# Engaging Consumers on Health Care Cost and Value Issues

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**CONDUCTED BY**

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POLICY & ACTION FROM CONSUMER REPORTS

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# Table of Contents

**Executive Summary** ____ **iii**

Findings ____ iv

Summary ____ vi

**Chapter 1. Introduction** ____ **1**

**Chapter 2. Mixed Methods Research Approach** ____ **2**

Literature Review ____ 2

Qualitative Research ____ 3

Nationally Representative Survey ____ 5

**Chapter 3. Qualitative Research Findings** ____ **7**

Health Care System Plagued By Problems, With Cost Being Primary ____ 7

Views on Health Care Quality ____ 17

Views on Medical Delivery Reform ____ 20

Views on Taking Action about Costs or Quality ____ 24

Absence of an Outlet Leaves Them Frustrated ____ 31

**Chapter 4. Role for Infographics** ____ **33**

Key Qualities for Motivational Infographics ____ 35

**Chapter 5. Conclusion** ____ **46**

# Executive Summary

As the United States improves access to health insurance coverage, we are able to turn attention to the problems of unsustainable growth in health spending and unjustified variation in cost and quality. To address these problems, we need to embrace a wide range of innovative strategies to restructure how health care is delivered. New payment and delivery systems are essential to sustaining coverage gains, improving the affordability and quality of health care, and allowing consumers to be more involved in their own health care.

But progress on health care cost and value issues is hindered by a lack of public awareness of the problems and potential solutions. In general, the American public has very little understanding of our cost and quality problems and even less awareness of or support for reforms to address the problems. Yet consumer support for effective measures to control costs and improve the quality of care is fundamental to getting policymaker and regulator action.

Our incomplete understanding of consumers' attitudes towards health system problems has hampered efforts to increase public awareness. Effective consumer engagement means "meeting consumers where they are," and we have much to learn about consumers' preconceived notions about health care costs and quality, the root causes of high costs and poor quality, the best way to frame solutions that could address these problems and how to better involve consumers in the public debate.

This study used a mixed methods approach to closing these evidence gaps with respect to consumer awareness and attitudes on health care cost, quality and reform issues. We engaged in a literature review and a series of focus groups to learn more about this topic. These results informed a nationally representative quantitative survey designed to supplement and validate findings. As part of the focus group testing, we developed a series of infographics to illustrate health care cost, and quality and reform issues to learn how to educate consumers about the health care system, or even inspire them to support and demand change.

As detailed below, developing this nuanced information tells us how to "unpack" key policy issues for consumers, revealing areas ready for engagement while also identifying remaining challenges. In many cases, our focus group findings were reinforced by the literature review and by the survey, lending additional credence to the findings.

## Findings

This study explored consumers' attitudes and awareness in four general areas: health costs, quality, reforms, and motivating action.

### *Health Costs*

- Participants associated the U.S. health system with high costs, over and above any other attributes.
- Participants thought about costs on two levels. Their own out-of-pocket costs were the primary lens by which they viewed the health system and many worried about affording care for their families. Participants also were aware of system-wide costs and had these costs in mind when thinking about reforms that might address problems.
- Participants expected some variation in costs as a result of market forces. However, in this study, participants were shocked by *how much* costs varied by facility for the same procedure in the same area. Because this variance was unexpected, their first reaction was to try to explain it away.
- Participants were quick to assume that insurers were the culprits behind high costs. Many also thought that hospitals and pharmaceutical companies contributed to high costs and many blamed the failure of people to take responsibility (e.g., eating right, not smoking, using too many services, etc.).

### *Quality*

- Many participants associated health care quality with the use of "soft skills" by their doctor and office staff, such as: the doctor listens to me, I feel valued, I get my questions answered.
- Participants wanted their doctors to have technical proficiency but assumed this is the normal state of affairs.
- Participants generally assumed their personal doctors provided high quality care but they were aware of poor quality care elsewhere in the system.
- Participants were mostly unaware of more technical measures of quality, such as infection rates, adherence to protocols, coordinated care, or other metrics used to track quality.
- Participants reacted strongly to information showing that deaths from hospital infections exceeded drunk driving deaths by a factor of seven.
- Participants indicated they would use information on quality, once they were exposed to examples of what it would look like, but they were unsure how and where to find this information, and it was important to them that it come from a trusted, impartial source.

- In lieu of technical quality, participants relied on reputation and referrals by family, friends, and professionals they knew.

### *Reforms*

- Many participants were surprised to learn that it might be possible to address high costs or poor quality.
- Once introduced to the idea that these issues could be addressed, participants (some of them reluctantly) concluded that government was in the best position to do something, although they also saw a role for individual consumers.
- Many participants were aware of electronic health records (EHR) and viewed them positively as improving health care delivery, leading to improved communication between doctors and fewer errors.
- Many participants responded positively to the idea of coordinated care, but were unsure this was a real possibility. Differences were observed depending on whether the participants had prior experience with an HMO.
- In our focus groups but particularly in the survey, participants endorsed a wide range of regulatory and legislative actions to address cost and quality issues, such as paying for outcomes, not by service; caps on prices; disclosure of "fair" prices; and requiring upfront cost estimates.

### *Motivating Action*

- Participants were generally excited to learn that there were specific opportunities for achieving change in the health care system.
- Participants already felt there were many problems in the health system, but providing information which validated their perceptions or built upon their existing knowledge greatly increased their motivation to take actions to improve the health care system.
- To succeed in motivating consumers, the information needed to have two characteristics:
  1. The information either was not too far outside their existing beliefs and perceptions or was anchored to information they already knew; using information that was too extreme and far outside their beliefs and perceptions was not effective.
  2. The information invoked an emotional response.
- Some information had only limited potential for consumer engagement. When something was a logical improvement (for example, "Of course doctors should follow best practices"), participants tended to have little emotional response. Without a negative consequence or a sense of being able to effect change, participants were neutral and less likely to take action.

- Participants were extremely frustrated if given information that outraged them, but had no clear action to take.
- Participants expressed interest in both personal and civic actions.
- Acceptable personal actions included taking responsibility for one's health and being better shoppers by looking at comparative costs and quality data.
- Some participants moved quickly from taking personal actions to taking civic actions, such as encouraging legislative/regulatory action by writing letters to elected officials.
- Even more than personal or civic actions, participants wanted a means to act collectively. They were fully aware that a "voice of one" is not necessarily heard and does not have much power. But they would readily embrace a collective voice that increases the likelihood of impact.
- The concept of using their market power (i.e., shopping for a procedure or a doctor) was new to most participants, and most were quick to point out the difficulty of doing so. However, participants said they would use comparative information on treatments and providers, if they trusted the source and it was easy to find.

## Summary

Greater consumer support for effective measures to control costs and improve the quality of care is fundamental to getting policymaker and regulator action. The good news? Consumers are at the tipping point and ready to be engaged. They are either already outraged by information they know (such as, health care costs) or inclined to become outraged when provided with new information (such as, poor health quality). While they are not very familiar with the range of delivery system reforms that might be employed, their strong desire to "do something" creates a receptivity that can be leveraged.

The good news is that a pathway exists for engaging consumers on issues and ideas that are less familiar. As this study shows, consumers responded forcefully to visual information that served to clarify the issues when information was not too far outside their beliefs and perceptions. In particular, they responded to information that was linked to cost or to something that they already knew about, such as drunk driving deaths. Information also was much more powerful and motivating if it clearly conveyed its personal impact on them. Information about the pervasive problems in our health care system—from high costs, to unwarranted variation in cost and quality to inadequate patient safety—is readily available and can be shaped to motivate consumers to personal and civic actions.

The more immediate challenge is providing consumers with concrete suggestions for what to do collectively. They want an unbiased, trusted entity that can provide them with information, tell them what to do and help them band together to better amplify their collective voice.

Next steps for advocates, policymakers and others ready to enact change include:

- Start with health care cost issues. Consumers are already outraged, ready to take action, and willing to embrace a wide range of policy approaches.
- Work to identify effective actions—particularly collective, civic actions—consumers can take. It is likely that these actions will vary, depending on the policy and health system environments in a state.
- Identify and promote one or more unbiased, trusted, and familiar entities so consumers know where to turn when they encounter something outrageous in their own lives. The "something" could be an outrageous bill, an inability to get price information or poor care.
- Use patient safety problems and better care coordination to engage consumers on quality and medical delivery reform issues.
- Consider a public information campaign to create greater awareness of these issues, given the motivating power of new information that reflects our findings.
- Conduct additional research to complete the consumer picture. We need additional nuanced information on consumers' current attitudes in the following areas:
  - quality measurement,
  - quality variation across providers;
  - health safety issues; and
  - when high costs are a proxy for high quality and when they're not.

# Chapter 1. Introduction

In many respects, our health care system works poorly for consumers. The existence of wasteful and even harmful care is well documented, as is unjustified variation in health care costs across providers, a lack of cost transparency, and unacceptable variation in quality. These problems contribute to unsustainable year-over-year increases in health care costs and compromise patient safety. Moreover, reforms are underway to address these problems but consumers are often unaware of the existence or purpose of these efforts.

Greater consumer awareness of system issues and potential reforms is critical to bringing sustained policy attention to health system problems. Our limited understanding of consumer views on health system problems and reform approaches has hampered efforts to increase public awareness.

We know that health care spending, quality and potential reforms are complex issues and difficult to unpack for consumers. Reporters from *Time* and the *New York Times* have tackled this complexity. Steven Brill's "Bitter Pill," an investigative piece in *Time*, March 2013, chronicled the high cost of medicines and the befuddlement of American consumers when faced with understanding and paying these costs. Elisabeth Rosenthal's series of seven *New York Times* articles from June 2013 to July 2014 expanded the focus on cost to include procedures, maternity, care for chronic conditions, hospital care, specialist care and vaccines.[1]

These articles invoked an enormous reader response, signaling the potential to engage consumers around cost and value issues. Despite the complexity of their topics, these authors succeeded in explaining it clearly and revealing the enormous impact on consumers of high, unjustified costs and uneven quality.

To build further on these efforts, we must engage consumers by "meeting them where they are." Yet, we have much to learn about consumers' preconceived notions about health care costs and quality, the health care system that produces these high costs and unacceptable variation in costs and quality, and the appeal of solutions that might address these issues.

This project used a mixed methods approach to begin closing these evidence gaps with respect to consumer awareness and attitudes. While this report focuses on the results from our qualitative, consumer focus group work, we reference the accompanying literature review and nationally representative survey when appropriate to either bolster our findings or to highlight a rare inconsistency across the data.

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[1] Paying Till It Hurts: Colonoscopy – June 1, 2013; American Way of Birth, Costliest in the World – June 30, 2013; In Need of a New Hip, but Priced Out of the U.S. – August 1, 2013; Soaring Cost of a Simple Breath – October 2, 2013; As Hospital Prices Soar, a Stitch Tops $500 – December 3, 2013; Patients' Costs Skyrocket; Specialists' Incomes Soar – January 14, 2014; Even Small Medical Advances Can Mean Big Jumps in Bills – April 5, 2014;The Price of Prevention: Vaccine Costs Are Soaring – July 2, 2014.

# Chapter 2. Mixed Methods Research Approach

The overall goal of this study was two-fold: (1) to collect general information about consumer attitudes toward and awareness of the health care system and (2) to develop and test a set of infographics that might be used to raise consumer awareness about various aspects of the health care system.

The overall project included:

- Literature Review
- Qualitative, focus group research
- Nationally representative survey

We believe the three approaches complement each other. Surveys can be persuasive because they allow us to generalize results from a sample to the larger population of interest. However, with surveys it is not always possible to tease out the underlying reasons and motivations that characterize consumers' responses. For example, in our survey, respondents gave the U.S. health system an overall grade of "B" for quality. From the focus group work and the literature review, we learned that consumers consider quality to be the presence of soft skills, like "does the doctor listen to me." In contrast, policymakers might think quality refers to providers' adherence to evidence-based protocols. By synthesizing the results across approaches, we end up with a much richer picture of consumers' views.

