desire was tempered by an underlying perception across the groups that even with such information available, consumer choice may remain limited due to the constraints of the health care payment system.

*I feel that there's no way to know the cost ahead of time, except for the copay. ... Okay, you've got five doctors that the insurance company will let you [see], you read their bios, you go, "All right, this one," and you ask your friends, and then you get there and whatever the costs are, they are. You don't really have—you're not gonna negotiate. You have no negotiating power. (Buffalo focus group participant)*

*I know people are concerned about hospital infection rates, and there's been some effort in New York State to have that information more available to people. But transparency isn't choice. Choice is hard, because we're bumping up against such big regulatory bodies and the insurance companies. It wasn't that long ago that a lot of employers offered three kinds of insurance to people. Now, you're given one and your choice is to take it or leave it, pretty much. (Albany focus group participant)*

# Participant Recommendations for Health Care Information

*If [the data were] somewhere and I knew to go there and put in a doctor's name and have statistics pop up as opposed to me having to figure out what those statistics are, I'd probably look at them and consider them. (Albany focus group participant)*

## Quality Indicators Preferences

Participants felt that it would be helpful to have access to standard quality indicators for use in selecting a health care provider. As discussed in the sections above, most were unfamiliar with many of the clinical quality indicators utilized in the health care field. However, they were able to list a number of quality-related factors that they would like to use in decision-making and that might be easily compiled into a database accessible to consumers. As shown in Figure 1, specified indicators focused on provider education and practice characteristics, including patient and procedure volume, as well as patient outcomes.

**FIGURE 1. PREFERRED QUALITY INDICATORS**

<b>PROVIDER BACKGROUND</b>	
Education	Years in practice
Certificates	Malpractice information
<b>PRACTICE INFORMATION</b>	
Hospital affiliation	Patient volume
Average wait time	# of repeat patients
Procedure volume	Outcomes data (both positive and negative)
<b>HOSPITAL-SPECIFIC INFORMATION</b>	
Nurse to patient ratio	Infection rate

Participants also wanted data on patient experience and noted that they had, on occasion, been asked to complete satisfaction surveys. However, aggregated results had never been provided to them. They felt the findings should be publicly available as they would include information on interpersonal skills, wait times, and other factors that are important to patients.

*I always fill out surveys for my son's pediatrician and my own doctors. I guess they come from my insurance company. It always [asks], "How long did you wait for an appointment?" or "Did you feel that this physician was sensitive to your needs?" or "Was your presenting problem addressed?", things like that. So I rate all this, I mail it in, but I never hear anything really back. (Albany focus group participant)*

### **Format and Source Preferences**

There was an expressed desire across focus groups for a resource that incorporates a range of indicators, including access (e.g., location, hours, wait time), provider training and experience, interpersonal skills, volume and outcomes data, as well as patient reviews. Recognizing that preferences differ by person and by need, participants also suggested that an interactive resource—with easy to navigate filters—would be most appropriate.

*I think it would be great if there was one website that put that all in one place for you. Right now when you hit Google, you just get a mish-mash, and then you have to wade through it. (Buffalo focus group participant)*

*Well, it would be nice if it was all in one place. [If] it had all statistics but also reviews from people, but the statistics would include the bad stuff, too. I mean like successful knee [replacements] and how many people were crippled after they did them or whatever. (Buffalo focus group participant)*

*She's looking for someone with a good bedside manner, who's a good, warm, caring person, because at the end of the day she knows she's going to get better care from that person. Give me a cold robot that's going to answer all my questions and I'm fine. We're going to rate doctors differently. Why can't there just be some sort of a database full of questions and answers and honestly [a] scale of one to ten? How close is this doctor a match for what you're looking for? For what you're being treated for? (New York City focus group participant)*

For some (but not all) participants, simplicity was paramount: they wanted to be able to understand the bottom line easily. Many felt that a rating system would be helpful in this regard, with the caveat that a worthwhile rating requires a trustworthy source and clarity as to how the rating was determined.

