



Consumers debate costly treatments: is the gain worth the expense?

October 2006



# GETTING GOOD VALUE

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Sacramento Healthcare Decisions (SHD) is a non-profit, nonpartisan organization that seeks the public's perspective on improving healthcare policy and practice.

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**Getting Good Value** was supported by a grant from California HealthCare Foundation.

## **GETTING GOOD VALUE**

#### **INTRODUCTION**

The rising cost of healthcare has emerged as one the biggest challenges facing this country. It affects the number of people who are uninsured, the amount that patients must pay out-of-pocket for their medical care, the economic wellbeing of many businesses, and the fiscal burden on the national government. With baby boomers now entering their 60s, healthcare costs are expected to grow even faster in coming years.

Advanced medical technologies, including pharmaceuticals, medical devices, tests and procedures, are a major driver of increasing costs. When new advances show significant benefit, they bring tremendous value to patients and to society. Yet some advances bring a relatively small benefit at a very high cost.

There is growing concern about value in healthcare. Recent research shows that while medical advances have brought increased longevity for younger persons at a reasonable cost, the cost of additional years of life for older individuals is extraordinarily high.<sup>1</sup> Although some health policy researchers have proposed that the federal government consider value – assessing if the gain is worth the expense – as an integral aspect of allocating healthcare resources, others are hesitant. This reluctance is based in part on Americans' distaste of limits.<sup>2</sup>

#### ASKING THE PUBLIC

To explore this aversion to limit-setting, Sacramento Healthcare Decisions (SHD) recently completed *Getting Good Value*, a project assessing the public's reaction to taking cost into account when considering coverage of medical interventions. The project sought answers to these questions:

1. Do consumers believe that a medical treatment can be *too expensive* compared to the benefit it brings to patients?

2. Should society use a value-based approach (considering the cost of an intervention relative to its clinical benefit) when making decisions about insurance coverage?

From October 2005 to April 2006, SHD conducted 27 discussion groups with 297 individuals in Northern California. Participating organizations and demographic characteristics of project participants are included in the Appendix.

In two-hour group discussions with 10-12 people each, SHD asked participants to imagine being members of a National Health Benefits Committee. The Committee would make decisions about which medical interventions should be approved by the federal government for coverage by public insurance (such as Medicare) with the likelihood that private insurance would also adopt these decisions.

After a brief introduction about cost-benefit considerations, participants read and responded to three different scenarios (see page 2) based on real medical interventions:

- **(()** *Heart-Spark:* Considered a *life-saving* treatment, this device is for those with severe heart disease.
- **Cognimax:** Considered a *quality-of-life* medication, this drug slows the progression of Alzheimer's disease.
- **(Considered a** *preventive* intervention, this exam offers the possibility of early detection of medical problems.

Participants voted individually on whether the government should approve the intervention for insurance coverage and then discussed the rationale for the decisions they made. The facilitator later asked them to change the facts of the scenarios in any way that would change their minds about covering the intervention. Reaching consensus was not a goal, although participants were encouraged to debate their perspectives. At the end of each session, participants completed a short anonymous written survey.

SHD tape-recorded, transcribed and reviewed the details of the discussions to identify the prevailing themes that formed the basis for participants' decisions.

<sup>1</sup> Cutler, DM, Rosen, AB, Vijan S. The Value of Medical Spending in the United States, 1960-2000. NEJM 355;9. August 31, 2006. pg. 920-927.

<sup>2</sup> Neumann, PJ. Why Don't Americans Use Cost-Effectiveness Analysis? The American Journal of Managed Care, 10;5. May 2004. pg. 308-312.

## **S**CENARIOS

#### Heart-Spark

George is 62 years old and has severe heart disease. He takes good care of himself and also takes the heart medication that his doctor prescribes. Despite advances in medical science, heart disease is still the #1 cause of death among older adults.

Even when patients take good care of themselves and take their medication as directed, 29% of those with severe heart disease will die of this condition within five years.

Researchers have recently developed a small electronic device that can be surgically implanted to help prevent sudden death from an irregular heart beat. If patients have this new device, *Heart-Spark*, only 22% of them will die of heart disease within 5 years.