## Literature Review

As a first step in this project, staff members at Consumers Union did a review of the literature on consumer attitudes about the health care system.[2] The review explored six areas where we would like to better understand consumer attitudes:

1. Cost of health care;
2. Paying for health care;
3. Quality of health care;
4. Reforms that might improve care coordination and/or lower costs;
5. Priorities (health care system improvement relative to other issues); and
6. Taking action.

[2] Sarah Melecki, Victoria Burack and Lynn Quincy. Consumer Attitudes Toward Health Care Costs, Value and System Reforms: A Review of the Literature, Consumers Union, October 2014.

The review found fairly good documentation of specific gaps in consumers' understanding of health system problems:

- Reasons why health care costs are so high.
- How providers are paid by insurers.
- Reforms that might improve care coordination and/or lower costs.

However, the literature we reviewed also did not contain very robust information on the following topics:

- **Patient Safety.** Very little is known about consumers' attitudes towards patient safety issues.
- **Variation in provider treatment styles.** There is a perception, though not thoroughly documented, that variation in provider treatment styles and treatment intensity is not widely recognized among consumers.
- **High health care prices as a proxy for quality.** There is mixed information about whether consumers believe high health care prices signal high quality.
- **Taking action.** We found little information on how to frame the issues of high health costs, unwarranted quality variation and medical delivery reform in a way that will harness consumer outrage and get them to take action.

## Qualitative Research

Based on what we learned from the literature review, we designed a series of focus groups to elicit more nuanced information about the remaining evidence gaps as well as participants' reaction to information shared as an infographic. Because we would be unable to address all of the gaps identified above, the team focused on these discrete areas in the qualitative research phase:

- Consumer views of health care system costs and variation in prices
- Consumer views of quality in the health care system
- Consumer views on reforms that can address problems with costs and quality
- What would inspire consumers to take action
- How participants reacted to information displayed in infographics

We used a formative approach in designing the focus groups, using the results from one focus group to shape the discussion for the next. All groups started with open-ended questions about the health care system. After that, we introduced a topic and then returned to it in a later focus group from a slightly different perspective to create a more robust understanding of consumers' views and their understanding of the health care system. Hence, the emphasis that each topic

received varied across groups. After the initial round of focus groups in Denver, we developed a series of infographics to represent key ideas within a topic area. We focused on how well participants understood the infographics as well as whether the infographics' content motivated consumer to support change in the health care system.

As Exhibit 1 indicates, we conducted a total of 8 focus groups in three locations: Denver, CO; St. Louis, MO; and Bethesda, MD. At each site, one group consisted of people who self-identified as high users of health care and one group of people who self-identified as low users of health care. To examine the specific infographics, we used the 5 focus groups in St. Louis and Bethesda, and also conducted 8 informal one-on-one interviews at local Starbucks Coffee Shops in four locations: Arlington, VA; Denver, CO; St. Louis, MO; and Tulsa, OK.

**EXHIBIT 1. TESTING SITES**

| LOCATION | METHOD | PARTICIPANTS | PRIMARY TOPICS |
|---|---|---|---|
| Denver, CO | 3 focus groups | 1 high use of health care<br>1 low use of health care<br>1 Medicare recipients | Health care quality<br>Health care cost<br>Improvements to health care |
| St. Louis, MO | 3 focus groups | 1 high use of health care<br>1 low use of health care<br>1 combination of other two groups | Health care quality<br>Health care cost<br>Improvements to health care<br>Infographics |
| Bethesda, MD | 2 focus groups | 1 high use of health care<br>1 low use of health care | Health care costs<br>Improvements to health care<br>Infographics |
| Arlington, VA | 2 informal one-on-one interviews | varied | Infographics |
| Denver, CO | 2 informal one-on-one interviews | varied | Infographics |
| St., Louis, MO | 2 informal one-on-one interviews | varied | Infographics |
| Tulsa, OK | 2 informal one-on-one interviews | varied | Infographics |

*Participants represented a range of demographics, such as age, education, income, and gender.*[3]
*The one-on-one "Starbucks" testing was a convenience sample.*

[3] For complete demographics of testing participants, please contact Consumers Union.

### *Analysis Approach*

This project used an inductive methodology or grounded theory method to analyze the transcripts from each focus group. In grounded theory, the researchers allow themes to emerge from the data, rather than impose predetermined and preconceived analytical codes. We compared results across groups and across locations to confirm larger findings.[4]

Working with transcripts of the focus groups, we assessed informally if consumers were familiar with a topic and had a frame of reference. A frame of reference is an individual's prevailing, habitual way of thinking about an issue or topic. A frame, or schema, enables individuals to ground their understanding of a particular topic or element of information and can allow them to build additional information into it for a more sophisticated understanding. When a frame of reference is missing or not well-developed, new information can cause a tension between the frame and the new information. New information that violates a current frame of reference causes cognitive dissonance as the new information collides with the old frame. Cognitive dissonance is the mental stress or discomfort experienced by individuals who confront new information that conflicts with an existing frame of reference.[5] Because individuals are uncomfortable with cognitive tension or dissonance, they tend to use one of several ways to reduce this tension: they reject the information, they rationalize why the information is not true or they incorporate the information and modify their frame.

Among other things, this report describes how participants reacted to new information and the approaches that seemed to ensure that the new information is incorporated and not ignored.

## Nationally Representative Survey

We used findings from both the literature review and the qualitative research to construct a survey designed to elicit consumers' views on our core health system topics.

The Consumer Reports National Research Center contracted with GfK Research to conduct a nationally-representative survey of 1,000 adults about their experiences with, and attitudes of the U.S. health care system, in July, 2014. The online survey used the web-enabled KnowledgePanel®, a probability-based panel designed to be representative of the U.S. population.

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[4] Glaser, B. & Strass, A. (1967). Discovery of grounded theory. Chicago: Aldine.

[5] Festinger, L. (1957). A Theory of Cognitive Dissonance. California: Stanford University Press.

The survey design also included two supplemental sample groups to ensure ample sample sizes for analysis: (1) 500 "heavy users" of health care services (2) 500 uninsured respondents. For analysis, these supplemental samples were added to those identified as belonging to each group in the original sample of 1,000, resulting in 1,079 heavy users and 620 uninsured.

The full survey is available online.[6]

[6] Consumer Experiences with Health Care Costs, Consumer Reports National Research Center Survey Research Report, October 2014, www.consumerreports.org/cro/healthcostsurvey.

# Chapter 3. Qualitative Research Findings

This chapter summarizes the results from our qualitative consumer focus group work. We have organized the findings from the qualitative work according to the following areas:

- Consumer views of health care system costs and variation in prices
- Consumer views of quality in the health care system
- Consumer views on reforms that can address problems with costs and quality
- Consumer views on health care system reforms; and
- Consumer views on taking action, personally as well as by policymakers
- What would inspire consumers to take action
- How participants reacted to information displayed in infographics. See Chapter 4.

In many cases, these results are supported by research described in the literature review and the national representative survey. We reference these components when appropriate, noting any inconsistencies across the data.

## Health Care System Plagued By Problems, With Cost Being Primary

Participants had a strong sense of the U.S. health care system as being plagued by many problems, but costs weighed most heavily on participants.

In response to the first, open-ended question at the beginning of the Denver and Bethesda focus groups, "What is one word that describes the US health care system," nearly all participants wrote down "Expensive," "Money," "High costs" or a variation[7]. One participant even noted, "If you take the 'U' and the 'S' part of the health care system and put them together or overlap one of them—one over the top of the other, you get a dollar sign," (CO-Group 1). The theme of high costs ran throughout our discussions in all groups.

They, nonetheless, tended to believe that the system had better quality than that of many other countries and the Literature Review revealed a similar finding. In the national survey, respondents gave the U.S. Health System an overall grade of B for quality, but gave just a mark of C for affordability and C+ for fairness.

***I just think from my point of view, the increases are arbitrary and they make them when they get a chance to. (MD-Group 1)***

[7] Many participants, especially in Denver, identified "Obamacare" as the first word they associated with the US health care system. However, we reframed the question, asking them to focus on current and past experiences, rather than on future possibilities. We report the results of the reframed question.

As we also saw in the Literature Review, participants were quick to assume that insurers were the culprits behind high costs. They attributed this to a predilection of insurance companies to focus primarily on making money whether by overcharging, having high administrative costs, or denying care. Further, they stated that lobbyists for health insurance companies are influencing government, which in turn protects the insurance companies.

### *Views on Why Health Care is Expensive*

> They are gougers, what the market will bear. (CO-Group 3)
>
> If Kaiser raises their insurance, Blue Cross/Blue Shield raises theirs, and Aetna raises theirs, and I can't think of all the names, but they all sit at a table just like this and it is a monopoly. (CO-Group 3)
>
> Obviously…the villains here are the insurance companies and the pharmaceutical companies because they are the ones making all the money. Doctors are almost being dictated to by the insurance company has to here is how much we will pay you for that procedure. (CO-Group 1)
>
> I just think from my point of view, the increases are arbitrary and they make them when they get a chance to. (MD-Group 1)
>
> In health insurance, I can expect that with this kind of a number, you are looking at somebody who has figured out how to add an arbitrary amount to the cost and just pass that on to somebody who sort of has grease in the wheels so to speak, making money off of this. (MD-Group 2)
>
> Again, the people that are working for an insurance company don't do anything as far as giving you health care [and] that adds to the cost of health insurance or health care…We used to call them paper pushers. (CO-Group 3)
>
> The problem is the Government does have a dog in the fight in that insurance company lobbyists are paying to put people in Congress. (MO-Group 2)

Participants were also quick to challenge the behavior of pharmaceutical companies. They perceived a focus on making money to the detriment of the patient. They saw companies—pharma and others—as financing research studies to create a market instead of treating illness, and creating tests merely to increase patient billings. Further, they saw the pharmaceutical companies as preventing less expensive medicines from coming to market in order to maintain their high prices.

> I think it is okay for pharmaceutical [companies] to make money within reason. When they are sitting in their billion dollar mansions, cars and such and we, the people, are sitting in our modest house, so I think it should be within reason. (MO-Group 1)
>
> I think there is probably medications say for cancer and such that is available in Europe but not here because the pharmaceutical companies will

not allow them to come in because they somehow want to make their money on the backs of whomever… (MO-Group 3)

Many also blamed the failure of people to take responsibility for their own health (like eating right, not smoking, etc.).

By that same token with health care, if I can take better care of myself so I'm not running back and forth getting surgeries, and so on and so forth, then that lowers my costs of health care because somewhere along the way I have to pay. (CO-Group 1)

…it basically comes down to your personal health care, how you are taking care of yourself. Even the poorest of the communities are starting to find ways to help themselves or be better dietary, eating better and try to have their kids be more involved in things, the obesity thing. (CO-Group 1)

Few participants, however, were ready to identify doctors as a root cause of high costs. Primarily they thought that doctors and health care professionals were dedicated to the well-being of patients, but limited by insurance companies.

I wish it [the people with the power to make a change] was the doctors, nurses and therapists because they are…they have these jobs to make money but they also have these jobs because they care about patient care and they really want to help people and provide the best services, but their hands are tied and they are being limited by what people can afford or by what is available or what is covered on your insurance plan, (CO-Group 2)

I had a heart guy I never met before who came in and said if you had better insurance I'd be doing this to you and that to you and we'd get you the best for $3,000 but you don't, so we're going to give you these pills instead and it will be okay, just go walk and do this and that. He was straight up but he was a surgeon. I was shocked. (CO-Group 1)

When we gave participants information about hospitals showing markup over costs,[8] many more participants saw hospitals as culprits.

