

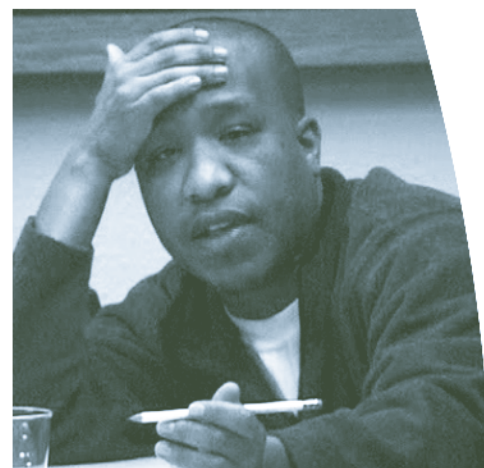
WHAT MATTERS MOST

Californians'
Priorities
for Healthcare
Coverage

May 2009

CENTER
FOR HEALTHCARE
DECISIONS
when there are no easy answers.

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What Matters Most

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May 2009

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Executive Summary

When it comes to healthcare benefits, Californians do not expect insurance to pay for everything. But they are very clear about the medical problems that matter most for coverage.

In an effort to understand how people prioritize healthcare benefits, the Center for Healthcare Decisions (CHCD) developed *What Matters Most* to address an important question for state and national healthcare reform: what types of medical problems are essential for coverage? This project is part of CHCD's on-going commitment to bring the public's voice to healthcare policy.

Approach

What Matters Most was conducted in two stages: a random-sample telephone survey to learn how Californians prioritize coverage of various medical situations and a series of discussion groups to identify the reasons that differentiate higher and lower priorities.

Field Research Corporation surveyed 1,019 Californians, presenting a series of short medical vignettes ranging from curable cancer to mild forgetfulness. Examples:

A 24-year-old woman has long-standing asthma that prevents her from being active. With an inhaler and medications, she can live a more normal life.

A 32-year-old man is very active with sports and his glasses often get in the way. Laser surgery would correct his vision so he wouldn't need glasses anymore.

Each respondent was randomly assigned 19 vignettes (from 87 total) and asked two questions for each:

- 1) On a scale of 1 to 10, what priority would you give to cover this if you were designing a health plan for a general population in California?
- 2) Given that the more that health insurance covers, the more the plan may cost you and others, would you want health insurance to cover this service or not?

Following the phone survey, CHCD conducted 15 two-hour group discussions with 176 community members throughout California. At each session, group members discussed a sampling of the vignettes, providing the rationale for why some services are rated high, mid-level and lower priority.

Results

- There is strong agreement among Californians that insurance coverage is most important for saving lives, preventing illness and restoring or maintaining basic activities of living.
- When medical problems do not have a major impact on an individual's functioning or life span, or when treatments are not likely to work well, Californians consider them a lower priority for coverage.
- Certain situations – such as those regarding obesity and substance abuse – elicit intense debate, reflecting differing views about illness and the obligations of health insurance.
- Several themes dominate discussions about coverage priorities, including:

Personal fulfillment. Self-esteem, happiness, good mental health and individual achievement are goals that some view as high priority for coverage. Others regard them as intangible, without boundaries and not the purpose of health insurance. This topic divides discussion group members more than any other.

Personal responsibility. Seen as important in avoiding medical problems or taking actions to resolve them, it is a value that everyone embraces. But for many, a person's lack of personal responsibility is the overriding rationale for making a problem a lower priority for coverage.

Prevention. As *saving lives* is the preeminent health outcome, preventive care is regarded as the best use of health insurance. Its value is two-fold: avoiding or reducing suffering and saving societal and personal dollars.

Based on the survey data and discussion findings, Californians' coverage priorities are grouped at three levels:

What Matters Most. Medical situations that matter the most to most people:

- Problems that are likely to lead to illness, disease, disability or death if not prevented or treated.
- Problems that interfere with functioning that is essential for the most important activities of daily living (work, self-care, family care).
- Problems that may bring much higher societal costs if not treated early.

Among these high-priority situations, people support coverage when:

- Less expensive or non-medical ways of treating the problem have been tried first.
- There is medical treatment available that is proven to be effective.

What Matters Some. Medical situations that some people also regard as important for coverage:

- Problems that cause physical discomfort but do not interfere with major activities of living.
- Problems that bring personal distress to the individual.
- Non-medical services that are designed to help individuals become or remain healthy and fit.

What Matters Least. Medical situations that fewer people regard as important for coverage:

- Problems that are unsightly but not physically harmful.
- Problems that delay or prevent individuals from pursuing recreational activities.
- Treatments that are requested by patients for convenience or to feel reassured.
- Problems that are not medically significant or would resolve over time without treatment.

Next Steps

As healthcare and policy leaders explore ways to reduce costs and extend coverage to more people, *What Matters Most* results could help develop a prototype basic coverage plan:

- 1) Focus first on those medical situations that matter most, assuring that there are no financial barriers to getting the care. Foregoing 'inconsequential' care is no bargain unless patients can obtain and afford the care that matters most.
- 2) Review the services rated at mid-level priority – such as dental, vision, substance abuse and obesity – and develop options that balance benefits with resources.
- 3) Consider developing a tiered cost-sharing model for lower-priority situations and for medical treatments with low effectiveness.
- 4) Keep the public actively involved in these decisions. Their participation can help policymakers design coverage standards that are most likely to be accepted by individuals in their roles as patients, as taxpayers and as concerned citizens desiring a system that is fair and affordable.

Introduction

Basic Healthcare Benefits

The increasing cost of healthcare dominates local, state and national discussions of healthcare reform. While covering the uninsured is a high priority, the public is now even more concerned about affordability.¹ Policy experts propose a variety of ways to control rising costs, among them, expanding health information technology, increasing preventive care, improving chronic care management, and promoting research on treatment effectiveness. Yet there has been little public discussion of another aspect of affordability, the scope of benefits.

To offer healthcare coverage to more people, some local and state programs have developed lists of exclusions.² These exclusions – e.g., treatment for infertility or impotence; treatment for problems resulting from high-risk behavior; genetic testing and counseling; treatment of learning disabilities; weight loss programs – are presumed to be a lower priority than other medical needs. But are they?

One visible effort to set limits was Kaiser Permanente’s proposal to disallow coverage of Viagra when it was introduced in 1997. At the time, The Permanente Medical Group’s Associate Executive Medical Director Dr. Sharon Levine contended:

“We must ask ourselves: when astronomically expensive new drugs for toenail fungus, afternoon drowsiness and hay fever come to market at the same time as expensive drugs for conditions that threaten life and cause serious disability, will we be able to create a social consensus on how to balance the costs of each with the benefits derived? Or will we simply avoid responsibility until the entire insurance system comes crashing down around us?”³

The public has an important role in helping to craft a responsible healthcare model, because they have three vital perspectives: as patients using health insurance; as taxpayers or employees whose dollars help pay for insurance; and as the body politic that sets the rules for bringing fair and sustainable coverage to more people.