*I would like a five star rating system of how good the doctor is and number of patients, how many patients recover, things like that. (New York City focus group participant)*

*I think just a good point to make about the rating system is make sure that the user understands what the rating system is and how it works, so that they understand if it's a one to five kind of thing, they understand what one means versus five, as opposed to just assuming—obviously one's better than the other, but in terms of some sort of standards that go with each level of the rating. (Albany focus group participant)*

Participants also felt it was important they be able to compare indicators across providers. This was described as a way to contextualize the information and an important part of utilizing any quality information made available to them.

*If I was looking at a particular procedure, as somebody mentioned, I would like to know how many he did and what was his success rate, and what percentage that was. And if his was in line with everybody else's who did that same sort of procedure, then I'd say, "Well, he's as good as any other doctor out there." But if he's hitting 70 percent, everybody else is hitting 95, I'm going to try to avoid him if I can. (Buffalo focus group participant)*

In general, participants did not make strong statements about how cost information should be made available to them. However, they did make clear that cost and quality were interconnected and therefore should be made available together.

*Well, a one stop shop I think would be easier for the customers because the thought that you're choosing something based on cost alone is a terrible feeling. Everybody wants quality health care. The more information we have about that the better. (Albany focus group participant)*

Most participants felt that a website was the best way to provide cost and quality information to consumers, which may in part reflect our internet based recruitment methods. A smaller number felt that a smart phone app would also be appropriate. Participants were sensitive to the needs of the broader public, including those who do not use computers and/or smart phones. They suggested a telephone hotline as well as printed information in community publications or pamphlets.

*I think the internet would be a good source for people who have access to it ... for people who are more database savvy they could maybe do their own search. (Albany focus group participant)*

*Everybody uses their phone. We don't always have the convenience of a computer in front of us. I would like the access in case I need to look up something on the app. (New York City focus group participant)*

*Or maybe a 1-800 number you could call and say I'm thinking about going to Dr. Jones, do you [what is] the information you have on him or her. (Buffalo focus group participant)*

Discussion of the ideal format to provide information to customers sometimes prompted comments about the need for assistance due to the complexity of health care information. In one focus group, participants recommended a navigator service for health care decision-making similar to that available to assist individuals with health insurance enrollment.

*I would like to see references, like a number that you can call and ask questions. Not just “Google it,” you want to talk to a person live, like a nurse practitioner. ... Somebody that works within the hospital environment.*  
[New York City focus group participant]

*Another thing that might be good is ... having some sort of training program so that people either at the library or at the social services place get trained on how to access the site and how to move around through it, so they can actually help people find what they're looking for.* [Albany focus group participant]

A number of models—mostly Internet-based—from outside of health care were mentioned as exemplary sources of consumer information. They included Yelp, Consumer Reports, Kayak, Match.com, the Better Business Bureau and Angie's List. Yelp was mentioned most commonly and was praised for its combination of star ratings, which give people an overview of quality, and narratives describing patient experience. Consumer Reports and the Better Business Bureau were mentioned as independent, trusted rating agencies, and Kayak and Match.com were mentioned for their ability to compile data from different sources (in the case of Kayak), as well as match people based on personal characteristics and preferences (in the case of Match.com).

*When you're finding a slice of pizza, it's so much easier than finding a doctor because you can go on Yelp and you can literally see photos that people have uploaded. You can read all the reviews. You can see what's the closest. And then you can look at the restaurant and you can see their rating. If it was the same thing for doctors, showing all the information a pizza slice has, along with the A-rating, then you would know where to go. Because you want to go to the five-star, A-rating pizza place, you want to go to the five-star, A-rating doctor.* [Albany focus group participant]

*I mean simply something like the Better Business Bureau. That's still a very powerful organization. If you have a bad review from them, you're not gonna make the sales that you normally would. So if we had something, again, similar to that.* [New York City focus group participant]

In general, participants felt it was essential that the data source be neutral, one without financial or other vested interests. Perspectives on which entity would fit these criteria best were mixed; some felt it was the government, while others felt that the private or non-profit sectors would be better.

*I'd want somebody that was like third party, not government, not New York State, not insurance just somebody that really, truly had the best interest of just the people. (Buffalo focus group participant)*

*I wish the State would have something ... I would trust it because they're not gonna lie. (New York City focus group participant)*

*Maybe some kind of nonprofit that's not going to make any money over recommending one [provider] versus the other, because sometimes politics does come into play with the State, although it's theoretically neutral. (Albany focus group participant)*

There was some discussion among participants about the merit of receiving information from their insurance companies. Although several people said they would trust their insurance company to provide information, others felt insurance companies would be inappropriate because of their financial interests.