If you look at these numbers, I would also like to see, "Okay, Mr. Hospital, give me the explanation of why it [the charge] went up that high. I don't want a lot of BS here; I want it explained to me. If you are going to blow smoke at me, go. (MO-Group 1)

I think it is even worse. You can call the manufacturers and get the actual cost of the product, and then when you get the bill why am I getting charged $90,000? (MO-Group 1)

They really have you over a barrel…when you are sick and in the bed. (MO-Group 1)

[8] See Chapter 4 for a description of infographic testing.

Across the focus groups, participants were aware that hospitals may inflate charges to cover patients who do not or cannot pay, then perhaps unfairly pass on the cost to those who can pay.

> A lot of times what they will tell you is we jack these rates up for people who have insurance that will pay these ridiculous costs so we can cover people who don't have insurance. I don't know if that's true. (MO-Group 2)
>
> …I'm close to a lot of people who have extensive medical bills and whose insurance is fairly decent. But [they] still [are] paying quite a bit whereas other people can go to the hospital and they can't pay so they don't pay and then that cost gets put onto other patients who can pay. (CO-Group 1)
>
> I might be off base. But sometimes I feel like certain people's bills are higher because other people can't pay and so the cost is offset that way. (CO-Group 1)

Further, participants saw the hospital practice of offering discounts for paying immediately or in cash, as an inequity, especially to those least able to afford it.

> What discount can you give me off of my bill if I pay this in full today? They can take 20 to 25% off that bill if they get their money right away. How are they able to do that? (MO-Group 2)
>
> I had a major hospital…they actually called me and said—hello, Mr. T., if you would pay your bill right now we will cut it by 50% and it's only for a short term. I said why the hell can you do this? (MO-Group 2)
>
> The person who has to make payments because they're living paycheck to paycheck—they get screwed. (MO-Group 2)

No participants identified the cause of their high health costs as the overall health care system-- in part, the complexity of the overall system is simply overwhelming. Instead, participants identified the parts of the health system that were familiar to them. They could identify that the actual cost to provide care is opaque and that final prices are hidden. They understood that there are financial incentives to deliver more care than is sometimes needed. They even understood that the current system requires an excessively large administrative cost burden. What they rarely, if ever, was to fit these pieces into the larger health care delivery system.

Responses from the nationally representative survey were similar to those of our focus group participants except in one respect. Responses to the question "Which ONE of the following would you say bears the MOST responsibility for making health care costs higher?" introduced a culprit not much discussed in the focus groups: the federal government. In addition, we saw that heavy users of the health system assigned somewhat more blame to hospitals for high costs than light users (15% vs. 11%). See Exhibit 2.

***The person who has to make payments because they're living paycheck to paycheck— they get screwed. (MO-Group 2)***

**EXHIBIT 2. CONSUMER VIEWS ON RESPONSIBILITY FOR HIGH COSTS**

| WHICH ONE OF THE FOLLOWING WOULD YOU SAY BEARS THE MOST RESPONSIBILITY FOR MAKING HEALTH CARE COSTS HIGHER? | TOTAL POP |
|---|---|
| Health insurance companies | 28% |
| The federal government | 24% |
| Drug companies | 16% |
| Hospitals | 11% |
| Patients | 4% |
| Primary care doctors | 4% |
| Medical device companies | 2% |
| Other:_____ | 5% |
| None of the above bears that responsibility | 6% |
| Base | 988 |

*Source: Consumers Union Survey Report, October 2014.*

The most frequently identified culprits are well aligned with consumers' views on who has profited excessively from the health system. See Exhibit 3.

**EXHIBIT 3. CONSUMER VIEWS ON EXCESSIVE PROFIT TAKING**

| WHICH ONE OF THE FOLLOWING WOULD YOU SAY HAS PROFITED MOST EXCESSIVELY FROM THE HEALTH CARE SYSTEM? | TOTAL POP |
|---|---|
| Health insurance companies | 34% |
| Drug companies | 26% |
| Hospitals | 10% |
| Specialist doctors | 7% |
| Primary care doctors | 5% |
| Medical device manufacturers | 2% |
| Other:_____ | 2% |
| None of the above have profited excessively | 14% |
| Base | 988 |

*Source: Consumers Union Survey Report, October 2014.*

### *Concerns about High Costs Reflect What Participants Pay Out-Of-Pocket*

When asked for more details about what they meant by "high costs," nearly all participants framed their thinking in terms of their personal costs, such as premiums, co-pays, and deductibles. They also mentioned common services for which patients pay a large share such as prescriptions, emergency care, and medical equipment like wheelchairs or crutches. As such, participants linked what they pay out-of-pocket to an underlying concern about the affordability of health care.

> The thing that is mind-boggling is the deductibles. I mean, you have to pay $4000 out of your own pocket before they even partially pay for some of your health care. (MD-Group 1)

> Just meaning if my family has already hit our deductible, we still have to pay a lot of out-of-pocket, and I had an appointment every week so paying $100 out of pocket on a minimum wage salary was very difficult. (CO-Group 2)

> Co-pays, premiums and also for prescription drug coverage, I take very expensive prescriptions for asthma and those types of things and they are just not covered, and they don't make a generic. It is $300 and I need it, and it is kind of a problem. I also have older parents that I'm taking care of and helping, and the expense is outrageous. (CO-Group 2)

> A lot of insurance premiums I see cost an arm and a leg…it is crazy because you should not have to sacrifice…a little bit, not a whole lot. (MD-Group 1)

Participants were not only concerned about their current costs, but also worried about the financial strain of high unexpected costs that they might face.

> Even with health insurance, trying to go to the ER or trying to go to the doctor's…There's still plenty of other bills they send you even when you have health insurance. (CO-Group 1)

> I'm trapped at the job I'm at. We can't relocate. I can't leave my job. I can't stay home with my kids because I carry the insurance in the family. And to try to get it on your own it's almost impossible to even afford it. (MO-Group 2)

The Literature Review found several studies that also found out-of-pocket costs are front-of-mind for consumers.

### *Incomplete Sense of System-wide Costs*

Participants had, for the most part, only a general sense of the broader system costs, including the portion paid by third parties (a majority of our spending). However, system costs were not completely absent. Most had broader system costs in mind when they talked about problems and reforms.

Only a few participants mentioned insurers or patient mix as affecting costs.

> I feel like I know experiences I've had in the emergency room the bills are crazy huge and I think it's because other people can't pay and the cost gets shifted to people who can. (CO-Group 1)

> It's what you're paying for—the services you're getting, the prescriptions, how much you are paying and how much your insurance is paying…deductibles and co-payments. (CO-Group 1)

An important subset of participants recognized that insurance was paying a majority of overall costs and did not see high costs as directly impacting them because of their coverage.

> I almost don't care what the price is; it's what is the bottom line to me. I don't care if the insurance covers 80% or 90%. What is the bottom line dollar? (MO-Group 2)

> It doesn't cost me anything so it's hard for me to say something when my benefits are actually really good. I don't pay for a prescription or any of that stuff. (CO-Group1)

> I'm poor and I could care less about [high costs] because I don't pay much anyway, either way. (CO-Group 3)

***Even with health insurance, trying to go to the ER or trying to go to the doctor's…There's still plenty of other bills they send you even when you have health insurance. (CO-Group 1)***

### *Variation in Hospital Prices: A Surprise to Participants*

While participants had an almost universal understanding that the U.S. system has very high costs, participants were surprised by how much variation could exist in the same city for the same procedure. When asked about price variation initially, participants said they would expect some variation. They saw price variation in other aspects of their everyday life and expected the same would be true of health procedures. We then presented participants with specific information about local hospital price variation for an echocardiogram, treating chest pains, and joint replacement. See Chapter 4, Infographic: Same City, Same Service: How Much Price Variation is Reasonable?

In processing this information, we saw participants go through three stages:

- They expected that some variation would occur.
- But, they were shocked by the amount of variation and attempted to justify it.
- They focused on the profit/cost ratio within each hospital and were outraged by the amount of profit.

**Stage 1. They accepted that some variation would occur.** Before we showed infographics to the group, most participants had strongly held preconceived notions that some price variation was justified because most things vary in price. For example, several participants knew about price variation from first-hand experience, having shopped for medical services, such as Lasik or MRIs

> With Lasik they're different. It seems like everything is going to be different essentially. When you go shopping around, you're going to find different prices. I don't see why anything else would be different. (CO-Group 1)
>
> I found that there's a tremendous difference in price and I think it makes a difference in what happens to health care cost overall. I not too long ago shopped for an MRI. It was $1,400 at one hospital and $400 at a standalone facility. That has a bearing on what I ultimately have to pay out-of-pocket. (MO-Group 2)

**Stage 2. They were shocked by the amount of variation and attempted to justify it.** Nearly all participants were shocked by the amount of variation within their own community.

Because the actual numbers were so wildly different from one hospital to another, the extent of the variation created cognitive dissonance. As we expected, participants' first reaction was to try to "explain" or justify why the variation occurs. Many suggested that the large cost variation was due to differences in reputation, amenities (such as a private room versus a semi-private room), and location.

…maybe the reason it's higher in certain areas is because those are the areas where the doctors get paid more. (CO-Group 1)

[Hospital A] is tied to [the] University's medical school. These other three are not tied and it could be the reason for the significant difference. (MO-Group 1)

Here's what I wondered—whether the price is higher at a certain hospital because it's a smaller hospital and they do fewer. If you've got factory medicine and you're doing these things all the time the price per individual service is less. But if you have a smaller hospital like [Hospital B] you wonder if that's why the price is higher? (MO-Group 2)

I want to know when I'm in the hospital, am I getting a private room, is that what the $24,000 is paying for? (MO-Group 1)

…somebody might be able to charge less, but if you're laying in that hospital bed and you're buzzing for your nurse and you're buzzing for your nurse and waiting for your medicine and waiting for your medicine and you never see a doctor, you're going to get pretty doggone aggravated. (MO-Group 2)

Because it was unclear in our infographics, we assured participants that all comparisons were apples-to-apples and that it was appropriate to compare hospitals. Participants then accepted the new information as true and a distinct emotion emerged as they were shocked and outraged that such variation could be possible.

A doctor has the same credentials. Different places—why does one place have to charge $1,400 other than $400? (MO-Group 2)

…I mean somebody has a broken leg for example. Set a leg. All the orthopedic guys do pretty much the same thing, the same screws, the same stuff. But depending on where you happen to be or the hospital—it's so arbitrary… (CO-Group 1)

…I would assume you are going to [Hospital C] or [Hospital D], I wouldn't expect there to be that much disparity between them. I understand maybe somebody has thicker blankets and nicer mattresses in their care facility than the other, but to have it be potentially doubled, that is just crazy. (CO-Group 2)

…I was just shocked to see the prices that they charge for these procedures and stuff like the hospitals. (MO-Group 3)

Some differences I can understand, but that much difference really surprised me. (CO-Group 2)

**Stage 3. Participants focused on the profit/cost ratio within each hospital and were outraged by the amount of mark up over costs.**
When price variation was broken down between costs and mark up, some participants then considered the wide variation in costs to be random, intentional greed, or symptomatic of the extremes the market will bear.

Yes, that [the profit amount] makes me very angry. Because they're just trying to gouge consumers. I mean they are really trying to gouge everybody. (MO-Group 2)

Where did that [price] come from? Did he [the doctor] just grab it out of the air or is there some tax advantage, or something that he has that is an advantage to charge either more or less. (MO-Group 1)

You are just getting gouged because of reputation. … Cadillac versus Ford. That is all it is, you are getting gouged because you are paying for name recognition. (CO-Group 1)

…they [hospitals] know that the average consumer doesn't know what we put into this [pricing] so they can charge this outrageous number because consumers don't have a reference point from the beginning. We've been conditioned to pay these things. (MO-Group 3)

### *Participants' Shock at Price Variation is Rooted in Dual Views of Health Care*

As we probed to figure out why participants found the price variation so shocking, we heard an interesting contradiction in their attitudes toward hospitals and health care in general. Participants struggled with the tension between the idea of health care as a business and health care as a social good or a right, believing both to be true.