Seeking a Social Consensus

Since 2002, the Center for Healthcare Decisions (CHCD)⁴ has engaged several thousand Californians in a computer-assisted process called CHAT[®],⁵ where groups create a simulated health plan benefits package when faced with more coverage options than available resources. This process has shown that while consumers consider comprehensive coverage essential, they discern differences between high- and low-priority problems in light of the overarching goal of keeping premiums and co-payments affordable.

Based on these CHAT results, CHCD developed *What Matters Most* to answer three questions:

- 1) Does the public regard some medical situations as being high priority for insurance coverage and others as less so?
- 2) If there are differences, what are the criteria that distinguish high-priority from lower-priority situations?
- 3) Can these criteria help provide direction for designing fair and affordable insurance coverage?

1. Kaiser Family Foundation/Harvard School of Public Health. (January 2009). The Public’s Health Care Agenda for the New President and Congress. Available at: <http://www.kff.org/kaiserpolls/upload/7854.pdf>

2. For example, see Washington State’s Basic Health program at <http://www.basichealth.hca.wa.gov/exclusions.html> and Fronstin P and Lee J, The Muskegon Access Health “Three-Share” Plan: A Case History, EBRI Issue Brief No. 282, June 2005: <http://www.ebri.org/pdf/briefspdf/0605ib.pdf>

3. TPMG Forum (publication of the Physicians of The Permanente Medical Group) (1998, Nov/Dec). Medical Miracles...At What Cost. 10(6).

4. Until early 2009, the organization was known as Sacramento Healthcare Decisions.

5. For specific information on how CHCD has used CHAT, see <http://www.chcd.org/what-prioritizingcoverage.htm>. For general information, go to www.chat-health.org.

Strategies for Public Input

CHCD designed two approaches for *What Matters Most*. The first was a statewide telephone survey to learn if and how the public prioritizes medical situations for the purpose of insurance coverage. The second was a series of small group discussions with California residents to understand the factors that people take into account in considering why some medical situations are higher priority than others.

A multi-organizational advisory committee and research consultants assisted CHCD in developing the project components, creating the vignettes and interpreting the results (see Appendix A).

Telephone Survey

This 1,000-person telephone survey asked Californians to rate the importance of insurance for covering a variety of healthcare needs, described by short vignettes of medical situations. This survey method was adopted from a project done in 1989 by Floyd Fowler, PhD, at the Center for Survey Research, University of Massachusetts.⁶

CHCD developed 55 separate medical examples described in a total of 87 vignettes. They ranged from dire illness highly amenable to medical care (e.g., curable cancer in a young adult) to mild functional disorders not always considered within the realm of medical need (e.g., mild forgetfulness in an older person). Examples:

A 24-year-old woman has long-standing asthma that prevents her from being active. With an inhaler and medications, she can live a more normal life.

A 32-year-old man is very active with sports and his glasses often get in the way. Laser surgery would correct his vision so he wouldn't need glasses anymore.

Some vignettes had multiple versions ('comparison sets') to test if a particular feature of the medical situation, such as patient age, gender or purpose of treatment, influenced how people responded to it. Other vignettes focused on the treatment itself rather than a medical problem per se. These vignettes often mirrored conundrums that providers or insurers face. Example:

A 27-year-old man developed low back pain after the heavy lifting he did the day before. Though MRI scans are rarely useful for managing this problem, he wants one so he will feel reassured.

Field Research Corporation conducted the survey in November-December 2008 with randomly-selected English- and Spanish-speaking Californians. In a 20-minute interview, each of 1,019 respondents considered 19 randomly-assigned vignettes, answering two questions for each vignette:

- 1) On a scale of 1 to 10 (10 being highest), what priority would you give to cover this if you were designing a health plan for a general population in California?
- 2) Given that the more that health insurance covers, the more the plan may cost you and others, would you want health insurance to cover this service or not?

The complete list of vignettes and their priority ratings and coverage approval scores are shown in Appendix B.

Discussion Groups

Following the phone survey, CHCD developed the discussion group process to identify the reasons that some vignettes received high-priority ratings while others were mid-range or lower. A description of the format for the two-hour discussion is included in Appendix C.

From February to April 2009, CHCD conducted 15 sessions in urban and rural areas of California with a total of 176 community members. Half the groups were a mix of ages, income, education and ethnicity and half were demographically specific, including Chinese (conducted in Mandarin), Hispanic (one session in Spanish, one

6. Fowler FJ, Berwick DM, Roman A, Massagi MP. Measuring Public Priorities for Insurable Health Care. *Medical Care*. 32(6): 625-639.

in English), adults with disabilities, adults over 65, and two groups of uninsured adults. Focus group houses recruited most of the group members; several community organizations recruited the Chinese, Hispanic and disabled groups. All group members received a stipend and participated anonymously.

The demographic characteristics of the phone respondents are shown in Appendix D and the discussion group members are shown in Appendix E. A detailed description of the development, methodology and analysis of the telephone survey is included in Appendix F. The limitations of the phone survey and discussion groups are described in Appendix G.

Results

The results include both the data from the phone survey as well as the responses of the discussion groups to the question: *Why are some vignettes rated higher or lower than others?* The survey data are the summary results of all respondents. A separate paper will analyze the ways that demographics and other characteristics of respondents affect their ratings.

The results of the priority question showed that the ratings are predominately clustered in the top half of the 1-10 scale. The mean rating of all vignettes together is 6.6; the highest mean score of any vignette is a 9.2 and the lowest is 3.9. A typical respondent gives five of the 19 vignettes a rating of nine or ten and one vignette a rating of one or two.

The coverage approval scores closely match the ratings; the mean for all vignettes together is 69% coverage approval. A typical respondent says that the services described in 13 of the 19 vignettes should be included in a general health plan for Californians, and the services in six of the vignettes should not. Below are key project findings:

Very Important

The vignettes that are the highest priority for coverage (whose mean priority rating was 8.0 and above) show strong agreement from the phone respondents; i.e., when a vignette rates near the top, almost everyone agrees that it should. For example:

A 31-year-old woman was hit by a drunk driver. Badly injured, she was rushed to the hospital for emergency surgery.

The mean rating for this vignette is 9.2 with 94% approving it for coverage. Only 10% of respondents give it a rating of eight or below, showing a high degree of consistency in respondents' views about this situation.

In group discussions, members are also in strong agreement and can easily articulate what they find to be most appealing and appropriate. For example:

Though she was careful about avoiding the sun, a 48-year-old woman learned that she has skin cancer. She has a good chance of being cured if she gets chemotherapy for several months.