*I think some of that burden should fall on the insurance company to tell us, "This is the doctor's credentials. This is why we chose them. Not because we negotiated the lowest rate, but because we feel that they're a good provider." (Buffalo focus group participant)*

*I'm not for sure I would trust the insurance company, because I think they're looking at the bottom line and not necessarily the best doctor. (Buffalo focus group participant)*

## Dissemination

Participants felt that any trustworthy and reliable resource on cost and quality yet to be created should have good name recognition. Some thought that a high quality resource would develop a positive reputation on its own without the need for advertising, while others thought that publicity and branding would be an important part of creating name recognition and trust. Advertising suggestions included Facebook, billboards, radio, television, insurer websites, and in provider waiting rooms.

*Ease of access and a catchy name—something that people will remember and they'll go, "Oh, I need to know about health care and I live in New York State. I'm gonna go to New York whatever."* (Buffalo focus group participant)

*Don't worry about it. People will come to you. They'll read about it in the press if it's a good job. And then—don't worry. Don't spend any energy on that at all.* (New York City focus group participant)

*You could be listening to the radio and have it [on] a commercial break. They're gonna advertise maybe five or six different things, so if the medical field kind of went along the lines of what everybody else was doing, I feel like information would be available to a lot more people.* (Albany focus group participant)

*It should be [advertised] above every door when you're sitting in that room for 10, 15, 20 minutes waiting for the doctor. You're just swinging your legs on the table waiting and you're looking at everything on the wall.* (Buffalo focus group participant)

# DISCUSSION

Focus group findings indicate that consumer perspectives on provider quality are variable and complex, and include factors ranging from bedside manner, wait time, and office environment, to broadly defined “provider competence.” When independent sources were utilized to predict quality, participants focused on credentials and experience, such as education and/or affiliation at a prestigious institution, years practicing, and relevant licensing and certification, as well as qualities related to provider accessibility. Clinical quality indicators utilized within the health care field, such as patient volume or infection rates, were mentioned less frequently, and were associated with specialized care and surgery.

Information regarding provider quality was neither easily accessible nor consistently reliable. Friends and family were the most commonly cited resources for information about a prospective provider, with Internet research via Google or other search and ratings sites close behind. Participants were generally unable to point to one consistent, reliable resource for access to a range of objective quality indicators. The information participants did find and utilize was primarily the proxy indicators described above (e.g., physician education, hospital affiliation, etc.). Notably, participants were generally unfamiliar with standard clinical quality indicators or how to access them, although they felt such information would help them to make better choices if available. Furthermore, there was a question as to whether indicators for the quality of primary care or care of chronic conditions existed, which seemingly represented their most common health care decisions.

**RECOMMENDATION:** Underutilization and lack of knowledge regarding indicators demonstrate that consumers are not yet well versed in the vast array of health care systems and provider data that could be available through the APD. As a result, consumer education and navigation support may be necessary to ensure that information available is effectively utilized.

Cost, although viewed as important, appeared less relevant to consumers for health care decision-making than quality and was described as largely determined by insurance. Many felt they have little choice or control over the cost of care, the exceptions being use or avoidance of uncovered services and choices regarding in-network versus out of network providers. Participants also described the health care payment system as complicated, given the separate charges for particular components

of care (e.g., lab tests) and negotiations between insurers and providers, making it difficult to seek cost information in a useful and timely manner. Comments on cost of care also suggest that it is difficult for consumers to include financial considerations when care is urgent or highly specialized. Finally, among some participants, cost-related health care decisions were seen as antithetical to those based on quality and were therefore avoided.

**RECOMMENDATION:** A multifaceted approach to transparency—one that includes incentivizing providers and payers to increase the accuracy and clarity of the cost information they provide, as well as a shift in consumer knowledge and attitudes regarding cost—may be necessary in order for individuals to consistently and effectively make meaningful cost-based decisions about care. Engaging consumers around medical bills and out-of-pocket expenditures may facilitate an improved dialogue with respect to health care decision-making that incorporates cost considerations.