Most participants accepted that hospitals were businesses and needed to make a profit to remain solvent, and thus, they expected and would accept a certain amount of cost markup.

I get that it's a business and that's fine. Make your money. But don't rape people along the way. (MO-Group 3)

…There should be a range. Like this test can cost from this price to this price, but not a 200% increase or 2000%. (MO-Group 3)

To be able to maintain the facility, the costs need to go up to keep up with the facility and around staff, the medication and everything, so I think that is one of the reasons the costs go up. (CO-Group 2)

However, they also believed that a social contract exists with medical institutions—they exist to take care of sick people.

You should be able to go and get good care, and not have to worry about paying more or less, or shopping around or anything. (MO-Group 1)

I don't feel like health care should be a privilege; it should be a right that we are all entitled to. (MO-Group 3)

…it's not that I necessarily want to go in and make every decision about my hospital care based on what the cost is. (MO-Group 3)

***…they [hospitals] know that the average consumer doesn't know what we put into this [pricing] so they can charge this outrageous number because consumers don't have a reference point from the beginning. (MO-Group 3)***

When confronted with the both ideas at the same time, participants felt a tension that was typically resolved in favor of health care as a social good. The literature review strongly reinforced this finding, namely, Americans are uncomfortable talking about the role money plays in their health care.

## Views on Health Care Quality

Health care quality is a concept that is less concrete for participants and one they feel more neutral about.

### *Initial Focus is Doctors' Soft Skills*

In initial open ended questioning, participants were invited to list the aspects of care that represent good quality. Participants associated high quality health care with their doctor and focused on attributes we typically consider the "softer" side of a practice, such as the communication style of the medical staff, a careful attention to medical details, and wait time.

> Not necessarily treated like a number, not rushed out of there… Just treated nicely, [going to] the doctor is nerve-wracking and if they can calm me down and really walk me through what is going on I appreciate that. (CO-Group 2)
>
> For me, one is how the medical professional is communicating with me. (CO-Group 1)
>
> How much time they spend with you. (CO-Group 1)
>
> They get back to you. They promise something, they carry it out. They might just say, "I'll get back to you to see how you feel" or even the reverse, "Call me within a certain time, I want to know how you feel." (CO-Group 3)
>
> Sometimes it's that time you're waiting in the waiting room to get in. You don't feel very valued. You feel like sometimes you're just a number. Or even waiting time when you're in the doctor's office. Your appointment is for 3:00 and you're waiting in the waiting room until 3:15, they call you back and then you're waiting in the doctor's office for another 15 to 30 minutes and then the doctor finally comes in. (CO-Group 1)
>
> I can ask questions, they will answer my questions and give me a comprehensive plan with some suggestions on what I can do, (CO-Group 2)

In some instances, participants looked beyond these softer issues to whether the doctor improved their situation.

> Do I feel better? Do I have a clear path to a result? Do I have a specific plan how to get better or do I know and understand what's going on so I can fix my problem? (CO-Group 1)
>
> I think that the high quality is going to be determined by life after, meaning if I go in for a hip replacement and he or she replaces my hip, I'm going to rate the quality on whether I have to go back, whether my hip is bothering me,

whether it hurts or did my life return to normal as it was prior to the injury that resulted in the surgery. (CO-Group 2)

### *Little Ability to Assess Technical Proficiency*

When prompted about doctors' technical proficiency, participants said that they valued the doctor's experience, including how often the doctor had done a procedure, and success rates.

> Quality of the doctors based on how long he has been in the field. The longer he has been there the more quality he has. (CO-Group 2)
>
> I personally have allergies so I think it's important that they follow strict guidelines. I have seasonal asthma, so I know what that's about and I'd like them to follow certain things for that. (MO-Group 2)
>
> I think that peer critique and peer standards is [sic] very important. These are doctors setting examples based on standards they've seen through experience and research. (MO-Group 2)

Although many also said that they valued following best practice guidelines, participants assumed that these guidelines were standard practice, and thus had never even asked about them. The literature review and survey also found that many consumers don't feel doctors should be paid more for something they "should be doing anyway."

> They're [doctors] not really going to recommend something if they know it doesn't work. I mean are they going to waste and spend their time doing it? (MO-Group 2)
>
> I gave two stars [for importance] to the best practices guide, and I never asked the doctor that… I've never found it be so important that I've asked about it. (MO-Group 1)

However, once aware that the information could be important, they were not sure how to find this type of information. Some were not even sure that the information existed.

> If you asked your doctor, "Do you follow Best Practices Guidelines?" what do you expect him to tell you? "Of course, I do." Do you think he is going to say, "No, I don't."? (MO-Group 1)
>
> There is no way. I don't know how anyone would find that information online. If you friend says go to Dr. Smith, he's great. How am I going to know whether or not he follows best in practice guidelines? (MO-Group 2)
>
> Along that line, I'm not aware of my doctor being reviewed by anybody. Does the state come in every couple of years and retest him? And who comes in and says okay, Mark, you're doing this, you're doing that, you're doing this, you're doing that. Or you need to do this, you need to do that? I'm not aware of anything like that. (MO-Group 3)

> I think there's a difference between finding out what that specific doctor's success rate is for the procedure and overall average doctors' success rate for the procedure… It's a lot more difficult to determine what the success rate is for that doctor unless they just happen to be exceptionally good at it or if they invented it. (MO-Group 2)

> How do you measure? There isn't a test or standardized set of qualifications that a doctor has to go through to say yes, they are up to the "standard" (MO-Group 2)

Participants felt they had no credible way to judge quality or best practices. They also cited that other sources of "quality" such as magazine rankings were unreliable because they are often "paid advertisements." As a result, participants reported relying heavily on the experience of friends and others. This reliance provides a cognitive shortcut to select a doctor or hospital since an assessment of objective quality is difficult or nearly impossible to obtain.

> When I picked my OB it is not like I thought about how successful they were in terms of delivering babies, I just had an assumption that if my friend likes it, they are good enough and I don't really care what her success rate is. If her reputation is good enough I just assumed she was good. (MO-Group 1)

> I think that everybody who would be going to look for a doctor is going to talk to their friends and discuss it. They'll say I went to this doctor and I liked him, and you are going to go there. (MO-Group 1)

> I have a friend that is a nurse practitioner, and I've even called her and asked her do you know anything about this doctor, is he good or whatever. I guess it is helter skelter how you find out. (MO-Group 1)

***I have a friend that is a nurse practitioner, and I've even called her and asked her do you know anything about this doctor, is he good or whatever. I guess it is helter skelter how you find out. (MO-Group 1)***

### *High Costs Did Not Always Signal High Quality*

Our Literature Review found mixed evidence with respect to whether consumers believe a high price for a health care service signaled high quality. Most of our focus group participants did not believe that there was a correlation. In Denver, however, some participants initially thought that quality and cost were linked.

> …the more you can afford, the more quality of health care you can get. (CO-Group 1)

> It's a reality. If you've got more money and you pay for a better health plan, you're going to get more perks and you're going to get better health care. (CO-Group 1)

As the group discussion continued, some participants discussed personal experiences with high quality care received at hospitals with lower reputations and the discussion separated the concepts of quality and cost. In St. Louis, when we showed participants low prices associated with hospitals with a good reputation, they too separated quality and cost.

> Yes, I think I may have gotten some of the best care for my particular problem in the state, even though it was through a public hospital. (CO-Group 1)

> The fact that [Hospital B] [hospital with lower reputation] is charging almost $5,000 for something I can get at [Hospital A] [hospital with higher reputation] for $1,200 because that is why all of our health care costs are so expensive… (MO-Group 1)

## Views on Medical Delivery Reform

In addition to asking participants open-ended questions about how they would address high costs, cost variation and health care quality, we led a discussion about reforms often grouped together and described as medical delivery reforms. Medical Delivery Reforms aim to improve outcomes and lower costs, often with a focus on high-cost, complex and vulnerable patient populations. These reforms include strategies such as strengthening primary care, promoting coordinate medical care and community-based support for patients; and reforming how providers are paid to encourage more coordination, better quality, and greater efficiency.

As with other topics, we began by asking an open-ended question about improvements that they had noticed in health care. Within the list they generated, participants' focused on aspects of electronic health records and coordinated care, and brainstormed a number of improvements. For the next discussions, we elected to develop infographics about several specific medical reform issues or solutions: hospital safety; waste in the health care system; the impact of health care costs on salaries; and coordinated and uncoordinated care.

In general, medical delivery reform items elicited a more neutral reaction from participants. They tended to think of these steps as logical developments. As a result, participants had little emotional response to these improvements. To some extent, they could not see how these reforms had a direct impact on them, and certainly did not see a connection between the reforms and safety or costs. However, we had moderate success engaging participants around the hospital safety infographic, which suggests a pathway into talking about other medical delivery reforms and creating consumer interest about these topics. The literature review also revealed an overall ambivalence to delivery system reform.

### *Brainstorming about Changes and Improvements*

When we asked participants to brainstorm improvements that they were aware of in the health care system, they identified a full range of improvements, including in preventive care, technology, and treatment. Few seemed to think of any of these ideas as solutions to health care delivery problems, rather that they were merely evolutionary changes—that is, changes that were going to occur any way.

> An encouragement for using more preventive [care]… I do believe in prevention, and I think it's cheaper. But at the same time, I don't know if it's

a cultural thing that people just leave it. [They] don't want to go preventive like go to the doctor at least once a year or twice a year to prevent certain things. (MD-Group 2)

I like the satellite emergency rooms. In other words, if you break an arm or a leg it is not going to cost you twenty-five hundred dollars. You can go into these little emergency care centers and maybe spend two hundred, four hundred. (CO-Group 3)

I like that they [doctors] are putting blame on us a little bit. They are making us own up to our own mistakes. You go to the doctor, the doctor will give you pills and the doctor will give you shots. They are saying you know what, you have a part in this and you need to clean this up. If you have childhood obesity, adult obesity, all these things, you need to help out, help yourself. (CO-Group 1)

More holistic, like they are recommending acupuncture or massage rather than just chemicals. (CO-Group 2)

Less invasive procedures too. You can get a knee arthroscopic done with just a little pinhole instead of cutting you open. (CO-Group 2)

While participants had lots of ideas, they spent more time and were more animated when talking about electronic health records and coordinated care.

### *Electronic Health Records Viewed Favorably*

In our general discussions of quality and their own experiences, participants volunteered stories of how electronic health records had changed and improved a situation.

[With EHRs], you get care faster. Things move faster. If you go to another doctor or specialist, they don't have to waste time. (MO-Group 1)

[Without EHR], the same tests run by two different doctors because they're not electronically connected, because they're not in the same facility. (MD-Group 2)

I think that the best idea they came up with was when they decided to put your medical records on the computer as opposed to paper. (CO-Group 2)

…getting back to these computers, if they enter something in there, no matter what other doctor you see in that place they know they can get on a computer and can already see your record completely. (CO-Group 3)

### *Coordinated Care Viewed Favorably*

Participants had experience with and were frustrated with un-coordinated care. They had a lot to say about the amount of effort it took them to coordinate their own care or the care of others.

***So one doctor may be saying one thing and start them on a medicine, the other doctor stops it and there should be one team that is in charge of that patient. (MO-Group 1)***

> So one doctor may be saying one thing and start them on a medicine, the other doctor stops it and there should be one team that is in charge of that patient. (MO-Group 1)
>
> There are too many doctors and they are all adding their costs. And drugs too. They prescribe drugs. The services too, these different co-pays, the office visits, tests that maybe are run in day one and day fifteen they could be run again by another specialist. (MO-Group 1)
>
> And all prescribing different drugs, and you may use them for a week and decide you don't need them. When my father-in-law died, there was a closet full of drugs at his house, literally. Once the drug is at your house, even if it is not opened, you can't do anything with it, you can't return it. That all was just wasted. (MO-Group 1)

Participants were less familiar with the idea that care coordination could be improved. When the moderator introduced the idea of improved care coordination, participants mostly welcomed the idea and saw its advantages. However, they viewed it as a logical, evolutionary improvement to the status quo, not revolutionary. For participants in the Colorado groups, coordinated care and one-stop shopping was the status quo because many of them were enrolled in the Kaiser Permanente HMO.

