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## Focus Groups Highlight That Many Patients Object To Clinicians' Focusing On Costs

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### Abstract

Having patients weigh costs when making medical decisions has been proposed as a way to rein in health care spending. We convened twenty-two focus groups of people with insurance to examine their willingness to discuss health care costs with clinicians and consider costs when deciding among nearly comparable clinical options. We identified the following four barriers to patients' taking cost into account: a preference for what they perceive as the best care, regardless of expense; inexperience with making trade-offs between health and money; a lack of interest in costs borne by insurers and society as a whole; and noncooperative behavior characteristic of a "commons dilemma," in which people act in their own self-interest although they recognize that by doing so, they are depleting limited resources. Surmounting these barriers will require new research in patient education, comprehensive efforts to shift public attitudes about health care costs, and training to prepare clinicians to discuss costs with their patients.

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Cost-conscious health care decision making is necessary, given limited resources and unsustainably rising health care costs.<sup>1–3</sup> Many medical organizations, health policy experts, and bioethicists consider controlling costs at the provider level to be ethically justifiable if patients are appropriately involved in the decision-making process.<sup>1–4</sup>

An explicit cost containment approach—in which physicians discuss treatment options with patients, including the relative effectiveness and costs of those options—has several

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advantages. Such an approach is more transparent and procedurally fair than implicit forms of cost containment, in which patients are not fully informed when treatment options are limited for reasons of cost containment.<sup>1,2</sup> Moreover, informing patients about costs allows them to have more input into decisions that affect their own out-of-pocket costs.

Yet explicit cost containment at the provider level cannot succeed unless patients are amenable to discussing costs in the clinical encounter. Here we report the results of a 2011 study in which we investigated patients' attitudes toward considering their own out-of-pocket costs and the insurer's costs when making medical decisions. In particular, we examined whether participants were willing to weigh costs when choosing between nearly comparable clinical options, and whether they were willing to accept the less expensive option.

## Study Data And Methods

### STUDY POPULATION

Participants were recruited from two geographically distinct locations—the Santa Monica, California, and Washington, D.C., metropolitan areas—by a recruitment agency using a screening protocol (see the online Appendix for the screening tool used).<sup>5</sup> All participants had health insurance, but the population represented a range of ages, races or ethnicities, education levels, and income levels. At least half of the recruited participants had family incomes below roughly 300 percent of the federal poverty level, and 43 percent reported having incomes under \$40,000 (Exhibit 1).

### FOCUS GROUPS

Experienced, bilingual focus-group facilitators at RAND conducted twenty-two focus-group discussions with an average of ten participants per group, for a total of 211 participants. Groups were selected according to participants' income level, age, relationship to dependents, and dominant language (see Appendix Exhibit 1 for a list of group characteristics).<sup>5</sup>

Participants were presented with scenarios in which physicians talked with patients about diagnostic and treatment options that differed marginally in expected effectiveness but varied substantially in price. The prices assigned to different treatment options were chosen to approximate real-world variations in medical treatment costs. In some scenarios, the extra cost of the most expensive treatment was to be borne by patients out of pocket; in others, the extra cost was to be borne by the insurer.

For example, in one scenario, participants were asked to imagine that they had had an unusually severe headache for three months, for which their doctor was recommending either a magnetic resonance imaging (MRI) study or a computed tomography (CT) scan. The doctor explained that the difference between the two is marginal: "The MRI presents a slightly more detailed picture and might find something that the CT misses, such as an extremely uncommon blood vessel problem, but nearly all problems serious enough to need treatment would be seen on either the MRI or the CT."

In one variation of this scenario, the CT scan would cost \$400 out of pocket, whereas the MRI study would cost \$900. In another, the patient would pay \$70 for either test, but the insurer would have to pay \$330 for the CT scan and \$830 for the MRI study. The participants discussed how costs might influence their thinking and what options they would prefer.