Ultimately, participants would like to have and use better data sources. They expressed interest in adding meaningful clinical quality indicators to the sources they currently use to make health care decisions. However, in order to be useful to consumers, participants felt this information must be provided in a format that is accessible: web based (for most), easy-to-navigate, interactive, and composed of data representing multiple domains including quantitative indicators, simple ratings, and patient reviews.

**RECOMMENDATION:** Participants use generic Internet tools, such as Yelp and Google, in addition to their insurance companies and providers, to find health care information. Resources developed for consumers should be accessible through these sources and should incorporate qualities considered important to consumers, including ratings and patient perspectives.

Importantly, findings indicate that any resource seeking to effectively provide cost and quality information to consumers must be from a source that is considered unbiased, with the interest of the consumer primary. According to many participants, New York State may be an acceptable source of trustworthy cost and quality information.

**RECOMMENDATION:** Transparency regarding the origin and makeup of data provided is necessary, as is an interface consistent with (regarding ease, appeal) the standards consumers are accustomed to from use of commercial websites.

While this research highlights many of the factors and attributes consumers feel would be helpful to them in health care decision-making, it is also clear that consumers are not yet poised to take advantage of the information that can be made available to them through the APD. This lack of readiness is also apparent in the underutilization of current sources of cost and quality information. Thus, any effort to develop a consumer resource must address the need for a shift in consumer culture so that individuals have the knowledge, motivation, and sense of empowerment to effectively utilize potentially available data.

## Acknowledgements

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*The views presented in this publication are those of the authors and not necessarily those of The New York Academy of Medicine, or its Trustees, Officers or Staff.*

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## Citations

<sup>1</sup> *Healthcare Price Transparency: Meaningful Price Information Is Difficult for Consumers to Obtain Prior to Receiving Care*. Washington DC; 2011.

<sup>2</sup> Wu SJ, Sylwestrzak G, Shah C, DeVries A. Price transparency for MRIs increased use of less costly providers and triggered provider competition. *Health Aff*. 2014;33(8):1391–1398. doi:10.1377/hlthaff.2014.0168.

<sup>3</sup> Miller P, Peters A, Porter J, Sullivan E. *New York's All-Payer Database: A New Lens for Consumer Transparency*; 2015.

<sup>4</sup> Price Transparency Initiatives for Patients. *Cty Heal Rank Roadmaps*. 2015.  
<http://www.countyhealthrankings.org/policies/price-transparency-initiatives-patients>.

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# APPENDICES

Date: \_\_\_\_\_

Study ID: \_\_\_\_\_

## CONSUMER FOCUS GROUPS ON HEALTH CARE INFORMATION AND DECISION MAKING

### Participant Screening Form

Thank you for your interest. The New York Academy of Medicine, together with the New York State Department of Health, is conducting focus groups to better understand the information New Yorkers think is most helpful in making health care decisions, as well as the most useful ways to access or receive that information. If you are interested in participating in a focus group on this topic, please answer the following questions.

1. In what year were you born? \_\_\_\_\_  
*If you were born after 1997 you are not eligible to participate in this focus group because it is for adults 18 or older.*
2. Are you currently covered by a private or commercial health insurance company?
  - Yes, please specify company: \_\_\_\_\_
  - No → *Unfortunately, you are not eligible to participate in this focus group because you are not privately insured.*
  - Don't know
3. What is the yearly deductible in your health insurance plan? If you are not sure, please give your best estimate.
  - Less than \$1,000 → *Unfortunately, you are not eligible to participate in this focus group because it is for people with very high deductibles.*
  - \$1,000 - \$2,000
  - \$2,001 - \$5,000
  - Greater than \$5,000

4. In the last year, approximately how often did you use publicly available information, including information from your insurer, patient ratings, “report cards,” etc. to make decisions about where to get health care or which doctor to see? If you are not sure, please give your best estimate.

Never → *Unfortunately, you are not eligible to participate in this focus group.*

1-2 times

More than 2 times

5. Approximately how many times in the last year did you see a doctor or go to the hospital or an emergency room? If you are not sure, please give your best estimate.