### *A Logical Next Step, But Not a Reform*

With respect to both coordinated care and EHRs, participants found the concepts accessible and appealing, but they saw these as logical next steps, not as big changes. In addition, if we did not explicitly link either idea to cost or safety, participants on their own did not extrapolate the impact these reforms could have on them personally. For these reasons, their response was muted when asked about actively supporting these changes or advocating for them in their personal care.

One Missouri participant even questioned the feasibility of coordinated care and another participant disliked the idea, since she felt she could do a better job.

> With so many people in their practice, how could they possibly coordinate everything? (MO-Group 1)
>
> My daughter sees seven specialists, maybe more, on a regular basis and I wouldn't want to go through my primary care every time I went to see one. I wouldn't want them to be the one coordinating. Not that I don't trust them, but they don't have the amount of time or care to look through it as much as I would. I know it is a lot of time on me and she is lucky that I can do that, but if I had to go through my primary care physician for that, it would be bad. (MO-Group 1)

### *Waste in the System Seen as Pervasive, but Irrelevant to Them Personally*

To learn more about their knowledge of and reactions to information about waste in the system, we showed participants an infographic illustrating the amount of waste in health care. See Chapter 4, Infographic: Wasted Spending on Health Care.

When provided with information about waste in the system, participants accepted that waste was a problem, but were not aware of the extent of the waste. They had a general sense of the categories of waste—in particular unnecessary testing—but lacked a concrete notion of what was included in the waste categories.

> …there is a gross amount of unnecessary costs going on for the average consumer in health care. (MD-Group 2)
>
> Doctors are afraid of getting sued so they order a lot of tests which normally would be unnecessary. (MD-Group 1)

A few participants were more sophisticated in their understanding, recognizing that waste is not a simple thing to eliminate because it is entwined throughout the system.

> In reality you can't just cut off the wasted spending because it is literally every step of the way. Here it [the infographic] shows it [waste] as some separate entity, you have the spending and on top of your spending you also have additional wasted spending, so all you have to do is remove the fraud and unnecessary services. You can't really do that…It is every step of the way. (MD-Group 2)

Overall, participants' reaction to the infographic was muted. Rather than motivating participants to pay attention and act to reduce waste, this particular infographic allowed them to distance themselves from the numbers. For many participants, the numbers of $9,700 annual per person on health care spending and the average $2,910 estimate of waste were not applicable since "I don't spend that amount on health care." Moreover, participants saw the benefit of reducing waste as irrelevant to them personally since they would not see that amount in their pocket. This particular handling of waste created an intellectual, not an emotional response. As we have seen with other infographics, participants need to see a personal impact for a specific topic in order to relate to it in a personal way.

### *Shocked by Frequency of Hospital Infections*

In contrast, participants reacted strongly to information about rates of hospital infections. To provide a concrete example of an issue that needs reform, we showed participants deaths from hospital-acquired infections compared to deaths caused by drunk driving. See Chapter 4, Infographic: Hospitals Can Be Dangerous.

Participants were shocked to learn that annual deaths from hospital infections (more than 70,000) vastly exceeded yearly drunk driving deaths (almost 10,000 people). They knew and accepted that patients could get an infection while in the hospital and were aware that the number of people killed by drunk drivers was high. However, the fact that deaths from hospital infections were 7 times higher than drunk driving deaths greatly exceeded their expectations and invoked an emotional response.

> I'm a little surprised. I guess I thought more people was [sic] killed by drunk drivers than by infections. (MD-Group 2)

> I'm shocked…And then it makes me scared. (MD-Group 2)

In this infographic, participants were acquainted with the generally high number of deaths from drunk driving, even if the precise number was not well-known. That familiarity allowed the drunk driving deaths to act as an anchor to help participants understand the (unexpected) magnitude of the number of infection-acquired deaths in hospitals.

> …but I think you see a lot of information that's being advertised about drunk driving and drunk driving kills. There's not a lot of information that's being advertised about hospitals and you can get an infection when you're in the hospital. That's probably why the numbers seem so skewed to some people. (MD-Group 2)

Participants' reactions suggest that for future discussions of medical delivery reforms, it may be necessary to make the impact on the consumers explicit and personal, rather than discussing the reform in an abstract way. The most promising approach to these more abstract issues is probably to create a strong link to cost or safety, to help consumers understand how a reform will impact them personally. For example, the coordinated care discussion might have elicited stronger responses if we had talked about the number of duplicate prescriptions or tests that can occur, and possible patient harm from duplicate tests.

## Views on Taking Action about Costs or Quality

Early in our discussions with consumers, many were surprised by the concept that *anything* could be done to address system problems. They assumed that high costs, opaque prices and little ability to identify a good health care value was something that folks just lived with.

But when provided with concrete information, including the idea that change was possible, the vast majority were quickly searching for actions that they could take.

In particular, visual, concrete information activated them. In St. Louis, we brought some participants back for a second round of focus groups, showing them visual information that they had not seen in the first round. Their reactions were much stronger, revealing the power of information to activate consumers.

***I've always known that health care costs are exorbitant and probably unfair in many regards, but I think with this reinforced general distrust in the system, and I think that was the most incendiary thing for me. (MO-Group 3)***

> And when I went home I guess I was angry about the cost of health care. Yes I was. After our group and talking about the stuff it just kind of made me a little more angry about it all. (MO-Group 3)
>
> I've always known that health care costs are exorbitant and probably unfair in many regards, but I think with this reinforced general distrust in the system, and I think that was the most incendiary thing for me. (MO-Group 3)
>
> …I had been home about an hour last night when I had a throbbing in my head and I couldn't figure out. I had gotten a headache because I kept replaying what we had discussed. I kept replaying the things that we talked about and it had made me really angry. (MO-Group 3)

Once introduced to the idea of action, participants had many ideas of what could and should be done to address costs and quality. These ideas can be grouped as follows:

- Personal actions that they could take at the level where they had control with no outside party needed, such as staying healthy.
- Personal actions that required help from an outside party, such as comparison shopping for elective services, if a reliable source of comparative information were available.
- Actions that were beyond the individual and needed to occur at the system level. Although many preferred that industry would self-monitor, nearly all agreed that this would not occur. Their proposed actions were therefore in support of government regulation, although some reached this conclusion with great reluctance.

### *Personal Actions They Can Do on Their Own*

As participants explored ideas for how to channel their outrage, many talked about personal actions they could take as the first step in reducing costs.

As noted above, they saw consumers as having some personal responsibility for good health care, such as taking care of themselves, following discharge instructions, and so on. One participant from Missouri suggested facetiously that the primary personal responsibility to take is to "Not get sick." (MO-Group 1) Others had more concrete actions to suggest—all within the personal control of the individual.

> When I get a prescription, I ask about generic versus branded, and I go in network, I don't go out of network, when I talk to my physician, I open up. (MO-Group 1)
>
> You are contributing because why did you even go to the doctor to start with if you aren't going to do what he tells you to do. The patients themselves, they get ill and want somebody else to miraculously cure them when they aren't doing anything to take care of the problem. (CO-Group 3)

> My wife and I, we just try to do our due diligence and we ask those questions that probably most people don't ask. Like how much will this cost? How much does circumcision cost? How much is this? How much is that? Literally, we line itemed out how much it would be and then we consulted with the insurance. (MO-Group 3)

### *Personal Actions That Require Help*

Participants mostly agreed that comparison shopping was a sensible action to take and even something they should have been doing all along. Many claimed they would shop for non-emergency services if they had easy-to-use, localized information on costs and quality from a trusted source. They saw having access to this information as a power that could inform their choices.

> Why wouldn't you? Now that I'm thinking about it I feel kind of dumb that I never thought about it. It's eye opening. You shop for cars. You shop for houses. Why wouldn't you shop for…you shop at stores, shop for everything else you pay for. (CO-Group 1)

> The thing is having that information so you can make the choice. And I think with so much of health care right now, we don't have that information and therefore we can't make an informed choice. (MO-Group 3)

> And so if that information was available in whatever form, whether on the internet in some kind of a publication or in an annual bulletin or something, I would be willing to look at it and I would take that information along with the information I gleaned from family, friends and associates to make a decision on the doctor. (MO-Group 3)

Many participants also saw this actions as not only a personal benefit, but also as a larger way to affect prices, by making hospitals, in particular, sensitive to the market overall.

> So I think if people said no, I'm not going to [Hospital B] because it is $23,000 for this procedure versus $12,000 at [Hospital A], I think that maybe [Hospital B] might come down in their pricing. (MO-Group 3)

> I think the thing is this information has to be more readily available to the consumer so you can make more informed choices or demand that they at least explain why it is costing more. (MO-Group 2)

Participants readily articulated the difficulty of acting as an informed shopper. They thought reliable information to distinguish among providers was not available. They cited the difficulty of getting prices even for a pregnancy and delivery because of all of the variations in circumstances. Additionally, those few who had tried to shop for the cost of a service ran into problems getting accurate prices.

> When you walk in the door there is not a price that says a cold treatment is fifty dollars. I've never seen that. (MO- Group 1)

> It is almost like what you've been groomed to accept. When it comes to the doctor's visits, you are groomed to accept that whenever that statement comes in the mail—that is what you have to pay. (MO-Group 1)

> Take the childbirth, you call up XYZ hospital and say I would like to know what your rates are for child delivery. They are going to say that will depend on. What do you mean what it is going to depend on? Well, it is going to depend on whether or not there are any kind of complications, the age of the spouse, this and this, and they will add things onto it, and just take a standard normal delivery for a normal person like you presented it to us. They are not going to come up with a normal, flat rate fee, like well the standard delivery is $10,000. (CO-Group 2)

Participants had mixed reactions as to who could serve as a trusted source providing unbiased health care information. As one participant stated, "It needs to be an independent source that doesn't benefit from the companies that are providing these services." (MO-Group 2) Consequently, they did not want the information to come from insurance or pharmaceutical companies or even hospitals. Initially many participants mentioned the government as a potential information source.

> Some sort of government agency preferably. The FDA or whoever. (MO-Group 2)

> I think you have to have a third party. Unfortunately, you may have to involve the government or some other governing body that would do audits that would do reviews to make sure what's being posted is accurate and allows a spot where people can comment.—put a comment it did agree or it didn't happen and all that stuff. (MO-Group 2)

In fact, many more participants were enthusiastic about information coming from an independent, consumer-oriented group. One participant suggested AARP as a possibility. However, without moderator prompting and unaware that the groups were sponsored by *Consumer Reports*, several participants quickly and frequently named *Consumer Reports* to be that independent, consumer-oriented group.

### *System Level Actions*

Participants understood that large system changes needed more than action at a personal level. Although comparison shopping might bring about some changes, participants understood that a complex system needs a greater and more coordinated effort to bring about change.

Some participants wanted the market to take care of the problem and provide fairer pricing, but they knew that it was failing to control the problems. As previously noted, while many accepted that health care is a business, most did not think that insurer, hospital, or pharma profits should be as excessive or at the expense of the patient care.

> I'm looking at what is going on in the market place and say you know what, the profits these companies are making is ridiculous… Unfortunately, by and large, the morale tenure of the folks and money doesn't seem to be there that are looking to help out their fellow citizens. So you are looking at these big companies that are answering Wall Street and all these other guys that are all about profit. They are trying to make up for the losses they've had in the past five years or ten years, and they are looking to try to earn as much money back. In the meantime, that means rising prices and all of us are paying incremental and greed. (CO-Group 2)

Almost all participants—some with great reluctance—thought that regulation needed to be part of the answer. They wanted a fairness that, for them, only government regulation could achieve.