This means for every 100 patients, seven more patients will be alive in five years if they have *Heart-Spark* than if they use medication. In other words, 7% of patients will still have severe heart disease but they will live longer with *Heart-Spark*. Most patients with severe heart disease are over 60 years old like George.

The *Heart-Spark* device costs \$30,000 more than the medication. There are 500,000 people who could use the device; if they all have one implanted, it would cost society an additional \$15 billion.

Should the National Health Benefits Committee recommend that the Heart-Spark device be covered?

#### **Responses of Participants**

Yes - 36% No - 32% Not sure - 32%

#### Cognimax

72 year-old Harriet started developing signs of Alzheimer's Disease (AD). Since she could no longer live alone, she moved in with her daughter Janet, who is learning everything she can that will help them.

Janet learned that AD afflicts millions of individuals and places a tremendous burden on their families. Patients with AD lose their ability to remember things and eventually depend on families or nursing homes for all their care. By the end of the disease process (which typically takes from 5 to 10 years), patients often do not recognize their loved ones, are unable to communicate, walk, etc. There is no cure or preventive treatment available.

A new drug, *Cognimax*, was developed that delays the progression of symptoms for those with mild-to-moderate AD. When patients take *Cognimax* their mental functioning declines about 3 months *later* than other patients, but does not prevent eventual loss of all abilities nor extend life.

For example, without *Cognimax*, in *six months* Harriet might no longer remember to always turn off the stove. If she takes *Cognimax*, she would lose this ability *nine months* later, giving Janet three more months of not worrying about her mother's safety.

The cost of *Cognimax* is \$1,000 per patient per year. Currently there are 2 million Americans who might take *Cognimax*, at a cost to society of \$2 billion each year.

Should the National Health Benefits Committee recommend that Cognimax be covered?

Yes - 32% No - 55% Not sure - 13%

#### Annual Work-Up

Doctors used to conduct complete work-ups for all patients each year, including a physical exam and lab tests. Though these patients had no specific illness or symptoms, it was assumed that the work-up would identify problems *before* patients had warning signs, enabling treatment to start as early as possible.

Medical experts studied the results of annual work-ups and discovered that for patients with no symptoms or "risk factors," new medical problems were found in only one in every 2,000 patients. Even when a new problem was found, earlier treatment would **not** have made a difference in the patient's health. There was no evidence that the work-ups were worthwhile for identifying problems in patients who were not at-risk.

Alternatives to annual work-ups are periodic doctor visits that follow preventive health guidelines, e.g., colon exams at age 50, mammograms starting by age 40, etc. People also see their doctor if they are having symptoms of a medical problem.

Many doctors and patients still believe there is value to annual work-ups. Even if no illness is detected, the doctor and patient get to know each other better, trust is developed and patients feel reassured.

Each work-up costs \$300. If half of all healthy adults want the annual work-up, this would add \$21 billion each year to the cost of healthcare.

Should the National Health Benefits Committee recommend that annual work-ups be covered if the doctor or patient believes it is worthwhile?

Yes - 32% No - 56% Not sure - 13%

## **Responses to scenarios**

Participants' voting results are noted at the bottom of the scenarios chart. Although these quantitative scores were noteworthy, participants' individual comments and group discussions provided the basis for identifying their views on value-based coverage decisions.

#### YES votes: coverage should be approved

The following reasons were the most common responses of participants who supported coverage of any of the three scenarios. Participants' quotes are included to illustrate these perspectives.

#### **W** You cannot put a price on life.

Some were offended by the idea that cost would be relevant when considering treatment that was lifesaving. For these participants, Heart-Spark should be approved regardless of how small the benefit or how high the cost. The only circumstance when insurance should not pay for the intervention was if the device provided no additional benefit over a less-expensive treatment.

"I am a yes because if it saves one person for one day, that's what we are here for. That's what those doctors all go to school for -- to help people live longer."

#### **(()** This could affect me or my family.

Though participants understood that their role on this "national committee" was to make decisions that affect everyone, some could not (or would not) separate their personal interest from their role as societal decisionmaker.