Each focus-group session lasted approximately two hours. The sessions were facilitated, recorded, and—in the case of the four groups conducted in Spanish—translated by focus-group leaders at RAND. The transcripts were coded and analyzed for key themes by National Institutes of Health research staff, using the qualitative data analysis software Nvivo (coding themes are available on request from the authors). The intercoder agreement was greater than 90 percent on all twenty-two transcripts.

## LIMITATIONS

This study had several limitations. First, as with any study that uses focus groups, this one did not enroll a large, representative sample. Second, because the focus--group conversations were qualitatively analyzed, it was not possible to quantify the percentage of respondents who held particular points of view.

Third, the facilitators used a uniform discussion guide intended to help them pose open-ended, exploratory questions. Consequently, there was limited opportunity for follow-up probes or discussion among participants when they made ambiguous or contradictory statements.

## Study Results

We found that the majority of participants were unwilling to consider costs when deciding between nearly comparable options and generally resisted the less expensive, marginally inferior option. There were four times as many negative comments as there were positive ones on the theme of willingness to discuss costs. Comments indicating unwillingness to accept the less expensive option outnumbered comments expressing willingness three to one.

We identified the following four main barriers to participants' willingness to weigh costs when making treatment decisions: preference for the best care option, regardless of the costs involved; inexperience with making trade-offs between health and money; lack of interest in costs borne by society because of misunderstanding the way insurance works, lack of perceived personal responsibility, and disdain for insurance companies and the government; and noncooperative behavior characteristic of a commons dilemma, in which people act in their own self-interest although they recognize that by doing so they may be depleting limited resources.<sup>6</sup> The quotations extracted from group discussions and provided in the remainder of this section offer insights into participants' reasoning.

“I want the best health care. Money's no [object]. Either pay the best, or maybe they even miss something with the other scan.”

## WANTING ONLY THE BEST

Participants consistently preferred better care, even when the relative benefit it offered was marginal, and even when told that the second-best choice still met the threshold of “good enough” care from a clinician’s perspective. This preference for the best option, no matter what the cost, arose from participants’ belief that health is paramount, as reflected in the following statement: “When it comes to your health, there really is no value on it” (additional quotes from participants are in the Appendix).<sup>5</sup>

Another participant said: “It’s your health. [What] you’re talking about here is health versus money; in other words, life versus cost. But cost don’t come into effect when it’s versus life. I wouldn’t care if they said it cost \$10 million, give it here. I ain’t got \$10 million, but give it anyway.”

This preference for the best at any cost seemed to be a result of both participants’ personal values—that their health is paramount—and their default assumptions about the relationship between care cost and quality. For example, many participants assumed that more expensive care is always better, as reflected in this statement from one participant: “Look, this one’s this price, this one’s that price. This one’s better, of course. It’s more. You get what you pay for.” Similarly, another participant asked, “Why is the other one so much cheaper? Is it because it’s an inferior test?”

Furthermore, some participants’ preference for the best seemed to be motivated by a desire to eliminate uncertainty. Instead of seeking reasonable risk reduction, they seemed unwilling to tolerate any level of risk at all, as expressed in this statement from a participant: “I want the best health care. Money’s no [object]. Either pay the best, or maybe they even miss something with the other scan. And that one little thing—you’re dead. Who knows?”

Many participants expressed concerns about rare, highly adverse events, such as being the one-in-a-million person who has a rare cancer that could have been discovered if only the doctor had ordered the more expensive scan. The salience of such unlikely but devastating events was heightened for some participants by anecdotal evidence, media coverage of medical horror stories, and personal experiences with choosing “watch and wait”-type options and later regretting it.

For example, one participant reported: “I ended up having to go have an emergency operation, having them gut out my back, and now I have this nice, nifty scar up my spine. So I have no more faith in someone saying this and this, just take a couple x-rays and you’re all right. ... Every time someone says, ‘Oh, we can just do a couple things,’ I just say, ‘Do everything.’”

## RELUCTANCE TO MAKE TRADE-OFFS BETWEEN HEALTH AND MONEY

In general, participants seemed unaccustomed to thinking about the costs involved in opting for the best care. Presented with a choice between two treatment options—one marginally better but significantly more expensive, the other slightly inferior but still “good enough”—many participants tried to construe the situation so that it wasn’t a trade-off at all.