> I just think it should be regulated. I think there should be some type of government regulation that says, if I go to the doctor and I'm going to have a urinalysis, Doctors A, B and C can only charge seventeen dollars for it, that's it… (MO-Group 1)

> Yes, the government is the only one that is on their level who they will actually listen to. They are not going to listen to us. They are going to only listen to the government. The government is the only one that has the power to go ahead and do this, and I wish it wasn't the government… (CO-Group 2)

> I think the Government has to play a role eventually in some way. If we had a single payer system you would have the ability to negotiate prices of these drugs and get them down. (MO-Group 2)

> To keep the prices fair, you need the Government's intervention. You can't allow people to gouge. Again it's a morality issue. The only entity with enough control is going to eventually be the Government. It has got to step in. (MO-Group 2)

> Yes, I hate to say that as a conservative Republican, but if there is nobody else to do it…unfortunately it seems like the government is the answer at the moment. (CO-Group 2)

Having accepted that government regulation was necessary, they understood that government regulation is part of a political process. Participants identified how to support political action and quickly identified actions at both the state and the federal level. Participants even discussed the presidential election as one avenue of action. A few participants adopted the fervor of a grass roots organizer, urging others to become active, to complain, to act.

> President Obama ran on that platform of health care reform two times straight, and he got elected two times straight, so when you are asking, on a federal level that is what it is doing at this point. It may trickle down at this point because he has some regulations but the insurance company, when it comes to how much they can use for their payments for their big CEOs and

***"Yes, I hate to say that as a conservative Republican, but if there is nobody else to do it… unfortunately it seems like the government is the answer at the moment." (CO-Group 2)***

all that stuff, and the pre-existing conditions, it may come down to a state level at that point in time, but if you are asking directly right now what can you do, you've done it basically in the last two elections, on a federal level. (MO-Group 1)

…we all should behind this focus group, every last one of us should be finding out who the regulatory folks are in Jefferson City and do what we need to do. Because from personal experience I know a lot about this, but everybody here should be on top of it, contacting the hospital board or whoever, both locally and federally. (MO-Group 1)

Sign a petition and contact that agency, the state agency of regulatory whatever it is called. Believe me, all these people who have been surfing the internet, you will find it. (MO-Group 1)

Similarly, survey respondents assigned primary responsibility for fixing system problems to the federal government, but also assigned some responsibility to health insurers, consumers and state governments. See Exhibit 4.

**EXHIBIT 4: SURVEY RESPONSES ABOUT WHO SHOULD FIX THE BROKEN SYSTEM**

| WHO SHOULD FIX THE BROKEN SYSTEM? | |
|---|---|
| Federal government | 41% |
| Health insurance companies | 22% |
| Consumers | 13% |
| State Government | 10% |
| Doctors | 5% |
| Hospitals | 4% |
| Drug companies | 3% |
| Medical Device Manufacturers | 1% |

*Source: Consumers Union Survey Report, October 2014.*

### *Regulatory Actions They Would Support*

Participants volunteered a range of suggestions on how to control costs. Their ideas included caps on hospital charges, profits, and so on.

…it seems like our government agency should be able to come in and put some kind of…caps on the percentage of profit or something like that. Hypothetically let's say instead of making three hundred percent profit on each pharmaceutical drug, the cap might be two hundred percent. In other

***"…every last one of us should be finding out who the regulatory folks are in Jefferson City and do what we need to do." (MO-Group1)***

> words, I still believe in profitability and market competition, but it is just not answering the call. (CO-Group 2)
>
> I feel like what you all were saying is put a cap on it that you can't charge more than X amount for X procedure…But there should be a range. Like this test can cost from this price to this price. But not a 200 percent increase. (MO-Group 3)

We could not ask open-ended questions in the nationally representative survey but the results were still very similar, embracing a wide range of regulatory actions. Survey respondents firmly endorsed actions like paying for outcomes, not by service; caps on prices; disclosure of "fair" prices, and requiring upfront cost estimates.

### *Paying for Coordinated Care*

While participants are very interested in receiving the benefits for coordinated care, one reform that was not uniformly embraced was paying doctors for coordinating care or good outcomes.

In Bethesda, Maryland, we asked participants whether we should reward institutions for meeting standards or punish institutions for missing standards. Participants were more interested in paying hospitals less for low performance (like high infection rates) than paying them more for doing something they should already be doing.

> Isn't there a reasonable expectation that they should be doing everything the right way. Why should I be paying you an extra service because you weren't doing it right the first time? (MD-Group 2)
>
> It's just making [institutions] accountable by saying OK, have you seen your whatever; a lot of people have died, whatever, right? So then we're not paying you as much… (MD-Group 2)

The Literature Review found that while consumers want changes in care delivery, they do not want to discuss payment and reform. While they are not eager to think about the role of money in their personal health care, they are open to hearing about new methods of structuring the system, such as caps on payments, if it would result in more of what they want without more cost to them.[9]

[9] Robert Wood Johnson Foundation. Talking About Health Care Payment Reform with U.S. Consumers.

## Absence of an Outlet Leaves Them Frustrated

Participants understood that for regulatory change—or even industry policing—to happen, they needed to do something, indeed, they longed to do something. The energy was palpable as participants looked for an idea that could have traction and leave them with a sense of accomplishing something. But they experience great frustration because they don't know what to do.

Alongside the enthusiasm of activated participants exhorting people to take action, we also heard a more plaintive tone about just not knowing what to do to bring about change.

> I don't think people know how [to take action.] That gap, whether you consider it social, whether it is cultural or just economics, but I don't think people really know how. (CO-Group 2)
>
> I got thinking about it when I got home last night and the one thing that struck me was what are we going to do about it. When we're all done here are we all just going to go home and just say yeah, well I'm mad, but am I mad enough to do something? I don't know. (MO-Group 3)
>
> …but I wonder if more information was out there about what people could do if that would make them act more. It's easy to talk about it but if no one knows what to do about it then they're not going to do anything about it. (CO-Group1)

In addition, a few participants recognized the power of the status quo and the significance of the health care industry with its lobbyists to undermine political action.

> I need to feel like whatever organization is doing this has some sort of power or influence and it's probably going to have to be money because there is so much money in politics that a grassroots organization isn't going to be able to trump all the lobbyists for the hospital systems, for the pharmaceutical companies, for the insurance companies. They have so much power and a lot of it is power that's bought and sold. You could have three hundred million angry Americans but unless we have money we're not going to really accomplish much. (MO-Group 2)
>
> It is not like we have much power… I have [written a Congressional person] before, but what difference does that make, I'm one individual. (MO-Group 1)

### *How can I be more than one voice?*

Participants wanted a means to act collectively. They were fully aware that a "voice of one" is not necessarily heard and does not have much power. But they would readily embrace a collective voice that increases the likelihood of impact. Participants recognized the need to band together to make their voice more effective but they weren't sure how to go about it. They expressed a strong desire for an outside entity to organize them and direct their energy.

There are avenues that people can use. Even if you are one, you can get your one voice heard. Just because you are one doesn't mean there aren't a hundred people thinking just like you. (MO-Group 1)

…if you fight and you stand, and you stand, and you fight and as you are doing that, you are going to start running into people who have that same opinion that you have on this issue, and they are going to come in with you and they are going to fight with you and before you know it, you have created a group of people. You have 100,000 people. Okay the Mayor is going to listen to that 100,000 people. You have his ear now, but it started with one person. (CO-Group 2)

Well, I still think that there needs to be some type of a board that regulates cost. And who would set it up? Would Consumer Reports?[10] (MO-Group 3)

I think [we need] some type of private organization. An organization of people who are concerned about that [health care costs]. (MO-Group 1)

[10] Participants were not told who was sponsoring the research.

# Chapter 4. Role for Infographics

To activate consumers, we need to provide them with information. The right information can create the energy and the emotion that something must be done.

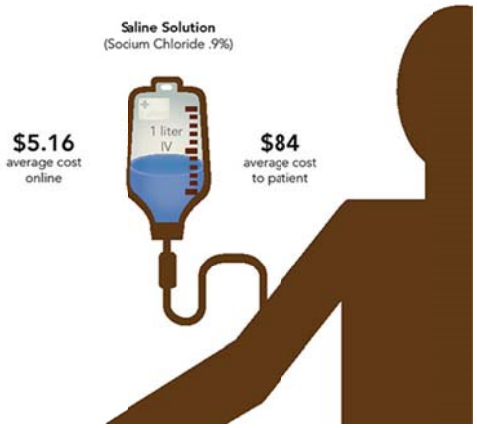
In our first focus groups (Denver) we did not show any infographics, but our information still elicited an emotional response and created a willingness to act. But (as described above) in St. Louis, where the same group was first given verbal information, followed in a second session with visual information, the latter information proved particularly motivating.

Infographics combine data and visuals in a way that reveals relationships and significance more quickly than traditional text. Text is necessarily processed linearly, while visuals are viewed as a whole and processed more quickly by the brain.

For this study, we developed two types of infographics. One set used readily available statistics to convey facts about the health care system, such as the cost of a blood test or the variable charges by local hospitals for a particular procedure. The second set conveyed more abstract or complex topics, such as the insurance cycle or the relationship of health cost increases to take-home pay. In both instances, our goal was to motivate participants to want to take action for change and we let this guide our design iterations.

To test participant reactions, we gave them an individual infographic with no prompting from the moderator and initially asked a simple, “What is your reaction?” Based on their feedback, we modified an infographic or discarded an approach completely. For example, we showed participants three graphics about hospital mark-ups: the cost of one Tylenol pill, the cost of one bag of saline solution and the cost of one dose of the cancer drug Rituxan. Participants found the cost of one Tylenol pill interesting and even shocking at the markup compared to buying a bottle at a pharmacy, but ultimately felt the cost was affordable. They reacted to the saline solution graphic in much the same way. Fully recognizing that it was salt and water, they still found the cost “reasonable.” See Exhibit 5.

**EXHIBIT 5: "AFFORDABLE" MARKUPS NOT AS COMPELLING**




Because the participant response was muted, we dropped these infographics and focused instead on refining the cost of Rituxan because it elicited a much stronger reaction.

Overall, the individual infographics are working—participants understood the messages when viewed individually—and many elicited a motivation to act. That said, participants had more difficulty with those that conveyed more complex and abstract information. These infographics were understood, but may need to be combined with a second infographic in order to elicit a desire to act. When participants looked at the infographics as a series, they created a story with a major theme—cost and wasted spending. Advocates, policymakers and others can use the infographics in either of these two ways.

The 9 final infographics—discussed in detail on the following pages—reflect this honing process:

- Hospitals Can Be Dangerous
- The Cost of a Blood Test...You Might Be Surprised
- Is the Cost Reasonable? One Dose of Cancer Drug Rituxan
- Same City, Same Service: How Much Price Variation is Reasonable?
- Approximately 1 in 3 Health Care Dollars is Waste... Can We Afford This?
- Rising Health Insurance Costs Reduce Take-home Pay
- Too Many Patients Have to Manage Their Own Care
- How Health Insurance Works
- Patients Deserve Coordinated Care—Take Action!

## Key Qualities for Motivational Infographics

While participants responded forcefully to our visual information, they also helped us understand when infographics might not succeed, for example by introducing information that is too far outside consumers' knowledge base. Participants helped us identified these key qualities for successful health care infographics.

### *Keep Graphic Simple and Accessible*

- Consumers want to understand the graphic at a glance. If it looks hard to understand, consumers may feel overwhelmed.
- Break complex topics into simple, accessible pieces.

### *Make Information Close to their Existing Frame of Reference or Anchor to Something Familiar*

- Do the legwork to understand what consumers' frame of reference for the topic.
- EXAMPLE: In the hospital infections infographic, the familiar side of the comparison (the number of drunk driving deaths) can help consumers understand and put the new information into context (the number of deaths from hospital infections).
- If consumers cannot personally relate to information or it is too unfamiliar, they react in one of three ways: reject the information, rationalize why the information is not true, or they incorporate the information and modify their frame. Motivation to act will only occur under final scenario, if then.
- EXAMPLE: consumers disputed our information on international health cost and quality comparisons and we were unable to get traction on that information.