"You know, if it was my parent, I would want 3 more months of memories, I would want 3 more months of the possibility of them coming up with something better."

#### Government wastes money on less important things.

With the view that government squanders other resources, some had difficulty denying payment for a treatment that worked even marginally. Until the government does a better job of reducing waste and fraud (both in medicine and outside it), they did not want to reduce coverage. The war in Iraq was a frequent reference for arguments about wasteful spending.

"When I see the numbers that are being put forth to go out and do war and kill people, and they are so huge compared to this. And this is for life. And this is the number one health concern, and it's not just hitting older people – it's hitting everybody. People are dropping like flies."

#### *Coverage encourages innovation.*

Though believing that an intervention may not be good value, participants approved coverage because they saw these interventions as necessary to developing other, more effective treatments. They also felt that an intervention could "buy time" until better treatment could be developed, and costs would decrease over time.

"So, if it's accessible, and people use it, then they learn how... they learn more about how it works and how it doesn't work, and what needs to be tweaked and changed. And that 7% [success rate] goes up and the price goes down."

#### *It may save money in other areas.*

If participants believed an intervention could forestall future costs, then it was appropriate to cover a marginally beneficial treatment. This was particularly noted for Cognimax where participants saw the possibility of avoiding nursing home placement if there were a delay in symptoms. Those who supported the Annual Work-Up also saw this as prudent, since many believed that any preventive service inevitably will save lives and money.

Summary: For many "yes" voters, the straightforward balancing of unit of benefit per unit of cost was not sufficient for making coverage decisions; there were other factors to consider, as noted above. A significant subset of "yes" voters were so strongly opposed to the concept of cost-benefit assessment that those other factors were not relevant. These participants were unwavering in their conviction that the only fact of the scenario that was germane was that Heart-Spark enabled a patient to live longer. For them, any introduction of cost into the scenario was inappropriate and unethical. When questioned about rising healthcare costs, their responses focused on reducing waste (especially profit-making) as a means of controlling costs. Some felt that allowing healthcare costs to increase was acceptable because healthcare is vitally important and should not be subject to restrictions.

#### NO votes: coverage should not be approved

The following reasons were given most frequently by participants who did not support coverage of at least one of the scenario interventions.

#### **(()** Not enough people benefit.

This was the primary reason given for denying coverage of Heart-Spark (which enabled only 7% of patients with the device to live longer than those without it). When asked to "change the facts" to make the intervention one that they would support, most people increased the total percent of patients that would benefit from 7% to numbers varying from 30% to 70%.

"I think we have to be realistic and say, at some point, 'You have to do the greatest good for the greatest number of people.' And this just doesn't seem to do it for me."

#### *(It is too expensive.*

Some participants focused on the unit cost as the problem (\$30K for Heart-Spark) rather than the small number of patients that benefited. When asked to change the facts to make the intervention acceptable, these participants had no difficulty finding a price they thought was reasonable.

"I'm pretty sure if we put the contract out there for who can build Heart-Spark the cheapest, we might get one for \$15,000."

#### **(()** There are better ways to spend the money.

Other participants identified this as their biggest concern – they looked at the billions of dollars mentioned in the scenarios and imagined how else the money could be used. They often suggested preventive health measures as better investment of resources. Many said they would rather see the cost of Cognimax used instead for daycare services or other programs to help family caregivers of Alzheimer's patients.

"Even in a world where we spend huge amounts of money on bridges that go nowhere, \$15 billion is a lot of money that can be used for research, maybe to develop cures for cancer, and all sorts of other productive things."

#### **(()** The impact isn't significant enough.

Whereas many thought that Heart-Spark did not benefit enough people, with Cognimax the concern was that the effect wasn't "good enough." The vast majority of participants who voted no coverage for this drug responded that three months just wasn't enough benefit. This was a similar reaction to those who voted no on the Annual Work-Up: it made no sense to pay for an intervention that had so little tangible impact. This rationale also applied to situations where patients were not likely to have a long-term benefit.