Some argued that the more expensive option would be cheaper in the long run. Others argued that the less expensive option was actually superior medically. This clear desire to avoid having to make trade-offs is captured in the following participant statement: “If they give you the cheaper one, and it was no good for what’s wrong with you, they’re going to send you to have the other one and it’s going to be more expensive. So it’s better to have the more expensive one [at the outset].”

Participants asserted their lack of interest in making trade-offs between health and money. When probed about their views on shared decision making versus directive communications from their health care providers, many participants said that they preferred that their physicians tell them what to do. For example, one said: “Doctors shouldn’t leave it up to you. He’s the doctor.”

Furthermore, some participants balked at the discussion of trade-offs, saying that they bought insurance precisely so that they could avoid thinking about whether medical procedures were really worth the money. This view is reflected in the following statement made by a participant: “That’s the whole point of having health insurance, so you don’t have to worry so much [about costs]. ... That’s why we pay every month.”

Overall, participants seemed unable or unwilling to incorporate cost information into medical decisions. Indeed, one of the most common sentiments expressed by participants was that only medical considerations should enter into health care decisions, whether those decisions were made by patients or by physicians.

That belief is captured in this statement by a participant: “I don’t want the doctor practicing in terms of numbers, financial numbers. I want him telling me as if money is not an issue.” Similarly, another participant said, “I want to know what treatment will give me the best results, and I don’t want, in the back of my head, a cash register working.”

Participants did not evince any awareness that personal finances can affect adherence to medical regimens or that, more generally, personal finances can have a profound effect on health status. In contrast to what many health experts believe—that financial insecurity can have negative consequences for patients’ health and wellbeing—participants seemed to see health and finances as completely separate.

Many low-income respondents face financial barriers to health care. However, some of those respondents said that they would resent efforts to discuss financial hardships and their implications for medical decisions, because they are wary of being seen as too poor to receive good care.

As one participant put it, “If I’m penniless off the street and I don’t even have Medicare or whatever and the doctor were to evaluate me, I’d still want him to say, ‘Hey, you need the CT scan,’ just the same as if I got off my private jet because I just flew in.”

### **LACK OF INTEREST IN COSTS BORNE BY OTHERS**

Many participants expressed resistance to the idea of cost-consciousness when choosing between treatment options that they would pay for out of pocket. Even more unpalatable to

participants, however, was the idea of considering insurers' costs when choosing between treatment options that would be paid for by private insurers, Medicare, or Medicaid.

"It's asking us to bear the responsibility for the costs when we didn't have a part in creating these costs in the first place."

For example, one participant said: "I don't care whether Medi-Cal [California's Medicaid program] charges the government \$30,000 or \$20,000 to [pay] the hospital, or whatever. Just cure me." Another participant said, "I don't care what the other side has to pay. This is me right now."

Although participants were familiar with the national problem of unsustainable health care costs, few felt any personal responsibility for helping control them. Participants generally expressed confusion about why they were being told what insurers would pay, or they expressed indifference about those costs. We identified three main reasons why participants did not think they should care about costs borne by others.

**SKEPTICISM ABOUT COST-CONSCIOUSNESS**—A few participants did not think that cost-consciousness was necessary to reduce health care spending. Some expressed the view that if only the United States could eliminate bureaucracy or stop spending on wasteful subsidies, patients would not be asked to consider costs when making medical decisions.

One participant said: "The whole thing is that, if they had a watchdog group that would clean up the practices that are going on in Medicare, there wouldn't be a financial issue." Another participant said, "Why doesn't the government put some of that money [for ethanol subsidies] into the general mass fund for health care so we could not have to pay so much [in] premiums for health care?"