### *Use Examples that Produce an Emotional Response*

- Information that elicits an emotional response also elicits more willingness to take action.
- Use examples with data extreme enough to matter; Small dollar amounts did not motivate participants to want to act.
- EXAMPLE: When we showed high hospital markup for a Tylenol pill or for a bag of saline solution, the cost was too affordable. Participants reacted far more to the more life-threatening and costly example of the cancer-treating drug.
- Provide new information; information that seemed merely logical, such as many of the medical delivery reforms, generated little reaction. Participants said, "I already knew that."

***When we showed the hospital charge for a Tylenol pill or for a bag of saline solution, the cost was too affordable or too simple. Participants reacted far more to the example of the cancer-treating drug.***

### *Use Information from a Trusted Source*

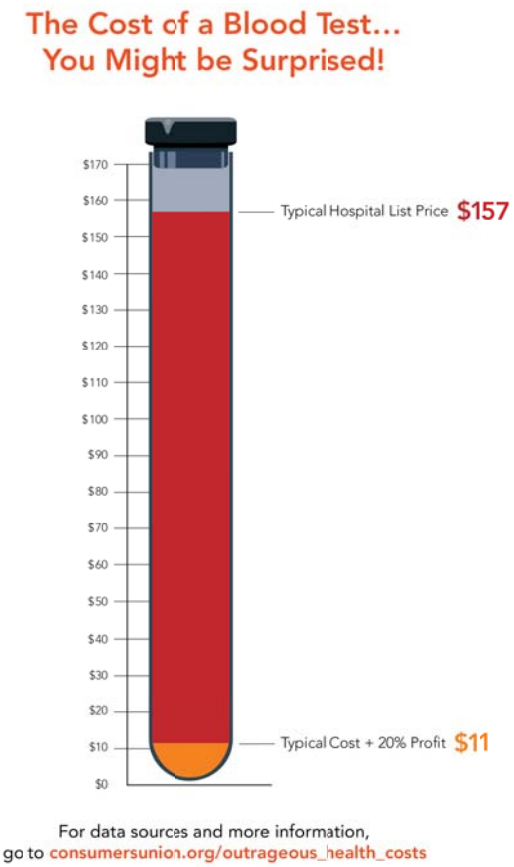
- Information outside consumers' frame of reference needs to be sourced and cited, so they can judge its reliability.[11]
- If they cannot identify the source, consumers will dismiss the information as unreliable, or suspect an agenda.
- Consumers want recognizable and reliable sources of information. They are suspicious of sources, such as magazines like the *Washingtonian* or Yelp reviews, that might tout a certain service for payment.

### *Use Local Information*

- Local information is more relevant because it directly affects consumers' lives. In addition, they can augment the information with their own, local understanding of the topic—for example, hospital reputation. As a result, it is also more motivating.

[11] To keep our infographics looking streamlined, we directed viewers to source data online. See consumersunion.org/outrageous-health-costs.

## Infographic: The Cost of a Blood Test... You Might Be Surprised




**A** This infographic is a concrete example of a systemic problem.

**B** Participants expected a markup, but the magnitude of the markup was shocking.

**C** This infographic was simple, produced an emotional response, but did not provide localized information.

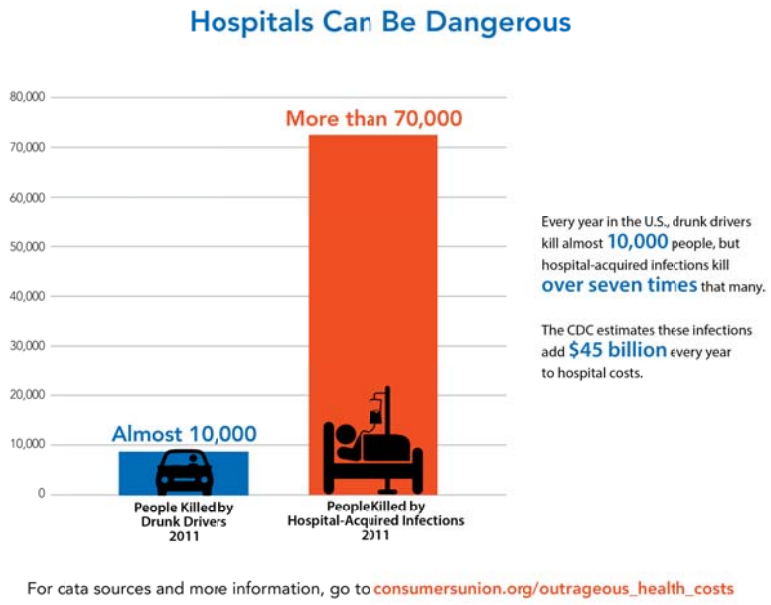
**D** This infographic resonated with participants and evoked emotion, but it did not motivate them to take action.

**E** Participants (correctly) assumed that the costs shown were typical costs and that $157 was a list price.

**F** Using an image that reinforced the topic being discussed worked better than a bar chart.

**G** This infographic could motivate consumer action if it provided comparative information by local doctors or hospitals.

## Infographic: Hospitals Can Be Dangerous




**A** This infographic was simple, produced an emotional response, but did not provide localized information.

**B** This infographic resonated with participants, evoked emotion and created some movement toward action.

**C** The comparison made between the known (drunk driving) and the unknown (hospital-acquired infections) gave participants an anchor on which to build additional information.

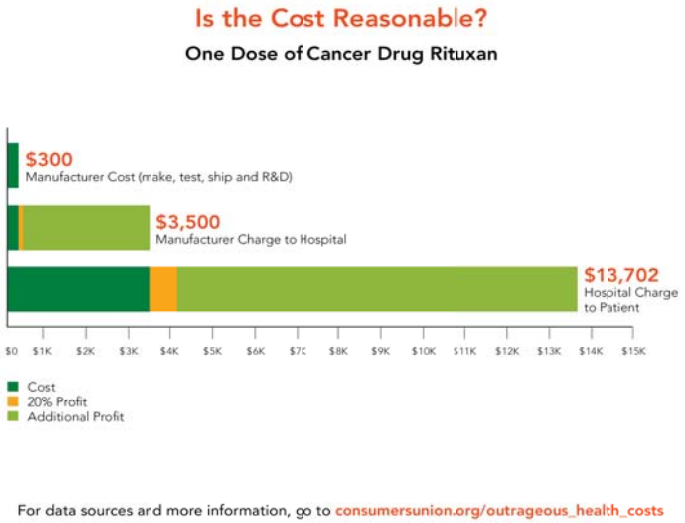
**D** Participants were shocked by the number of incidents that occur each year and that hospital-acquired infections kill more patients than drunk drivers.

**E** Scale emphasized differences.

**F** Because participants anchored themselves with what they knew MADD had accomplished, the infographic gave them a sense that they could do something—even if they thought in terms of personal, logical solutions, like cleaning hands.

**G** This infographic could potentially be more powerful if it provided information about local hospitals and local drunk-driving statistics.

## Infographic: Is the Cost Reasonable? One Dose of Cancer Drug Rituxan




For data sources and more information, go to consumersunion.org/outrageous_health_costs

**A** Participants were morally outraged by the costs the hospital charge to the cancer patient because they sympathized with a patient who was ill and who was already facing health and cost issues.

**B** Participants wanted to know why hospitals were able to take such a large mark-up at the expense of a cancer victim and believed "something" should be done.

**C** Participants directed their outrage at the hospitals, not pharmaceuticals because they thought the pharmaceutical mark-up was "just business" and that they needed to recover the costs of research and development.

**D** Scale emphasized difference visually, but not mathematically, since the percentage of increase was larger for manufacturer to hospital than for hospital to patient. The scale let participants "see" the difference between hospital cost and charge to patients more than between manufacturer cost and charge to hospitals.

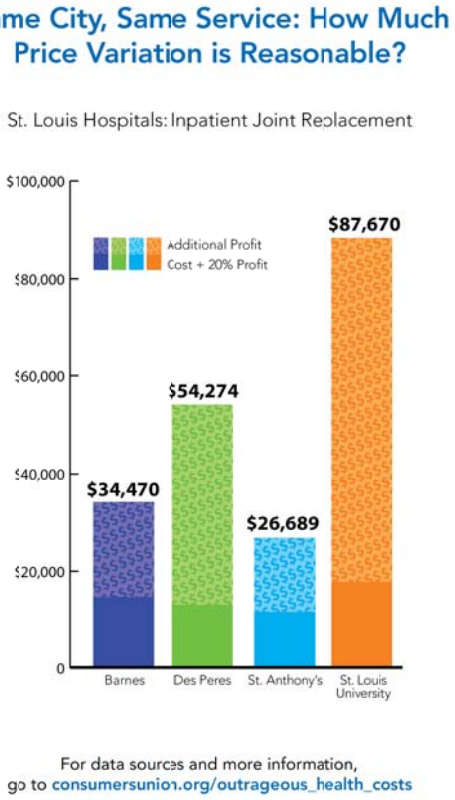
**E** We struggled with how to show acceptable profit and excessive profit in order to anticipate participants' tendency to explain away the magnitude of the differences.

**F** We tested but then removed percentages of profit markup because most participants ignored them, focusing instead on the bar graph.

**G** The infographic could more highly motivate consumers to action if it provided comparative information by local hospitals.

**H** We tried another approach using a set of images lined up in a row. The lack of a scale neutralized participants' reactions and they focused on questions of what was included in the costs, more than on the magnitude of the difference.

## Infographic: Same City, Same Service: How Much Price Variation is Reasonable?




**A** This infographic was simple, produced a strong emotional response, provided localized information and motivated action.

**B** Participants had a two stage response to this infographic. In the first stage, they expected variations between local hospitals, and were surprised only by the magnitude of the variation.

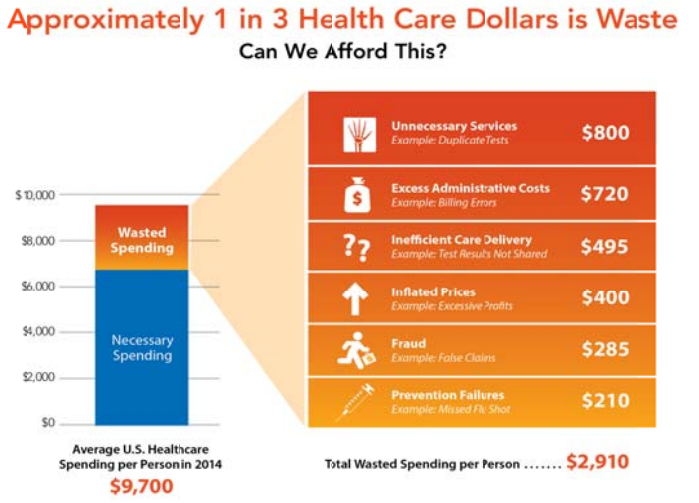
**C** Initially, participants tried to justify the differences between hospitals, especially if a less expensive hospital had a better reputation. To accept this information, participants needed to know that the cost included a generous profit.

**D** In the second stage, participants saw the variation between cost and profit within each hospital and were outraged doubly by the variation across and within hospitals.

**E** The localized information allowed participants to bring in their outside and personal knowledge of the hospitals' reputations to further inform the infographic's information. It helped give credibility to the information, even if some of it was surprising.

**F** This infographic motivated participants to want comparative pricing for non-emergency procedures.

## Infographic: Approximately 1 in 3 Health Care Dollars is Waste... Can We Afford This?




For cata sources and more information, go to consumersunion.org/outrageous_health_costs

**A** This infographic addressed a systematic issue. It was more complicated, yet participants understood the overall concept, even if the infographic did not create an emotional response.

**B** Participants were familiar with the idea that waste is everywhere, but not with the categories which seemed abstract and unclear how they would affect waste. Adding specific examples helped participants better understand each category.