"You are not going to give it to somebody 89 years old who has one foot in the grave and the other on a banana peel."

#### **(()** It won't cure the disease; you can't live forever.

Participants commented that Heart-Spark and Cognimax were just delaying the inevitable and had no meaningful impact on curing the disease. Many said that it was not a good use of resources to try to keep people alive with a severe end-stage condition and that these life-prolonging treatments fostered denial of the inevitability of death.

"....not a person here at this table gets out of this world alive. We're gonna go. And so, the bottom line is, I just think there is so much more to do with \$15 billion than to worry about seven people. They gonna go, too."

*Summary:* Those who thought that cost was relevant to coverage decisions had little difficulty proposing ways to get good value from the intervention in question: they lowered the cost, increased the percent that would benefit, improved the quality of the benefit or became more selective in who received the intervention. In short, they changed the ratio of cost to benefit, using their own spontaneous impression of what constituted good value. It is also noteworthy that participants tended to view this issue in terms of how the funds could be better spent, rather than as a means of reducing spending.

#### **NOT SURE votes**

While some participants simply couldn't make up their minds, others had specific reasons why they were uncertain about one or more of the coverage decisions.

#### Conflicting priorities: the individual vs. society.

Various participants struggled over giving individuals what they want or need versus doing what they believed was best for society.

"Like for us, well, for each person, we want them to have the very, very, very best care possible. But if it was like a society, then we wouldn't really think about it that way."

#### *Cannot decide in a vacuum.*

Some participants felt uncomfortable looking at one isolated intervention outside the context of all healthcare expenditures. They opined that what might appear wasteful in one scenario could in fact be much better value than hundreds of other healthcare expenditures. Several mentioned that it would be more useful to rank interventions in order of their value, rather than judge each one independent of others.

#### Mot enough information; did not want responsibility for such a big decision.

This was especially common with Heart-Spark. When asked what information was missing, many could not articulate what else they needed to know. A few felt overwhelmed by the gravity of the decision they were asked to make.

#### Looking for compromises

Many "no" and "not sure" responders looked for compromises that were less drastic than denying coverage altogether. For example, they described tailoring the patient's share of cost to the effectiveness of the intervention: i.e., if the intervention's value seems low, then the patient pays more out-of-pocket.

Other suggestions were:

Construction Study Heart-Spark more so doctors can learn who is more likely to benefit from it; provide it only to those patients.

( Have patients pay for half the cost of Heart-Spark or Cognimax.

• Set an age cut-off for who gets Heart-Spark; give to those who are younger so they have a chance to live a longer life.

**(Comparison of Comparison of** 

• Authorize the Annual Work–Up for every 2–3 years rather than every year or limit it to older adults who might benefit from more regular visits to their doctor.

### **ATTITUDES THAT INFLUENCE PERCEPTIONS OF VALUE**

The following themes surfaced frequently and seemed to affect participants' views on whether an intervention had value.

#### THE ROLE OF PERSONAL RESPONSIBILITY

Expensive treatment should benefit those who take good care of themselves and, more important, shouldn't rescue those who neglect their health.

"What do you mean, you are not exercising, what do you mean you aren't staying on a diet, you know, well then why would I spend the nation's money on trying to save you when you are not doing your part?"

#### PREVALENCE OF THE MEDICAL PROBLEM

The more people affected by the medical condition, the more favorable the reaction to supporting the intervention, regardless of its balance of cost and benefit.

"If you look at the statistics on baby boomers, there's just going to be a whole lot of people entering the age for this terrible disease, and I just think that any little bit would help."

#### AVAILABILITY OF OTHER TREATMENTS

Participants seemed less concerned about denying coverage of marginally-useful interventions if other treatments were available that provide some benefit for that medical condition. When no alternatives were available, participants seemed more willing to approve coverage.

#### VIEWS ABOUT FAIRNESS

Some were concerned that denying coverage for expensive, less effective treatments meant that only the wealthy could afford them. While believing that people should be able to buy whatever they want with their own money, they were troubled by the perceived inequity, especially for life-and-death situations.