**LACK OF PERSONAL RESPONSIBILITY**—Some participants felt that since they had done nothing to cause the problem of unsustainable costs, they had little responsibility for helping solve it. One participant expressed this view as follows: "It's asking us to bear the responsibility for the costs when we didn't have a part in creating these costs in the first place. So [why am I as a patient] responsible for now reducing the costs, which I had no part in creating?"

"To be kind of nonchalant about 'I don't care what my insurance company pays' is ridiculous because the cost is going to come back to you."

**ANTAGONISM TOWARD INSURERS OR GOVERNMENT**—In general, participants expressed negative attitudes toward insurers, at times seeming motivated to choose expensive care out of spite. For example, one participant said: "First of all, we're all against the government, or our insurance at work. So there, I'd go with the most expensive [treatment], without hesitation."

Some participants seemed to feel that because they had been paying for insurance for a number of years, they should be entitled to choose the best, most expensive care without regard for cost. One participant said, "It could cost them \$10,000 and so be it, that's why

I'm paying my premium." Another said, "I don't care what the insurance is paying. I pay my—you know, it goes through my check. They got my money. It's time to pay back."

At times the notion of payback took on a moral tone. Some participants seemed to feel that they had been wronged by their insurer, and they saw opting for more expensive care as a way to even the score. One participant said, "I think there's a backlash, too. We feel like we've been gouged for all these years." A second participant responded, "They keep increasing the deductible amounts and the copays." The first agreed, saying, "We have paid."

A third participant added: "It's kind of like our redemption, like 'No, I want my one pill.'" Yet another participant said, "That's something I think we all collectively would like—to screw the man, if you will. Yeah, I don't care how much my insurance is paying. I care how much I'm paying."

### NONCOOPERATIVE BEHAVIOR

Although the majority of participants' comments reflected the belief that the interests of the insurer and those of the patient are completely at odds—that it would hurt them if they chose an option that saved their insurer money—approximately a quarter of the comments reflected the opinion that it was in patients' long-term interest to spare private insurers, Medicare, and Medicaid from extra expenses.

Participants making such remarks believed that the public ultimately pays whenever patients opt for more expensive care, as reflected in this comment: "We should all be aware that these medical things [are] going to cost us in the long run. And if we overspend it, we're not going to get it, or our kids are not going to get it." Another participant said, "To be kind of nonchalant about 'I don't care what my insurance company pays' is ridiculous because the cost is going to come back to you."

Some of the participants who felt some responsibility to curb societal costs considered opting for the less expensive care as the virtuous choice. From their comments, it was clear that these participants perceived the problem as a "commons dilemma," although they did not label it as such. The commons dilemma describes situations in which people's short-term interests—in this case, getting the best medical care, no matter what the cost—are at odds with both their long-term interests, such as their future access to health care, and the larger social good, such as conservation of limited health care resources.<sup>6</sup>

These participants' comments suggested that although they understood that choosing the less expensive care was the ethical thing to do, they felt that their personal interests trumped their communal responsibility. Some participants justified their choice by citing others' noncooperation.

For example, one said: "Just because one person recycles, not everyone's going to recycle. And how can I trust the rest of society to be as good as I'm being at that moment?" Another said, "Ideally, in a perfect world, it'd be nice to have a sit-down and see who has what conditions and who really needs—yeah, exactly. You can't do that, so I agree with what

they're saying. It's really sad, but it's true. The country should work together, but ultimately everyone is just out to get their own."

Similarly, other participants' comments indicated that they felt they ought to choose health care options that saved money for insurers but that they believed the urgency of their own immediate needs would feel overwhelming, especially if the situation were an emergency.

For example, one participant said: "I wouldn't be all that concerned about [costs to insurers]. I probably should...[because] we're all going to end up paying eventually. But in the heat of the moment, I'd be like, 'I don't care! Just fix my problem.'" Another said, "All that's all well and good until you actually find yourself in a life-or-death situation, and you'll really see you're not even going to be concerned about the cost."

In contrast, some participants' comments reflected the belief that their personal interests should trump their communal responsibilities. These participants were unapologetically self-interested, as shown in this statement: "I don't care about everybody else. I care about myself. So why are you trying to push something cheaper on me?"