Groups consider this important because the woman is facing a deadly condition, and there is a good chance she could be cured. While people give other reasons for their support – she is relatively young and, by avoiding the sun, has not brought on the problem herself – these are not the primary factors.

In assessing high-priority vignettes, the discussion groups voice the characteristics that are most relevant to their high level of support:

- **Saves lives.** Unsurprisingly, for most people, saving lives is the most important function of medical care and of health insurance.
- **Cures illness/disease.** People put great store in the ability of medicine to cure, giving this greater weight than maintaining functionality.
- **Enables productive functioning.** This feature refers to contributing to society as a worker, taxpayer and/or family caregiver.
- **Prevents new illness.** Protecting against disease and keeping illness from worsening are considered essential aspects of medical care.
- **Controls physical pain.** While there are differing views about various types of pain (e.g., physical, emotional, mental) treating severe physical pain is one priority on which all agree.
- **Produces good results.** For a high-priority medical problem to be supported, there must also be evidence that the available treatment is effective.

The significance of these characteristics is evident when comparing the ratings of two vignettes whose only difference is the severity of the problem:

vignettes	mean priority rating	percent approval for coverage
<i>Since a bike accident, a 32-year-old man has had problems with his left knee. Now it is too painful to walk even short distances. If he has knee surgery, he will be able to walk without pain.</i>	7.9	90%
<i>Since a bike accident, a 32-year-old man has had problems with his left knee. Though he can walk easily, playing soccer is difficult. If he has knee surgery, he will be able to play in weekend soccer games.</i>	5.6	63%

Changing the purpose of the treatment – with the other vignette characteristics constant – results in the vignette dropping from a high-priority rating (to walk without pain) to lower priority (to play weekend soccer games).

Not So Necessary

The vignettes that score as lower⁷ priority (the bottom third with mean ratings of 3.9 to 5.9) show a rating pattern that varies dramatically among respondents. Compared to the high-priority examples, those with the lowest ratings show greater variation in respondents’ views. Typical of these vignettes are ones about marriage counseling for a young couple, elective C-section for convenience purposes, or a heart scan for a healthy

patient wanting reassurance. The C-section example illustrates this variation in ratings:

A 27-year-old woman is pregnant with her third child. Though it is not medically needed, she wants a C-section that she can schedule in advance, so she can time the delivery with her childcare arrangements.

The mean priority rating for this is 4.4 and 40% approve it for coverage. However, the ratings for this vignette are not clustered around the mean: 31% of the respondents give it a rating of one; another 36% rate it between two and five, and the remaining 33% rate it from six to ten. In other words, about two-thirds of phone respondents give it a low rating and one-third give it a high rating.

These diverse opinions are reflected in the discussion groups as well. Below are two examples of situations and the reasons people give for their ratings.⁸

After salsa dancing, a young woman notices stiffness in her ankle. This does not interfere with walking or standing but makes it uncomfortable to dance. Physical therapy (PT) will help her recover faster.

Lower priority because:

- This is for recreational activity; she can still walk OK.
- If she can recover without PT, recovering “faster” doesn’t justify the cost.
- If she was a dancer for a living, then the PT might be justified.

High priority because:

- If salsa dancing is important to her, then she should get treatment.
- It is helping her stay healthy; if she stops, her health may decline.

⁷ The term ‘lower’ priority is used in this report instead of ‘low’, because very few vignette ratings could actually be considered low on the 1–10 scale.

⁸ The reasons listed are paraphrased, not direct quotes.

A 35-year-old woman has a cholesterol level higher than normal. Her doctor says she can control it by simply changing her diet and he teaches her how to do this. There is also a medication she could take instead of changing her diet.

Lower priority because:

- If she can control it with diet, we shouldn't pay for medication.
- People need to take some responsibility and not rely on medication.
- The doctor showed her how to change her diet: she needs to follow this.

High priority because:

- Not everyone is capable of changing their diet, even if they want to.
- Need a 'plan B' if her diet doesn't work.
- High cholesterol is serious; this prevents worse problems down the road.

While there is ample debate about these lower-priority vignettes, the majority of group members agree that they are indeed lower priority. Like the statements noted above, common reasons given by group members are: it's not life-threatening or disabling; there are other ways to handle it; it's a normal part of life; it's a luxury, not a necessity.

The Muddled Middle

The mid-range vignettes (with ratings between 6.0 and 7.6) yield the most discussion and the broadest range of views and values. These situations have neither persuasive reasons for coverage inclusion nor for exclusion. The reasons that group members support or do not support coverage are linked to particular values or experiences that color their perspective about health and illness. The following are two examples where there are strong differences of opinion.

A 55-year-old woman with breast cancer had to have her breast removed. While a bra insert would give her a normal-looking figure, a surgeon could construct an artificial breast to help her feel whole again.

High priority because:

- Many women need this for their mental health or self-esteem.
- Breast cancer is devastating; feeling better about herself will help her recover faster.
- She wasn't responsible for the disease; we owe her this as part of her treatment.
- We replace other missing body parts (e.g., legs for amputees); this is no different.

Lower priority because:

- This is cosmetic treatment; an artificial breast has no function.
- "Self-esteem" comes from within – it's not about body parts.
- Insurance saved her from the cancer; that should be enough.
- She can appear normal without the surgery; this is a luxury.

A 12-year-old boy is 30 pounds heavier than is healthy. There is a medically-supervised nutrition and exercise program that could help him lose weight and avoid other health problems.

High priority because:

- 30 pounds is too much for a 12 yr. old – he needs serious help.
- The parents have been irresponsible; we can't expect them to change their habits.
- This is the time to make a difference for him, when he is still young and not sick yet.

Lower priority because:

- There are lots of ways to lose weight without expecting the medical system to do it.
- He is old enough to take some responsibility: play sports, turn off TV and computer.
- His parents should be held accountable for his health habits.

The 12-year-old boy vignette is typical of the types of medical situations that comprise this middle group: categories of services that, in many cases, are related to personal behavior, societal or cultural influences and expanded expectations of health insurance. For example, to some, smoking cigarettes and overeating are not medical problems but are personal habits that endanger one's physical health. Unlike the more dramatic situations that typify the highly-rated vignettes (e.g., organ failure, severe arthritis) these categories do not define illnesses per se, and an absence of coverage does not necessarily lead to a life-threatening situation. Yet most people recognize the impact they have on personal and societal health.

“We’re going to pay for the health problems that arise for the people that don’t take care of themselves. So it’s great to say take responsibility, but what if they don’t? Or can’t?”

—Community member, Sacramento

Other categories in the muddled middle include reproduction, dental care and less-severe mental health problems. Vision and dental care coverage, in particular, receive strong endorsement in the discussions. While many people are accustomed to having these services defined separately from medical benefits, most are adamant that they are important as preventive health measures (dental) and community safety (drivers who should be wearing glasses).