## **RESULTS OF SURVEY QUESTIONS**

How participants voted on the scenarios did not, by itself, indicate a willingness or reluctance to use a valuebased approach as a coverage criterion. The scenarios were simply tools to probe the extent to which the cost and benefit of an intervention had relevance to them in coverage decisions. An anonymous post-discussion written survey was distributed to see if participants' quantitative responses were consistent with the tone and content of the discussions. The term cost-effectiveness was used in describing value-based assessment.

#### Question #1: Using cost-effectiveness standards

This exercise asked you to decide if cost-effectiveness should be considered when the government makes decisions about what should be paid by health insurance. After doing this exercise, which statement is closest to your view about cost-effectiveness? (n=296)\*

12%	It should never be used when making decisions about what insurance should pay for.
29	It should be used in some situations but not routinely.
51	It is appropriate to use for most situations.
7	Other

\* not all participants responded to this question

These responses presented a fairly strong endorsement of value-based coverage decisions. However, since few participants had previously thought about costeffectiveness in health insurance, a second question gauged participants' reactions to this approach when presented side-by-side with other strategies for reducing the cost of healthcare.

#### Question #2: Using multiple strategies to control costs

There are different ways that may control the cost of health care, though most experts agree that it will take a variety of actions to do this. Of those listed below, which ones do you support (check all that apply):\* (n=295)\*\*

75%	Put more healthcare dollars into prevention to reduce the need for expensive care later.	
67	Have price controls on expensive drugs and other profit-making aspects of health care.	
56	Use cost-effectiveness standards like those we discussed in this exercise.	
49	Increase government oversight to reduce the amount of waste, greed and abuse.	
46	Reduce high administrative costs by financing healthcare through the government (like Medicare).	
22	Reduce the amount paid to doctors, hospitals and other providers.	
22	Establish an annual healthcare budget and stick to it.	
20	Have consumers pay more of the cost, so they are more careful about the services they use.	
8	Other	
5	Disagree. Should not try to control rising healthcare costs; too valuable to reduce.	

\* presented here in order of responses chosen, not the order listed on the survey
\*\* not all participants responded to this question

While Question #1 showed that 80% of participants believed that cost-effectiveness was appropriate at least in some situations, only 56% included it in the list above. Presuming that enthusiasm for this approach is tempered by the availability of other options, question #2 may be a more accurate gauge of acceptability than question #1. Nevertheless, more than half the participants still thought it was a strategy they would support.

#### **Demographic variances**

We also assessed whether demographic characteristics were associated with the responses to these questions. While there was some variation with several of the characteristics, the only ones that were meaningful were the categories of household income and education level.

#### Question #1 responses

Regarding question #1, we analyzed the responses to the option "cost-effectiveness should **never** be used when making decisions about what insurance should pay for." Household income showed the most variation; the chart below indicates how responses differed according to four levels of income.

**Percentage of participants responding** "cost-effectiveness should **never** be used when making decisions about what insurance should pay for."

All	Responses by household income		me	
participants (n=288)*	<\$20K (n=69)	\$20K to <\$35K (n=49)	\$35K to <\$60K (n=64)	>\$60K (n=106)
12%	26%	16%	8%	3%

\* not all participants responded to this question

Overall, participants with income less than 35K were nearly six times more likely to feel that costeffectiveness should never be used than those with higher incomes (p<.05). Participants' education level showed a similar but less striking trend – those with less education were more likely to reject cost-effectiveness.

#### Question #2 responses

For question #2, we assessed the demographic characteristics of those who included "use cost-effectiveness standards like those we discussed in this exercise" among the strategies they indicated for controlling healthcare costs. Education level had the greatest influence on whether participants included this: 50% of those with less than a 4-year college degree included this as a strategy, while 61% of those with a 4-year degree or more did so (OR=0.61, p<.05). For this question, income level showed less variation. Fifty-three percent of participants with incomes less than \$35K included this as a strategy, compared with 59% of those with incomes greater than \$35K. This difference, however, was not statistically significant.