0-1 time → *Unfortunately, you are not eligible to participate in this focus group.*

2-3 times

4-10 times

More than 10 times

6. Did you use the New York State Health Insurance Marketplace (“The Exchange”) to enroll in health insurance?

Yes

No

Don’t know

7. What is your home zip code?

8. Are you interested in participating in a focus group discussion on health care information and decision making?

No, please do not contact me about participating in this project.

Yes, I am interested:

Contact information

Name: \_\_\_\_\_

Email address: \_\_\_\_\_

Phone number: \_\_\_\_\_

Date: \_\_\_\_\_

Study ID: \_\_\_\_\_

## CONSUMER FOCUS GROUPS ON HEALTH CARE INFORMATION AND DECISION MAKING

### Focus Group Participant Survey

Please take a few minutes to answer the questions below. All answers will remain confidential.

1. What is your home zip code? \_\_\_\_\_

2. What is your gender? \_\_\_\_\_

3. What is your race or ethnicity? (Check all that apply)

American Indian or  
Alaskan Native

Asian, Specify:  
\_\_\_\_\_

Black or African American

Native Hawaiian or other  
Pacific Islander

Hispanic/Latino

White

Other, Specify:  
\_\_\_\_\_

Prefer not to answer

4. What is the main language you speak at home?  
\_\_\_\_\_

5. How far did you go in school? (Check only one)

Less than high school  
graduate

High school graduate  
or GED

Some college but no degree

College degree or higher

Prefer not to answer

6. Are you currently working? (Check only one)

No

Yes, I work part time

Yes, I work full time

7. When you make a health care decision (e.g., what health care provider to use, where to have an operation), where do you usually look for information to help you make that decision? (Check all that apply)

The internet, specify website(s): \_\_\_\_\_

My insurance company

A community based organization, specify: \_\_\_\_\_

A health care provider

Ask family members or friends

Other, please specify: \_\_\_\_\_

8. When you look for information to make a health care decision, what kind of information do you usually search for? (Check all that apply)

Cost of services

Quality of services

Availability of services

Other, specify: \_\_\_\_\_

9. What is the name of your current health insurance company?

\_\_\_\_\_

10. How long have you had your current health insurance plan? (Check only one)

0-1 year

More than 5 years

2-5 years

11. Which of the following health concerns do you currently face?  
(Check all that apply)

- |  |  |
|--|--|
| <input type="checkbox"/> Arthritis             | <input type="checkbox"/> Heart disease       |
| <input type="checkbox"/> Asthma                | <input type="checkbox"/> Hepatitis C         |
| <input type="checkbox"/> Cancer                | <input type="checkbox"/> High blood pressure |
| <input type="checkbox"/> Chronic pain          | <input type="checkbox"/> High cholesterol    |
| <input type="checkbox"/> COPD                  | <input type="checkbox"/> HIV/AIDS            |
| <input type="checkbox"/> Depression or anxiety | <input type="checkbox"/> Mobility impairment |
| <input type="checkbox"/> Diabetes              | <input type="checkbox"/> Obesity             |
| <input type="checkbox"/> Drug or alcohol abuse |  |

12. Where do you usually go for health care? (Check only one)

- |   |  |
|---|--|
| <input type="checkbox"/> Primary Care Doctor's office   | <input type="checkbox"/> Urgent care center              |
| <input type="checkbox"/> Community/family health center | <input type="checkbox"/> Specialist, specify kind: _____ |
| <input type="checkbox"/> Hospital-based clinic          | <input type="checkbox"/> Other, specify: _____           |
| <input type="checkbox"/> Emergency room                 | <input type="checkbox"/> Prefer not to answer            |

13. What was your total annual household income last year? (Check only one)

- |   |  |
|---|--|
| <input type="checkbox"/> Less than \$10,000   | <input type="checkbox"/> \$70,000 to \$89,999  |
| <input type="checkbox"/> \$10,000 to \$29,999 | <input type="checkbox"/> \$90,000 to \$109,999 |
| <input type="checkbox"/> \$30,000 to \$49,999 | <input type="checkbox"/> \$120,000 or more     |
| <input type="checkbox"/> \$50,000 to \$69,999 | <input type="checkbox"/> Don't know            |
|   | <input type="checkbox"/> Prefer not to answer  |

14. Approximately how much have you spent out-of-pocket for your medical care in the last 12 months—excluding insurance premiums?