Influential Factors

The perspectives expressed in the discussion groups are the basis for understanding why people view various situations as more or less essential for coverage. These perspectives often surfaced when discussion led to debate and disagreements.

- **Personal fulfillment.** This topic divides group members more than any other and is apparent in situations related to personal attributes of self-esteem, happiness, good mental health and individual achievement. Some view those goals as high priority for coverage; others regard them as intangible traits that have no boundaries and are not the purpose of health insurance.

“We are not talking ‘self-esteem’ insurance; we’re talking health insurance!”

—Community member, Los Angeles

This theme is raised in a number of vignettes. Helping a couple with infertility; enabling a young man to return to biking; reconstructing a breast for a cancer patient – these and others are supported with the argument that an individual's personal sense of well-being is as important as their physical health.

- **Personal responsibility.** This is viewed as a critical role for individuals in avoiding medical problems or taking actions to resolve them. It is a value that everyone embraces, but for many, a person's lack of personal responsibility is the overriding rationale for making a vignette a lower priority.

The influence of personal responsibility is evident with this vignette where 68% of respondents approved coverage:

A 21-year-old woman has been using hard drugs for several years and now uses cocaine. She knows this is bad for her and is ready to turn her life around. There is a rehab program that gets good results.

In another vignette where migraine headaches also affect a young woman’s job, 93% approve coverage. This shows that when the problem is not the result of ‘irresponsible behavior,’ people are far more likely to approve coverage.

- **Prevention.** Just as saving lives is the preeminent health outcome, preventive care is regarded as the best use of health insurance. Its value is two-fold: avoiding or reducing suffering and saving societal and personal dollars. Prevention is advocated by everyone, but some group members put greater emphasis on its value than do others, using it as the rationale for supporting almost any medical situation. For example, group members who support physical therapy to speed recovery from minor ankle stiffness argue that returning her to full mobility quickly will prevent deterioration in her physical and mental well-being.
- **Effective treatment.** Even a high-priority medical condition is rated lower if the treatment is less than effective. When vignette variations are used to test respondents’ reactions to descriptions of the treatment, the responses show meaningful differences. For example:

vignettes	mean priority rating	percent approval for coverage
<i>A 50-year-old man has severe nerve pain in his shoulder following an accident. There is a medication that works well for this type of pain but it is very expensive.</i>	7.8	90%
<i>A 50-year-old man has severe nerve pain in his shoulder following an accident. The only medication for this type of pain is very expensive and often doesn’t work very well.</i>	6.5	75%

If the proposed treatment seems unnecessary or not likely to work well, group members deem this situation a lower priority. They also believe that if there are other ways for the problem to be resolved – over-the-counter treatment; self-management; watchful waiting – it is not appropriate to start with expensive care. Controversy arises when some believe that delaying treatment is unfair or risky for the patient.

- **Normal variation.** If the problem is viewed as a normal part of aging or within the range of human differences, many argue for lower ratings (e.g., teenage acne, age-related forgetfulness, erectile dysfunction). However, if symptoms have a severe impact on functional ability, coverage is supported.
- **Community impact.** This refers to societal disruption (e.g., the impact of substance abuse); loss of workers and taxpayers (e.g., when untreated problems disrupt the workforce); and public health concerns (contagious diseases, drivers with poor vision). To varying degrees, group members acknowledge community impact as an important consideration for the parameters of coverage.
- **Best use of resources.** For some group members, this exercise is one of examining medical situations relative to each other. They often do not think in terms of saving societal dollars but in opportunity costs: identifying the best way to spend the resources that are available. For example, it isn’t that nail fungus is not important, it is that so many other things are more important.

“We could use money to give someone a heart transplant or give them nice fingernails. What a choice.”

—Community member, Los Angeles

- **Something for everyone.** Younger people often feel pressed to pay for insurance but see little value when they are healthy. Thus, services they might use – e.g., laser surgery for vision correction, travel immunizations, health club membership – would help them feel that their insurance brings them a tangible benefit.

None of the themes listed above are wholly independent of any other. It is the conflicts between them and where people place the most emphasis that account for the differences in perspectives.

Chart of Priorities

Based on the survey data and discussion findings, Californians' coverage priorities are grouped at three levels in the chart below.

What Matters Most. For the purpose of healthcare coverage, these are characteristics of medical situations that matter the most to most people:

- Problems that are likely to lead to illness, disease, disability or death if not prevented or treated.
- Problems that interfere with functioning that is essential for the most important activities of daily living (work, self-care, family care).
- Problems that may bring much higher societal costs if not treated early.

Among these high-priority situations, people support coverage when:

- Less expensive or non-medical ways of treating the problem have been tried first.
- There is medical treatment available that is proven to be effective.

What Matters Some. Medical situations that some people also regard as important for coverage:

- Problems that cause physical discomfort but do not interfere with major activities of living.
- Problems that bring personal distress to the individual.
- Non-medical services that are designed to help individuals become or remain healthy and fit.

What Matters Least. Medical situations that fewer people regard as important for coverage:

- Problems that are unsightly but not physically harmful.
- Problems that delay or prevent individuals from pursuing recreational activities.
- Treatments that are requested by patients for convenience or to feel reassured.
- Problems that are not medically significant or would resolve over time without treatment.

There is no category titled ***What Matters Not At All***, because a portion of the survey respondents and group members find value in covering situations of any description.

Cost-Sharing Options

The phone survey respondents have just two choices when asked about coverage of each vignette: include or not include in a benefits package. For the discussion groups, however, a survey question at the end asks them to choose among four possible actions regarding lower-priority situations. Their responses are noted below.

“I just want to be clear: when I say that something is ‘lower priority’ I’m not saying that it shouldn’t be covered, I’m saying it is lower priority.”

—Community member, Los Angeles

How should insurance address lower-priority situations?	
Question: Thinking about the things that most people thought were lower priority for insurance coverage, which of the following four statements is closest to your view? (N = 168)*	
To help control the rising cost of healthcare:	% responding
1) Medical problems that are lower priority should not be covered by health insurance. Patients should pay the full cost if they want the service.	14%
2) Medical problems that are lower priority should not be covered entirely by health insurance. Patients should pay at least half the cost themselves.	36%
3) Medical problems that are lower priority should not be covered entirely by health insurance. Patients should pay a somewhat higher co-payment than they do for other services.	30%
4) Other steps should be taken. But even lower-priority medical problems should be covered by health insurance.	20%

* Out of 176 total; several participants did not answer the question or checked more than one answer.

Only 20% of the participants recommend that lower-priority situations be treated the same as high-priority ones. The 66% supporting some type of cost differential (responses 2 and 3 above) is consistent with the results of other CHCD projects where the public is more comfortable seeking compromise solutions than it is in drawing a hard line.