In a comparable statement, another participant said, "I still have a lot of years to go, and I'm going to take the best medicine, the best treatment. And if it raises the costs, I'll feel sorry. I don't want the company to go out of business. I don't want other people to suffer. But I'm sorry, I want to live. I'm not going to think about them."

## Implications

This study explored attitudes toward cost-conscious medical decision making among a diverse group of people with insurance. Participants occasionally acknowledged the problems associated with ignoring costs—for instance, higher premiums in the long run. However, they generally expressed unwillingness to consider costs when deciding between similar diagnostic and treatment options, especially when the costs were borne by insurers.

Many participants espoused the belief that medical decisions should be "pure"—that is, patients and physicians should not think about money when making decisions about health. These attitudes pose a significant problem for a cost containment strategy that seeks to involve patients in decisions about health care trade-offs.

Furthermore, the conviction that costs can be ignored is a problem, since health interventions use limited resources. Patients themselves acknowledge this trade-off when they defer a doctor visit or fail to take a recommended medication because of its cost.<sup>1-3</sup>

The focus-group discussions revealed the following barriers to participants' choosing less expensive care: the salience of unlikely but highly upsetting possibilities;<sup>7</sup> a desire for zero risk, rather than for reasonable risk reduction;<sup>8</sup> an assumption that price always signals quality; the misperception<sup>1,3</sup> that health care sustainability can be achieved by eliminating wasteful spending alone, without needing to forgo some marginally beneficial care; and the belief that choosing more expensive care constitutes a kind of victory for patients over the insurance companies.



Getting people to weigh costs when making medical decisions will require a substantial shift in public attitudes. Such shifts are not unprecedented, but they do not happen overnight. The palliative care movement is particularly illustrative. It took decades of research to identify strategies to improve end-of-life care, clinician training, curriculum development, and reimbursement for hospice services. It also took widespread efforts by mainstream media outlets to bring the issue into public consciousness and to shift norms surrounding talking about death.<sup>9</sup>

The result has been a gradual but steady decline in the number of deaths in the hospital among people over age sixty-five<sup>10</sup> and a marked increase in the number of Medicare enrollees receiving hospice services.<sup>11</sup> These changes suggest that similarly comprehensive efforts may be able to change public attitudes about considering costs in medical decision making.

Each of the perceptions and biases discussed in this article could be addressed through patient educational materials or psychologically informed interventions, such as those used to improve patients' understanding of medical risk.<sup>12</sup> These interventions ought to be informed by research that addresses a number of questions, such as the following: Is it possible to design effective patient decision aids that include cost information? Can financial literacy teaching materials<sup>13</sup> be used to increase public understanding of health care costs and, at a very practical level, to help patients read their own medical bills?

Judith Hibbard and colleagues have recently shown that simple, understandable information that offers ratings of medical options with regard to cost and quality can influence consumers' choices among health care options of varying quality.<sup>14</sup> And Marion Danis and colleagues have shown that when people are offered an opportunity to prioritize health insurance benefits, they have a better appreciation of the need to take cost into account in coverage decisions.<sup>15</sup>

Efforts to better prepare clinicians for discussing costs with patients will also be required. Many clinicians find the use of cost data confusing, in part because insurance coverage is so variable. Developing materials to teach clinicians how to address costs in the course of clinical practice offers a promising start.<sup>16,17</sup>

Additionally, better communication with the public on the part of professional medical societies regarding existing efforts to address health care costs is warranted. Many large medical and surgical professional societies support cost-conscious decision making.<sup>4</sup> We suggest that the endorsement of cost-consciousness on the part of professional organizations may make cost-conscious decisions on the part of individual clinicians more acceptable.

If patients and clinicians do not discuss and consider costs during the clinical encounter, the alternatives are problematic.