\$ \_\_\_\_\_

15. Approximately how much are your monthly insurance premiums?

\$ \_\_\_\_\_

# CONSUMER FOCUS GROUPS ON HEALTH CARE INFORMATION AND DECISION MAKING

*Thank you for taking the time to meet with us today. This project is supported by the New York State Health Department, which is considering ways of providing additional information to the public to help consumers choose health care providers like doctors or hospitals [not health insurance plans]. We want to talk to you about what types of information would be most helpful to you in making these decisions, as well as what is the most useful way for to you access or receive that information.*

*We understand that individuals often make health care choices based on personal recommendations and convenience. However, today we are interested in talking to you about how you might use publicly available information – including information from your insurer, patient ratings, “report cards,” etc.—to make these decisions.*

## ***Starting out with some general questions:***

1. What factors are important to you when making health care decisions regarding where to go for care and what doctor to see?
  - a. Which factors would you say are most important? Why?
  - b. Do they vary by provider type (primary care, specialist, hospital, etc.)?
  - c. Do they vary by procedure (surgery, routine exam, etc.)?
2. What kind of information do you look for when making decisions about providers and medical services? (Prompts: Practice location, education and specialty, malpractice claims or settlements)

## ***We would now like to talk about sources of information for making decisions about providers and medical services.***

3. Where do you get the information you use to make health care decisions? (Prompts: specific websites, apps, organizations, anywhere else?)
  - a. How did you find and choose those sources?
  - b. What factors were important? (prompts: trust, convenience)

4. Can you tell us about the kind of information you receive from those sources?
  - a. Is there information on cost? Quality? Provider experience? Volume of services?
  - b. Is the information sufficient? What's missing? What's hard to find?
  - c. How useful do you find the information available to you?
  - d. Is it easy to understand? What information is unclear?
5. From your experience, has the information been reliable (was your health care experience consistent with what you expected)?
  - a. In what ways was it reliable? Where were the surprises?
6. Focusing specifically on quality, what kind of information do—or would—you need to determine that a health care provider will be high quality?
  - a. Is the information available sufficient? What's missing?
  - b. Are there specific decisions that require additional information? (e.g., heart surgery, choosing a primary care provider or specialist, etc.)
  - c. Do you think information on disciplinary actions taken against physicians is needed?
7. Now thinking about cost, what kind of information is—or would be—most useful to you when determining the potential cost of health care?
  - a. Is the information available sufficient? What's missing?
  - b. Are there specific decisions that require additional information? (e.g., heart surgery, choosing a specialist, etc.)
  - c. Are you concerned about financial information other than out of pocket costs? If so, what and why?
8. Who would you trust the most to collect and present information on cost, quality or other important factors that you might use in decision-making? Why? (Prompt: State vs. Commercial)
  - a. Does this vary by type of data (e.g., price vs. quality) or type of provider or procedure?

9. What do you think are the best ways to make the information available?
  - a. Web site vs. mobile app vs. print etc.? Which would you be most likely to use?
  
10. Are there models (including outside of health care) that you think are suitable for making this information available (e.g., Consumer Reports, Yelp, etc.)?
  - a. What specifically do you like about those models? What might be improved upon?
  
11. How do you think health care information sources should be “advertised?” How would we get you or others to find out about them and to use them?

***Finally, some more general questions:***

12. Has your information seeking behavior changed in the recent years? If so, how and why?
  
13. Do you think your information seeking behavior will change in the future?
  - a. Do you think you will be more/less likely to seek information or data before you select a provider?
  
14. Is there anything that we should have asked that we didn't?

## **About the Academy**

The New York Academy of Medicine advances solutions that promote the health and well-being of people in cities worldwide.

Established in 1847, The New York Academy of Medicine continues to address the health challenges facing New York City and the world's rapidly growing urban populations. We accomplish this through our Institute for Urban Health, home of interdisciplinary research, evaluation, policy and program initiatives; our world class historical medical library and its public programming in history, the humanities and the arts; and our Fellows program, a network of more than 2,000 experts elected by their peers from across the professions affecting health. Our current priorities are healthy aging, disease prevention, and eliminating health disparities.

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