## CONCLUSION

The project findings indicate a qualified acceptance by most people in using value-based criteria for coverage decisions. Those with lower income and/or education were less inclined to support this, but their rejection of cost-effectiveness was not a dominant sentiment. Participants who objected most strongly were especially concerned about restricting availability of life-saving technologies.

Although this subject has had little exposure in the mass media, the prospect of using value-based coverage criteria surprised few participants. In fact, many were astonished that the federal government did not already use value criteria when considering coverage of new technologies, and they were convinced that private plans have been doing this for many years.

A willingness to consider value-based assessments may be a recent phenomenon. As individual patients and citizens, consumers may now be more attuned to the detrimental impact of rising healthcare costs and better prepared to live with coverage restrictions.

### Recommendations

Concerns about the value of healthcare interventions will likely accelerate in coming years. Assuming that these project findings are not an anomaly and the public is indeed receptive to using a value-based process for coverage decisions, it is time for healthcare leaders and policymakers to develop and evaluate pilot projects to test value-based models.

Yet the public's willingness to consider this approach was not unconditional. The group discussions revealed several strategies that would enhance the likelihood that a value-based approach would be accepted.

## 1. Introduce value-based criteria in conjunction with other cost-control strategies.

Since participants were aware of and supported other ways to help control costs, focusing exclusively on denying coverage of costly, low-benefit medical technologies would likely be met with fierce resistance. Other strategies should be initiated concurrently, such as increasing the emphasis on preventive health measures, negotiating lower prices and instituting efforts to reduce duplication of services and other "waste."

## 2. Present this strategy as a way of getting the best value for society's dollars and then demonstrate its impact.

While participants were very concerned about the rising cost of healthcare, their interest in balancing cost with benefit appeared to focus more on using societal dollars wisely rather than on saving money. But if the public does not see that this approach actually benefits society (as opposed to benefiting, e.g., industry CEOs), support will be short-lived.

## 3. Be prepared to address concerns that this will dampen technological innovation.

Americans value medical innovation and the public needs assurance that new standards would not curtail advances in medical science.

"I don't want to see the technology leave. And I want to give them that incentive, to keep developing, to keep pushing forward, and to keep bringing new stuff to the table."

#### 4. Make the process credible and transparent.

Some of the groups discussed what an actual National Health Benefits Committee might look like. They suggested that a committee charged with making these decisions be comprised of clinical experts and others with different perspectives. The consumer voice is also an important component, while those who stand to gain financially from approval of new technologies should not be a part of the process.

"So, what needs to happen for this situation to work is to have a dialogue with people with disabilities and business folks and healthcare professionals, and so forth, so that the different value sets... can be discussed between different philosophies."

#### List of Participating Organizations

We are grateful to the following organizations that sponsored *Getting Good Value* sessions.

#### **Business/government**

Archco Ventures, El Dorado Hills California Department of Managed Health Care Hill Physicians corporate staff, San Ramon IHSS Public Authority Sacramento County Department of Health & Human Services California State Assembly Fellows program Teichert Inc. Ukiah In-Home Support Services

#### Congregations

Cornerstone United Methodist Church Grace Lutheran Church University Lutheran Church, Berkeley Zion Lutheran Church, San Francisco

#### Community organizations

100 Black Men Area 4 Agency on Aging Californians for Disability Rights Community HealthCorps Volunteers, Berkeley Community Resources for Independence, Santa Rosa Fibromyalgia Support Network, Lodi Grey Panthers Toastmasters Women's Empowerment

#### Educational settings

California State University - Sacramento, School of Social Work University of Phoenix University of Southern California - Sacramento

#### **Other:**

Focus groups of low income individuals

#### **Demographic Characteristics of Participants**

n = 1	29	97
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Age	
18-29	23%
30-39	14
40-49	21
50-59	17
60 and up	24

Race/ethnic group	
Asian	9%
Black or A-A	14
Hispanic or Latino	8
Native American	2
White	62
Other	4

Education	
HS grad or less	11%
Some college	22
2 or 4-year college graduate	42
Post-graduate	24

#### Yearly household income

<\$35,000	41%
\$35-60,000	22
More than \$60,000	37

Gender	
Male	34%
Female	66