Conclusions

What Matters Most shows that most people recognize that health insurance cannot cover everything that anyone might want or need. In the phone survey, respondents are not required to reject any vignettes; they have neither a set budget to work within nor a finite number of vignettes that they could approve for coverage. Yet the typical respondent elects to exclude six of the 19 vignettes, suggesting that the public is not blind to the problem of finite resources.

This view is shared by the discussion groups, where 80% of the group members think patients should pay all or some of the cost of lower-priority medical services. Group members also suggest different types of insurance coverage geared to different needs and acknowledge that those who want more than a basic plan might purchase additional coverage at their own expense.

Nevertheless, coverage limits established by one group may be difficult for individual patients to accept if exclusions affect them personally. As noted by a community member from Ukiah, “If it comes to my family, I want every stone unturned; if other people, not so much.” Another from Oakland said, “Maybe you can’t understand unless it happens to you.”

Meeting both individual and societal needs is challenging. It is made all the more difficult when healthcare coverage is not viewed as a communal resource into which everyone pays, everyone benefits and everyone lives by the same rules. Rules are inevitable, and asking community members to help set the standards for coverage can foster a greater sense of community and ownership.

“My boyfriend has been on Lipitor I guess for like five years. And I said, honey, change your diet. And he goes, I don’t have to ‘cause I’m taking Lipitor. Is that not the stupidest thing on Earth?”

—Community member, Los Angeles

Next Steps

What Matters Most does not reveal a perfect template for designing a basic benefits package, but it provides the starting point for coverage based on meaningful, valued care for individuals and communities. While the public’s views are an essential element, the perspectives and needs of other stakeholders – such as purchasers and providers – should also influence efforts to reform a system that requires cooperation among disparate interests.

As healthcare and policy leaders explore ways to reduce costs and extend coverage to more people, *What Matters Most* results could help develop a prototype basic coverage plan:

- 1) Focus first on those medical situations that matter most, assuring that there are no financial barriers to getting the care. Foregoing ‘inconsequential’ care is no bargain unless patients can obtain and afford the care that matters most.
- 2) Review the services rated at mid-level priority – such as dental, vision, substance abuse and obesity – and develop options that balance benefits with resources.
- 3) Consider developing a tiered cost-sharing model for lower-priority situations and for medical treatments with low effectiveness.
- 4) Keep the public actively involved in these decisions. Their participation can help policymakers design coverage standards that are most likely to be accepted by individuals in their roles as patients, as taxpayers and as concerned citizens desiring a system that is fair and affordable.

More specifically, making coverage decisions about medical conditions may require targeted questions about costs and benefits, such as:

- If a medical service is not covered by insurance:
 - What does it cost individuals to purchase this uncovered service?
 - If they pay for the service on their own, are individuals likely to face devastating financial burden?
 - If individuals forego the service, what are the likely health outcomes?
- What is the total financial impact of covering this service relative to the significance of the benefit and the number of people who use it?
- Is it fair to deny coverage to those who cannot pay out-of-pocket for the service, knowing that wealthier people could afford to do so?

As both the survey and discussions show, it is far easier to define what health insurance should cover than it is to say what insurance need not cover. When communities or states have limited resources but a strong commitment to bring essential healthcare services to the uninsured or underinsured, difficult decisions are inevitable. Giving the public a voice in how these decisions are made helps ensure that both individual and societal values are taken into account.



Appendix A

CHCD is grateful to these individuals and organizations that helped develop and implement *What Matters Most*:

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Appendix B

The vignettes are listed by mean priority ratings; however, the ‘comparison sets’ are listed separately starting on page 21.

Priority Rating	Coverage Approval		
mean rating (1–10)	yes, should cover	vignettes	sample size
3.9	28%	1) A 23-year-old woman has a dark 1-inch birthmark on her upper chest. Though it is harmless, she is self-conscious about it. It could be surgically removed.	313
4.4	40%	2) A 27-year-old woman is pregnant with her third child. Though it is not medically needed, she wants a C-section that she can schedule in advance, so she can time the delivery with her childcare arrangements.	325
4.6	46%	3) After salsa dancing, a young woman notices stiffness in her ankle. This does not interfere with walking or standing but makes it uncomfortable to dance. Physical therapy will help her recover faster.	335
4.7	26%	4) Like many people, a 40-year-old man knows he needs more exercise to keep himself in good health. He would like to join a health club to help him be at a level of fitness that is most healthy.	363
4.9	41%	5) A 41-year-old woman has heartburn which makes it hard to sleep. Though the heartburn can be controlled with a non-prescription drug, she prefers a prescription drug so that her health plan will help pay the cost.	370
5.1	58%	6) A 28-year-old woman (28/52-year-old man) has a nail fungus that makes his/her fingernails very thick. Though it looks bad, it is not harmful. There is a medication that will help treat it.	335
5.2	53%	7) A 48-year-old man has been a loud snorer for many years. Nothing has helped, and it makes his wife very unhappy. Though there is not a medical cause, a minor surgical procedure could help stop the snoring.	340
5.4	58%	8) A 60-year-old man had a small stroke and his speech is not clear. This problem usually gets better on its own after a couple months. Studies show that speech therapy does not bring recovery any faster for conditions like this, but some patients want it.	345
5.5	55%	9) A 40-year-old man read about the high-tech scan that can diagnose potential heart problems. Though he has no symptoms and no family history of heart problems, he wants to get the scan to feel reassured.	330
5.5	56%	10) A 15-year-old boy has acne on his face. Although this is normal for his age and will disappear with time, a prescription medication would help clear it up.	324
5.5	58%	11) A 27-year-old man developed low back pain after the heavy lifting he did the day before. Though MRI scans are rarely useful for managing this problem, he wants one so he will feel reassured.	360

Appendix B – Vignettes

mean rating (1–10)	yes, should cover	vignettes	sample size
5.6	50%	12) A couple will be traveling to visit foreign countries. To protect against tropical diseases, they need several immunizations. These shots are required to get their travel visas.	327
5.6	53%	13) A 32-year-old man is very active with sports and his glasses often get in the way. Laser surgery would correct his vision so he wouldn't need glasses anymore.	352
5.6	57%	14) A teenager wants to play football in high school. Though he already gets regular medical check-ups, he must get a sports medical exam before joining the team.	307
5.6	61%	15) A 14-year-old girl developed poison oak when hiking with her friends. A medical advice nurse told her mom how to treat it. But the mother wants a doctor to examine her daughter.	347
5.7	50%	16) A young couple has been married for several years and are starting to have conflicts in their relationship. They would likely benefit from marriage counseling.	367
6.0	58%	17) A young couple learns that they have infertility problems. To improve their chances of having a baby, the woman will need hormone injections for several months.	335
6.0	65%	18) For several years, a 30-year-old woman has had severe low back pain. Though her doctor says it will get better with exercise and weight loss, there is also a back operation that could relieve the pain faster.	334
6.1	61%	19) A 65-year-old woman (28-year-old man/woman) lost her two front teeth in a car accident. Though insurance pays for a dental bridge, dental implants would give her a more natural appearance.	375
6.1	63%	20) A 42-year-old woman who was quite obese lost 100 pounds through dieting and exercise. But now she has large skin folds on her belly that cause severe sores. There is surgery that can remove these skin folds.	330
6.2	61%	21) A 32-year-old woman wants to quit smoking but has been unable to do so on her own. There is a counseling program at a local clinic that has good results.	359