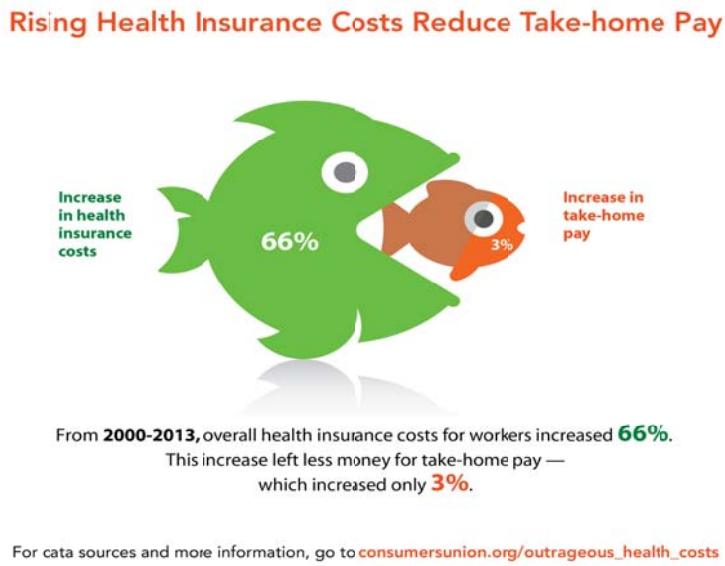
**C** Participants could not connect to the amount of waste personally because many of them did not spend that amount on health care. The infographic seemed not to be about them, but about others.

**D** This infographic did not motivate participants to act, primarily because many of the sources of waste are system issues with the exception of "prevention failures."

**E** The infographic was understandable to consumers and useful as an educational aid but may need to be coupled with a more personally relevant infographics to motivate action or tell as story.

**F** Participants could be motivated to action if we take a component of waste, make it local or anchor it to something participants are familiar with as in the hospital-acquired infections infographic.

## Infographic: Rising Health Insurance Costs Reduce Take-home Pay



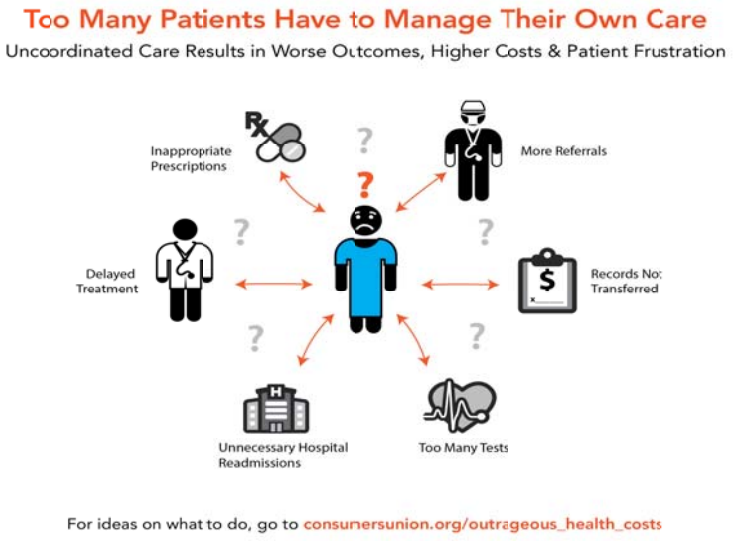

**A** This infographic was simple, failed to produce an emotional response, was not localized and failed to motivate participants to action.

**B** Although the infographic showed a big increase in health care costs and little increase in pay and used an effective visual, participants had a muted reaction and no outrage.

**C** This infographic seemed to merely provide participants with concrete details about something they already knew in a general sense. At the same time, the information was not personalized to the individual.

**D** This infographic may need to be combined with how health insurance works. It may function better as an element of a larger story that can connect the dots.

## Infographic: Too Many Patients Have to Manage Their Own Care




**A** This infographic was simple, did not produce an emotional response, was not localized, and did not motivate participants to action. Nonetheless, consumers understood the infographic.

**B** For many participants, this infographic confirmed their personal experience and made something they were vaguely aware of concrete. It gave them a visual of their experience and the vocabulary to talk it.

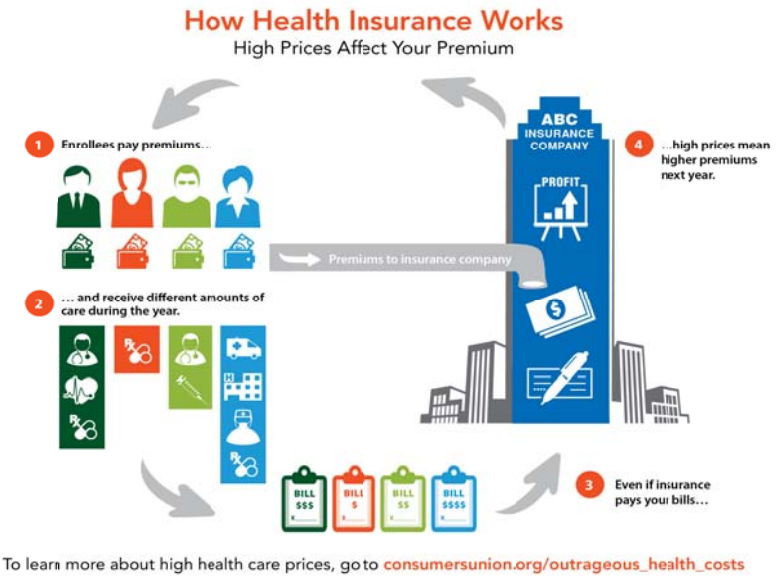
**C** Many of the ideas connected to medical delivery reforms seemed logical or common sense to participants and thus created a very flat response. Because it represented "reality," participants did not react strongly to this infographic.

**D** Many participants acknowledged that they currently solve the problem of uncoordinated care by taking the responsibility for managing their own care and that it is a hard job if they have medical issues.

**E** This infographic may be a possible entrée to discuss change because participants could see the experience as the same as theirs.

**G** Initially, we showed this infographic on the same page with "Coordinated Care." However, it seemed to present too much information for participants to take in at one time.

## Infographic: How Health Insurance Works: High Prices Affect Your Premiums




**A** This infographic addressed a complex fundamental process that few participants understood. Participants struggled to understand how high prices affected them when they had good coverage through insurance.

**B** This infographic was the most complex and challenging concept we presented.

**C** Participants understood the basic infographic. They saw that premiums, usage, payments and high prices were part of the process and they concluded that insurance companies make lots of money at the expense of others.

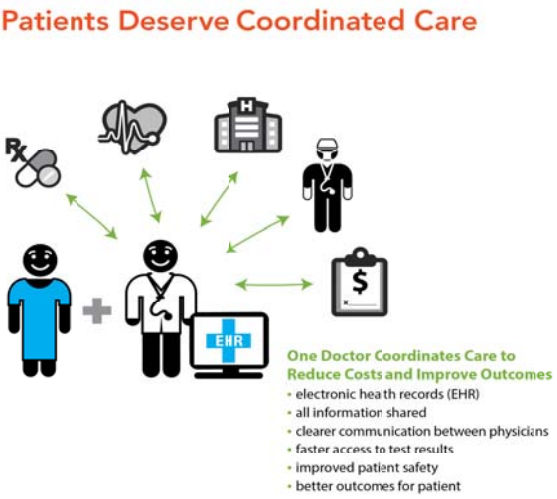
**D** On the other hand, participants had less understanding of the more complex message about the influence high prices have on inflating their personal health costs and on system costs.

**E** Participants saw an endless loop of escalating costs. They wanted change, but saw little possibility of breaking the cycle.

**F** Participants saw insurance companies as the primary cause of rising patient premiums, rather than understanding the multiple causes of rising patient premiums.

**G** This infographic, like others about complicated processes, should be a part of a larger sequence that helps consumers connect the dots.

## Infographic: Patients Deserve Coordinated Care!




To push for better care coordination, go to consumersunion.org/outrageous_health_costs

**A** Participants agreed that "coordinated care" was logical, that most would want it and that coordinated care would solve many problems.

**B** Participants felt this graphic showed a solution to many of the issues raised during the focus groups.

**C** Participants did not have a strong reaction to this infographic and it did not get them motivated to take actions.

**D** Participants absolutely agreed that uncoordinated care was a bad idea and they wanted coordinated care—even though many were not familiar with care being able to be delivered this way. Participants who already used an HMO were even more positive about care being able to be delivered in a coordinated way.

**E** Participants noticed the icon for Electronic Health Record and talked about this aspect the most because they knew about and understood it the best.

# Chapter 5. Conclusion

Greater consumer support for effective measures to control costs and improve the quality of care is fundamental to getting policymaker and regulator action. The good news? Consumers are at the tipping point and ready to be engaged. They are already outraged about health care costs or are readily outraged by new information, such as hospital-acquired infections as an example of poor health quality.

But not all consumer information is created equal. We need to understand consumers' current frame of reference with respect to an issue in order to target the new information. New information that violates a current frame of reference causes tension, discomfort or mental stress. Individuals tend to use one of several ways to reduce this tension: they reject the information, they rationalize why the information is not true, or they may incorporate the information and modify their frame.

With the goal of identifying information that would be motivating, this study identified the starting views held by consumers and the qualities of successful infographics. We found that engaging consumers directly on costs is relatively easy as it is part of their current frame of thinking for health care. But engaging consumers on specific medical delivery reforms is a challenging task because consumers' current beliefs and perceptions are that many of these reforms are logical changes that will likely happen anyway.

Consumers' strongly held desire that "something" be done with respect to system problems provides an entrée into talking to consumers about medical delivery reforms. Further, the hospital-acquired infections infographic elicited a strong reaction and desire for action because it evoked an emotional response and made the previously abstract issue of patient safety more concrete by anchoring it to more familiar information (drunk driving deaths).

Another key finding is that consumers' views of quality differ from policymakers' views. Because most participants have a limited frame of reference for quality, they rely on perceptions, such as physician reputation or their personal experience. In addition, they were unaware or only vaguely aware of measures such as hospital infection rates, adherence to evidenced-based protocols, HEDIS, CAHPS or any metrics that a policymaker or accreditation body might use to identify quality.

Once a solid understanding of consumers starting frame of reference is established, this study identifies a pathway—featuring motivational information—for engagement on issues that are less familiar to consumers. As outlined in Chapter 4, these steps include making the information simple and readily accessible; personally relevant; from a trusted source; and evoke an emotional response. Consumers will more likely have a strong reaction when they understand how a reform will impact them personally. It seems that the most

promising approach to these more abstract issues is to create a strong link to cost or safety, since both of these tapped participants' current beliefs and perceptions.

A critical step for policymakers and advocates is to identify the meaningful actions that consumers can take. They are willing to consider traditional civic actions, such as writing letters to government, but they see these actions as diffused and not always getting results. They want more. They want one or more, unbiased and non-government entities that can provide them with reliable information and that they can trust to provide them with concrete suggestions of how to take action.

Next steps for advocates, policymakers and others ready to enact change include:

- Start with health care cost issues. Consumers are already outraged, ready to take action, and willing to embrace a wide range of policy approaches.
- Work to identify effective actions–particularly civic actions–that consumers can take. It is likely that these actions will vary, depending on the policy and health system environments in a state.
- Identify and promote one or more unbiased, trusted, and familiar entities so consumers know where to turn when they encounter something outrageous in their own lives. These entities should also provide a forum where consumers can band together to amplify their collective voice. The "something" could be an outrageous bill, an inability to get price information or even poor care.
- Use patient safety problems and better care coordination to engage consumers on quality and medical delivery reform issues.
- Consider a public information campaign to create greater awareness of these issues, given the motivating power of new information that follows to our guidelines.
- Conduct additional research to complete the consumer picture. We need more nuanced information on consumers' current knowledge base in the following areas:
  - quality measurement,
  - quality variation across providers;
  - health safety issues;
  - more data to understand when high costs are a proxy for high quality and when they're not.