In this vein, the "Choosing Wisely" campaign, an effort by the ABIM Foundation and *Consumer Reports* to educate the public about the overuse of tests and treatments, is a collaborative effort worth expanding and reinforcing.<sup>4</sup> And the approach endorsed by the American Society of Clinical Oncology—that providers should explicitly discuss the costs of treatments with patients—serves as a particularly useful model.<sup>18</sup>

The need for responsible public leadership at every level of government in addressing health care costs is also pressing. At the national level, the Congressional Budget Office and the Joint Committee on Taxation recently estimated that the insurance coverage provisions of the Affordable Care Act will have a net federal cost of \$1.168 trillion over the period 2012–22.<sup>19</sup> At the state level, governors face the task of balancing their budgets and meeting rising Medicaid costs. And at the municipal level, public officials face concerns about the financial burden of safety-net health care facilities.

Elected officials in the United States may find it politically hazardous to tackle health care costs. However, a number of other countries serve as promising models for ways in which those costs can be controlled. Norway—with its gradual but consistent attempts, beginning with the Lønning Commission in 1987, to set health care priorities—illustrates one way to address health care costs in a manner that physicians and the public have come to accept.<sup>20</sup>

And the National Institute for Health and Clinical Excellence in the United Kingdom has demonstrated an explicitly nonpartisan approach to incorporating cost-effectiveness into coverage decisions.<sup>21</sup> The institute's recent decision not to recommend paying for costly but minimally effective cancer drugs for metastatic colorectal cancer demonstrates how its deliberative process for priority setting results in tough, explicit decisions based on cost-effectiveness that have gained some public acceptance.<sup>22</sup>

Policy makers in the United States may find it useful to adapt such approaches. Indeed, there are precedents for cross-national learning in health policy that may serve as grounds for fostering policy change.<sup>23</sup>

## Conclusion

If patients and clinicians do not discuss and consider costs during the clinical encounter, the alternatives are problematic. Clinicians might make cost-conscious decisions—for example, judging when high-priced resources such as operating room times, hospital beds, imaging, and specialty referrals are warranted—without informing patients that cost considerations influenced their decisions. Evidence from other countries indicates that clinicians do occasionally limit the use of medical interventions on the basis of concerns about cost.<sup>24</sup> Yet another alternative would be to make cost-conscious allocation decisions at the organizational level, with minimal clinician involvement.

Given the long-term projections about health care costs in the United States, it is inevitable that physicians will face increasing pressures to deliver cost-effective care to their patients. Doing so openly, in a way that allows patients an opportunity to hear the justification for cost-conscious decisions and to be active agents in thinking through treatment choices when feasible, is consistent with physicians' ethical duties to be transparent with patients and to provide patient-centered care.

But this study's findings suggest that for cost to be an explicitly recognized and discussed factor in clinical decisions, public attitudes about health care costs must first undergo a significant shift.

## Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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## Biographies



**Roseanna Sommers** is a first-year law student at Yale Law School.

In this month's *Health Affairs*, Roseanna Sommers and coauthors report on the results of twenty-two focus groups of insured people exploring their willingness to consider costs of comparable clinical options and weigh them with clinicians. The authors identified recurring themes, including a belief that high cost signals high quality, a lack of experience with making cost-quality trade-offs, and a lack of interest in costs borne by insurers and society as a whole. They observe that surmounting these obstacles will require new modes of patient and provider education and comprehensive efforts to shift public attitudes about health costs.

Sommers is a first-year law student at Yale Law School. She previously served as a fellow in the Department of Bioethics at the National Institutes of Health, where her work focused on health policy, law, and ethics. She holds a bachelor's degree in psychology from Swarthmore College.



**Susan Dorr Gold** is a professor of internal medicine and of health management and policy at the University of Michigan.

Susan Goold is a professor of internal medicine, School of Medicine, and of health management and policy, School of Public Health, at the University of Michigan. Her research focuses on the allocation of scarce health care resources, especially the priorities of patients and the public. She also studies trust relationships in health care settings and the impact of financing, care organization, and reimbursement on the doctor-patient relationship and the academic-industry relationship.