mean rating (1–10)	yes, should cover	vignettes	sample size
6.3	71%	22) Although a young woman is able to work and care for her family, much of the time she is bored and generally unhappy with her life. An anti-depressant medication and therapy sessions are likely to help.	319
6.5	72%	23) A 51-year-old man has been obese his whole life, causing him many other medical problems. He has tried weight-loss programs but they haven't worked. Stomach reduction surgery may improve his health and prevent future problems.	321
6.6	64%	24) A 21-year-old woman has been using hard drugs for several years and now uses cocaine. She knows this is bad for her and is ready to turn her life around. There is a rehab program that gets good results.	340
6.6	74%	25) A 35-year-old man was never taken to the dentist when he was a child. Now he has discolored and missing teeth which seem to be hurting his ability to get a job. Dental treatment will improve his situation.	350
6.7	65%	26) A 27-year-old woman (27/60-year-old man) knows his/her drinking is out of control and he/she is risking his/her job and his/her health. He/She is ready to change. An intensive alcohol treatment program could help.	351
6.7	77%	27) A 65-year-old woman is worried that she is becoming forgetful. Though her doctor says this is normal for her age and there is no medical problem, a medication may help her memory.	334
6.8	68%	28) A young couple wants to postpone children for a few years. Birth control pills would help them do this.	343
7.0	82%	29) A 50-year-old woman is going through menopause, and the hot flashes are very uncomfortable for her. Hormone replacement pills will help to control them.	349
7.5	82%	30) A 7-year-old girl is quite anxious about everyday things that do not bother most children. Because of this, she is doing poorly in school and has few friends. Regular visits with a child therapist will help her overcome these problems.	331
7.6	81%	31) A 28-year-old (55-year-old) woman with breast cancer had to have her breast removed. While a bra insert would give her a normal-looking figure, a surgeon could construct an artificial breast to help her feel whole again.	344
7.7	87%	32) A 21-year-old man took a bad fall from his skateboard and his arm is swollen and painful. An exam and an x-ray would determine if treatment is needed.	351
8.0	93%	33) A young woman has bad migraine headaches that are so painful, she often has to miss work. There is a medication that will reduce the number and intensity of her headaches.	342

Appendix B – Vignettes

mean rating (1–10)	yes, should cover	vignettes	sample size
8.2	90%	34) A 35-year-old man has been diagnosed with manic-depression, a severe mental illness. To keep his job and care for his family, he will need long-term medication and therapy.	338
8.2	93%	35) A 52-year-old woman has severe arthritis in her hands. Hand surgery will help her joints be more flexible and let her stay in her current job.	338
8.4	95%	36) A 9-year-old girl (24-year-old man/woman) has long-standing asthma that prevents her from being active. With an inhaler and medications, she can live a more normal life.	354
8.6	93%	37) A 32-year-old man was born with an abnormal liver. Recently his liver has begun to fail. To survive, he needs a liver transplant, which will give him a good chance of living an average life span.	361
8.7	95%	38) A 72-year-old woman slipped, fell and broke her hip. She needed hip repair surgery to get her walking again.	1017
8.7	96%	39) Though she was careful about avoiding the sun, a 48-year-old woman learned that she has skin cancer. She has a good chance of being cured if she gets chemotherapy for several months.	309
9.0	98%	40) A child is born with a cleft lip and cleft palate that will require four operations. The operations will make the deformity much less noticeable and help avoid medical problems like pneumonia.	319
9.2	94%	41) A 31-year-old woman (31/70-year-old man) was hit by a drunk driver. Badly injured, he/she was rushed to the hospital for emergency surgery.	353

COMPARISON SETS: these are vignettes that were written to compare differences in ratings when one feature of the vignette was changed. All of the ones here showed statistically significant differences in the priority ratings ($p < 0.05$).

mean rating (1–10)	yes, should cover	vignettes	sample size
5.0	40%	42) A 70-year-old man now has difficulty having sexual intercourse with his wife. His doctor says his problem, erectile dysfunction, is common for his age and there is no other medical cause. But a medication might help.	143
6.0	60%	43) A 70-year-old man now has difficulty having sexual intercourse with his wife. Recent surgery for prostate cancer caused his erectile dysfunction. But a medication might help.	166
6.7	78%	44) A 26-year-old single man has NOT been careful about protecting himself from sexually transmitted diseases. He now thinks he has one and sees a doctor for testing and treatment.	157
7.2	80%	45) A 26-year-old single man has tried to be very careful about protecting himself from sexually transmitted diseases. Yet he now thinks he has one and sees a doctor for testing and treatment.	185
5.6	63%	46) Since a bike accident, a 32-year-old man has had problems with his left knee. Though he can walk easily, playing soccer is difficult. If he has knee surgery, he will be able to play in weekend soccer games.	161
7.9	90%	47) Since a bike accident, a 32-year-old man has had problems with his left knee. Now it is too painful to walk even short distances. If he has knee surgery, he will be able to walk without pain.	167
4.8	45%	48) A 24-year-old man (woman) is very healthy but worries that he/she may have some hidden illness. Though he/she sees his doctor every year for a check-up, seeing him every three months may put his/her mind at ease.	224
5.6	62%	49) A 55-year-old man is very healthy but worries that he may have some hidden illness. Though he sees his doctor every year for a check-up, seeing him every three months may put his mind at ease.	115
4.9	39%	50) Since a college student began using on-line chat rooms many hours a day, his/her grades have dropped and he/she rarely visits with friends. Therapist visits would help him/her control this type of addiction.	216
5.6	42%	51) Since a 13-year-old boy began using on-line chat rooms many hours a day, his grades have dropped and he rarely visits with friends. Therapist visits would help him control this type of addiction.	97

Appendix B – Vignettes

mean rating (1–10)	yes, should cover	vignettes	sample size
6.1	60%	52) A 37-year-old (65-year-old) man is 30 pounds heavier than is healthy. There is a medically-supervised nutrition and exercise program that could help him lose weight and avoid other health problems.	237
6.8	66%	53) A 12-year-old boy is 30 pounds heavier than is healthy. There is a medically-supervised nutrition and exercise program that could help him lose weight and avoid other health problems.	107
6.2	68%	54) A 20-year-old man does not routinely brush his teeth, and he is developing cavities and gum infections. Regular visits to the dentist would help prevent serious dental problems.	164
6.8	78%	55) A 20-year-old man routinely brushes his teeth, but he is still gets cavities and gum infections. Regular visits to the dentist would help prevent serious dental problems.	163
7.1	84%	56) A 60-year-old man (woman) has problems seeing things far away. His/her doctor said this was not an eye disease but a problem with his/her vision. He/she should be tested and fitted for glasses.	209
7.6	86%	57) A 25-year-old man has problems seeing things far away. His doctor said this was not an eye disease but a problem with his vision. He should be tested and fitted for glasses.	121
8.2	90%	58) A 70-year-old woman has severe heart disease and she will probably die within 6 months. If she gets a pacemaker for her heart, she is likely to live at least 5 more years.	108
9.1	98%	59) A 40-year-old man (woman) has severe heart disease and he/she will probably die within 6 months. If he/she gets a pacemaker for his/her heart, he/she is likely to live at least 5 more years.	198
5.9	61%	60) An 82-year-old woman has had many strokes, is very frail and is expected to die soon. But if her family wants it, life support in the ICU may delay her dying for several days or weeks.	110
6.2	74%	61) An 82-year-old woman has had many strokes, is very frail and is expected to die soon. But if she wants it, life support in the ICU may delay her dying for several days or weeks.	106
8.4	93%	62) An 82-year-old woman has had many strokes, is very frail and is expected to die soon. Hospice services could provide her and her family with medical and emotional support during these last days.	102

mean rating (1–10)	yes, should cover	vignettes	sample size
5.6	59%	63) A 35-year-old woman has a cholesterol level that is higher than normal. Her doctor says she can control it by simply changing her diet and he teaches her how to do this. There is also a medication she could take instead of changing her diet.	167
6.9	78%	64) A 35-year-old woman has a cholesterol level that is higher than normal. Her doctor says she can control it with changes in her diet and he teaches her how to do this. For best results, she also needs a prescription drug.	178
7.5	80%	65) Age 50 is when many people get a colon exam, important for cancer detection. Although there is a standard procedure that works well to find cancer early, a new method is more comfortable for patients. However, it costs a lot more.	195
8.9	97%	66) Age 50 is when many people get a colon exam, important for cancer detection. There is a procedure that works well in finding cancer early.	168
5.4	46%	67) A 47-year-old man has high blood pressure. He helps control it with proper diet, exercise and a generic medication. Though there is no medical need to change, he wants to try a new brand-name drug that he heard about.	188
7.7	86%	68) A 47-year-old man has high blood pressure. He helps control it with proper diet and exercise. A generic medication would also be helpful to control this condition.	188
6.5	77%	69) A 50-year-old man has severe nerve pain in his shoulder following an accident. The only medication for this type of pain is very expensive and often doesn't work very well.	107
7.8	91%	70) A 50-year-old man has severe nerve pain in his shoulder following an accident. There is a medication that works well for this type of pain but it is very expensive.	117
8.0	87%	71) A 50-year-old man has severe nerve pain in his shoulder following an accident. There is a medication that works well for this type of pain.	114

Appendix C

<i>What Matters Most: Format for Two-hour Discussion Groups</i>	
Introduction	Group members were told that they would be responding to some of the results from a telephone survey about priorities for health insurance coverage.
Pre-survey	<p>Members were given seven vignettes in written form. These vignettes reflected the range of ratings from very high to low. Individually, they completed the form, answering this question for each vignette:</p> <p><i>The more that health insurance covers, the more it may cost you and others to pay for it. On a scale of 1 (lowest) to 10 (highest), what priority would you give to cover this if you were designing a health plan for a general population in California?</i></p> <p>The purpose of the pre-survey was to acquaint members with the types and variety of vignettes in the phone survey and prompt thinking about their own criteria for judging these situations. Their ratings were not discussed nor were the results tallied.</p>
Highly-rated vignettes	Group members were given a written list of 4 or 5 vignettes, those from the highest priority ratings of the phone responses. Each person indicated for each one if they thought the vignette was a ‘high priority’ or a ‘lower priority.’ With a show of hands, tallies for each vignette were noted on a flipchart. Facilitators led a discussion on why people felt the various vignettes deserved a high rating or not.
Lower-rated vignettes	Members were given a new written list of 7 vignettes, those with some of the lowest ratings. The same process was followed as above.
Mid-range vignettes	<p>Members were given a third written list of 7 vignettes, those in the mid-range of the phone responses. For this discussion, the instructions were:</p> <p><i>Imagine you are part of a group of Californians responsible for creating a health plan for the state. In order to make it affordable for the most number of people, you need to exclude some things from coverage. Therefore, at least 3 of the situations below will not be covered by this health plan. Which 3 would you exclude?</i></p> <p>Tallies were taken and members discussed why they chose the vignettes to be “dropped” from coverage and why they kept the ones they did.</p> <p>In all three segments of the meeting, members debated their views and often acknowledged if they changed their minds about a particular vignette.</p>
Post-survey	Members completed several demographic questions and one that asked if lower-priority medical problems should cost patients more.
Recording	The meeting co-facilitator took notes during all discussions, capturing the reasons people gave for why they rated the vignettes as they did. Tape recordings of the meetings were also transcribed and reviewed.

Appendix D

Demographic Characteristics of Phone Survey Respondents (N=1019)			
Characteristic	Weighted percent	Characteristic	Weighted percent
Age		Children under 18 in the house	
18-34	33	Yes	48
35-49	31	No	47
50-64		Health care worker in the house	
65 and over	15	Yes	15
Gender		Self-reported health	
Male	49	Excellent	23
Female	51	Very Good	29
Race / Ethnicity		Good	
American Indian	4	Fair/Poor	18
Asian / Pacific Islander	6	Disabled	
Black	5	Yes	13
Hispanic	36	No	87
Non-Hispanic White	50	Chronic medical condition	
Highest level of education		Yes	
Less than High School diploma	18	No	68
High school graduate	20	Person has health insurance	
Some college / trade / assoc deg	24	Yes	82
College graduate	24	Without insurance <1 yr	4
Post-graduate degree	14	Without insurance 1-3 years	4
Marital status		Without insurance >3 years	
Married or domestic partners	64	Source of health insurance	
Not married but living together	5	Through employer	62
Widowed	6	Self-purchase	15
Divorced or separated	9	Medicare	16
Never married	16	Medi-Cal	11
Household Income		Burden of personal healthcare expenditures	
Less than \$20,000	18	Major burden	22
\$20,000 - \$39,000	22	Minor burden	40
\$40,000 - \$59,000	13	Not a burden	39
\$60,000 - \$79,000	14	Use of health insurance relative to others	
\$80,000 - 99,999	10	More	11
\$100,000 or more	23	Same	44
Home region of California		Less	
Bay Area	21	Registered to vote	
Southern CA (not L.A.)	30	Registered where participant lives	70
Los Angeles	27	Registered somewhere else	3
Central / Southern Farm	11	Not registered	27
North and Mountain	5	Voted in last election	
Central Valley	6	Voted	94
		Did not vote	6