Goold is also the vice chair of the American Medical Association's Council on Ethical and Judicial Affairs. She earned a master's degree in health services administration and a medical degree from the University of Michigan and a master's degree in philosophy from Michigan State University.



**Elizabeth A. McGlynn** is director of the Kaiser Permanente Center for Effectiveness and Safety Research.

Elizabeth McGlynn is director of the Kaiser Permanente Center for Effectiveness and Safety Research. She is responsible for the strategic direction and scientific oversight of the center, a virtual environment designed to improve the health and well-being of Kaiser's nine million members and the public by conducting comparative effectiveness and safety research and implementing findings in policy and practice.

McGlynn is an internationally known expert on methods for evaluating the appropriateness, quality, and efficiency of health care delivery. She has also led major initiatives to evaluate health reform options under consideration at the federal and state levels. McGlynn is the winner of the 2012 AcademyHealth Distinguished Investigator Award. She earned a master's degree in public policy from the University of Michigan and a doctorate in public policy from the Pardee RAND Graduate School.



**Steven D. Pearson** is founder and president of the Institute for Clinical and Economic Review.

Steven Pearson is founder and president of the Institute for Clinical and Economic Review, at Massachusetts General Hospital, which is a leader in bringing stakeholders together to collaborate in the evaluation of the comparative effectiveness of medical interventions. He is a visiting fellow in the Department of Bioethics at the National Institutes of Health. He is also a current member of the board of directors of Health Technology Assessment International and the AcademyHealth Methods Council.

Pearson previously served as a senior visiting fellow at the UK National Institute for Health and Clinical Excellence and as special adviser on technology and coverage policy within the Coverage and Analysis Group at the US Centers for Medicare and Medicaid Services. He received a master's degree in health policy and management from Harvard University and a medical degree from the University of California, San Francisco.



**Marion Danis** is head of the Section on Ethics and Health Policy, Department of Bioethics, National Institutes of Health Clinical Center.

Marion Danis is head of the Section on Ethics and Health Policy in the Department of Bioethics at the National Institutes of Health Clinical Center. She also serves as chief of the Ethics Consultation Service at the center.

Previously, Danis chaired the International Society on Priorities in Health Care and served on the Medicare Evidence Development Coverage Advisory Committee. Her research focuses on finding strategies for fair rationing of limited health care resources, involving the public in priority setting, and promoting strategies to address the social determinants of health to reduce health disparities. She earned a medical degree from the University of Chicago.

**EXHIBIT 1****Characteristics Of Focus-Group Participants, Study Of Patients Attitudes Toward Considering Cost In Medical Decisions**

<b>Characteristic</b>	<b>Number</b>	<b>Percent</b>
Female	107	51
Black	72	34
White	94	45
Hispanic	57	27
High school graduate	180	85
Four-year college graduate	77	36
Annual family income less than \$40,000	90	43
Very good or excellent health status	101	48
One or more chronic illnesses	112	53
One or more cost-related barriers to access	80	38

**SOURCE** Authors' analysis. **NOTES** Characteristics are participants' self-reported age, sex, race, ethnicity, education, income, health status, chronic medical conditions, and experience encountering cost-related barriers to accessing health care as recorded on a survey administered before focus-group discussions. Health status was self-reported as excellent, very good, good, fair, or poor. Chronic conditions were self-reported in response to the following question: "Has a doctor ever told you that you have any of the following illnesses: high blood pressure, diabetes, cancer, heart disease, lung disease, other chronic or serious conditions?" Cost-related barriers were reported in response to the following questions: "In the past 12 months, have you (circle yes or no): NOT filled a prescription for medicine because you could not afford it? Taken medicine in smaller doses or less frequently than prescribed because of the cost? Skipped a medical test, treatment, or follow-up recommended by a doctor because you could not afford it? Had a medical problem but DID NOT go to a doctor or clinic because you could not afford it? Used up all your savings because of medical bills? Been unable to pay for basic necessities like food, heat, or rent because of medical bills? Had problems paying or been unable to pay medical bills?" Participants' mean age was 48 years, with a range of 19–86 years.