Appendix E

Demographic Characteristics of Discussion Group Participants (N=176)			
	Percent		Percent
Age		Do you currently have health insurance?	
18-29	22	Yes	70
30-39	17	No	30
40-49	22	Your ethnic background (check all that apply)	
50-59	20	African-American	14
60 and up	20	Asian-Pacific Islander	12
Gender		Latino or Hispanic	23
Male	53	White	43
Female	47	Other	8
Education level completed		Total annual household income	
Some high school	7	Less than \$20,000	20
High school graduate	25	Between \$20,000 and \$40,000	35
Some college	29	Between \$40,000 and \$60,000	16
AA degree	6	Between \$60,000 and \$80,000	12
4-yr college degree	20	Between \$80,000 and \$100,000	9
Post graduate	13	\$100,000 or more	8

Location of Discussion Groups

Fresno
 Los Angeles
 Oakland
 Placerville
 Pomona
 Sacramento
 San Diego
 Sunnyvale
 Ukiah
 Woodland

Appendix F

Development, Methodology and Analysis of the Telephone Survey

Development

Using vignettes as the basis for this phone survey followed a model used by Floyd Fowler, PhD, at the Center for Survey Research, University of Massachusetts in 1989. Dr. Fowler also became a consultant on this project.

CHCD developed 55 medical examples demonstrating a range of severity. In order to assess whether specific patient or treatment characteristics could influence coverage priorities, for each of a selection of examples, CHCD also developed comparison sets consisting of 2 or 3 vignettes that varied only slightly from one another. Variations could involve the age, gender or other patient characteristics or details concerning treatment rationale or effectiveness. With the addition of these comparison sets there were a total of 87 vignettes.

The vignettes spanned the categories of reproduction/sexuality, cosmetic, episodic, prevention /screening, mental health, behavioral health (substance abuse), obesity, chronic illness, dental/vision, stress reduction/personal fulfillment, life-limiting conditions, and treatment effectiveness. Most vignettes were written to have a patient problem as the point of inquiry. The intervention was described (implicitly or explicitly) as appropriate and effective, and in most cases patient preferences and physician opinions were muted so that respondents were only reacting to the medical situation, i.e., *is this a problem whose treatment warrants coverage by insurance?*

Some vignettes focused on treatments of questionable effectiveness or necessity rather than a medical problem per se. These vignettes often reflected situations faced by providers or insurers (e.g., use of MRI scan for low back pain to reassure patient; replace generic medication with new brand-name drug at patient request).

Before the survey was conducted, vignettes were reviewed by physicians for clinical credibility. CHCD then piloted the survey with several dozen community members to assure that the medical descriptions were familiar to the lay public, terminology was clear, and vignettes were short enough to be understood in a phone interview. It was determined that a 20-minute survey could accommodate 19-20 vignettes and demographic questions.

Methodology

The survey was conducted by Field Research Corporation, a full service opinion research firm. Field translated the survey questionnaire into Spanish; programmed both the English and Spanish versions of the questionnaire into its computer-assisted telephone interviewing (CATI) system; conducted a pre-test of the instrument; and performed the sampling, data collection and preliminary data processing, including the development of appropriate statistical weights. Interviewing was conducted by telephone in English and Spanish between November 14 and December 7, 2008 from Field's central telephone interviewing center in San Diego.

The sampling frame for the study consisted of residential household (landline) telephone numbers within the state of California. A random digit dial (RDD) sampling methodology was used to select telephone numbers for contact and one adult per contacted household was surveyed. A total of 11,424 telephone listings were dialed with a cooperation rate of 37% and a response rate of 15.8%; 1,019 interviews were completed. Each respondent was queried with respect to a random selection of 19 of 87 vignettes, as well as a variety of demographic items.

The first vignette (concerning a hip fracture) was asked of every respondent as a way to orient them to the idea of assessing value. Then for each respondent, the other 18 vignettes were selected in a two-stage process. In the first stage, 18 of the remaining 54 medical conditions were selected. In case a selected medical condition had multiple (either two or three) vignettes associated with it, a random selection was made among them. Hence, each respondent was queried with respect to 19 distinct vignettes representing 19 distinct medical conditions.

Analysis

Following the completion of survey data collection, Field prepared statistical weights that would allow survey data analysis to be adjusted for minor sampling-related variations in the representation of the regional and demographic subgroups. The survey data were then provided to CHCD in SAS system file format.

Survey data analysis was conducted by faculty and staff in the Center for Healthcare Policy and Research at the University of California, Davis. Descriptive

Appendix F

analyses summarized the demographic characteristics of respondents. The intensity and consistency of support for each vignette was assessed using sample-weighted means, standard deviations and quantiles for each of the two primary outcomes. Bivariate and multivariate (regression) survey data analysis methods were used to assess whether mean priority ratings and coverage approval proportions were associated with respondent characteristics or, in the

case of vignette comparison sets, with particular patient or treatment characteristics. Comparisons associated with two-tailed p-values less than 0.05 were considered statistically significant.

A full analysis of how the demographic characteristics of the phone respondents influenced the ratings of their vignettes will be forthcoming in a separate paper.

Appendix G

Limitations of the Survey and Discussion Groups

Survey Methodology

By their nature, phone surveys have a variety of limitations that must be taken into account, including the possibility that survey respondents differed from non-respondents. This vignette approach is also limited by the amount of detail that can be provided (e.g. frequency of the condition/situation and cost of treatment were excluded) and the amount of time available for respondents to consider their answers. The range of vignettes used is also restricted to situations or medical problems that are commonly understood by the general public. The survey approach uses respondents' "gut reaction" to the situations presented, rather than a careful and deliberate discussion about what each vignette represents to the individual and to society in general.

Discussion Group Method

Since discussion group members were not the ones who answered the phone survey, this process assumed that the rationale for ratings are likely to be similar or the same as the reasons the phone respondents would have given if they had been asked. In the discussions, group members also were responding to written vignettes, rather than oral ones and had more time to consider their answers.

Not surprisingly, many group members related to the vignettes from their experience with a similar medical situation that they or a loved one had faced. While this can provide insights that benefit the group discussion, it also can be misleading: sometimes people read into the vignette details that were not there or assumed that their experience would be true for everyone else. However, testimonials were often balanced by the experiences of other group members and seemed to have only a modest influence on others' views.

Engage your public. We can help.

The Center for Healthcare Decisions (CHCD) is a nonpartisan, nonprofit 501(c)3 organization near Sacramento, California. Understanding there are no easy answers in healthcare policy, we are dedicated to advancing healthcare that is fair, affordable and reflects the priorities of an informed public.

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