

JUST COVERAGE

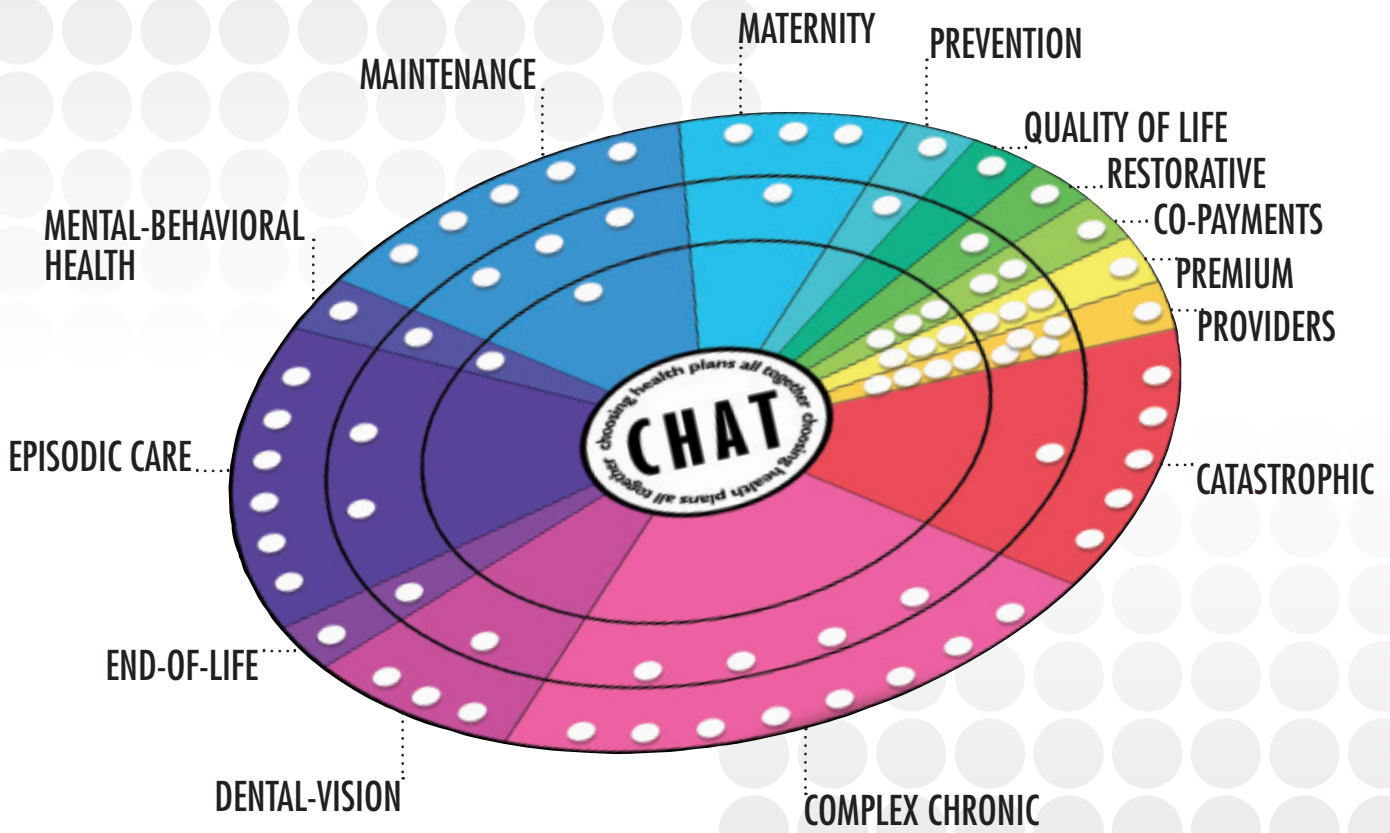
Citizens define the limits of 'basic' healthcare



November 2006

JUST COVERAGE OPTIONS

76 MARKER SPACES, 50 MARKERS TO SPEND





JUST COVERAGE

TABLE OF CONTENTS

Executive Summary.....	2
Introduction.....	3
Process For Setting Priorities.....	3
Six Values That Influenced Decisions.....	4
Results: A Model For Basic Coverage.....	6
Individual vs. Group Priorities.....	8
Attitudes About Basic Coverage.....	9
Conclusions.....	10
Creating A Basic Plan.....	11
Appendices	
A: Coverage Categories and Groups' Decisions.....	12
B: Health Event Lottery.....	15
C: Demographic Characteristics of Participants.....	15
D: Views on the Limits of Health Insurance.....	15
E: Project Limitations.....	16
F: Participating Organizations.....	16
G: Advisory Committee and Consultants.....	17

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

Just Coverage was funded by a grant from California HealthCare Foundation.

For additional copies of this report contact SHD at (916) 851-2828 or visit www.sachealthdecisions.org. For information about using CHAT® visit <http://healthmedia.umich.edu/chat/>

The individuals depicted in this report were participants from various *Just Coverage* sessions.

EXECUTIVE SUMMARY

Despite growing interest in bringing healthcare coverage to the uninsured, policymakers realize that the current high cost of health insurance makes expansion efforts difficult. Seeking alternatives to current models, they commonly refer to “basic” coverage, implying a less expensive plan that offers sufficient protection.

SHD designed the *Just Coverage* project to learn what consumers believed are the elements of basic coverage within a budget representing approximately 2/3 of the cost of a typical employer-based health plan. Using a computer simulation process called CHAT®, nearly 800 Northern California residents participated in 71 interactive *Just Coverage* sessions in 2005-06.

Through a process of individual and group decision-making involving explicit coverage trade-offs, most project participants agreed on two key principles:

1. Basic coverage must be affordable to individuals at low to middle income levels and to those with extensive healthcare needs.
2. Basic coverage must be as comprehensive as possible to address life-threatening situations; prevent or delay illness, disease, or disability; and restore vital functions.

To support these criteria, participants accepted the following restrictions:

- Eliminate coverage of healthcare needs that are not critical to essential human functioning.
- Employ strict limits on provider choice and use of specialists.
- Expect adherence to clinical guidelines and, whenever possible, prescribe the least-costly interventions.
- Exclude coverage of unproven, ineffective or expensive and marginally-beneficial treatment.
- Exclude coverage of costly treatments for conditions that could be avoided or remedied by change in personal behavior.

Implementing this model of basic coverage would be challenging. It holds providers and patients to standards of treatment efficiency and effectiveness that are not used now or not applied consistently. It reduces the authority of physicians and patients in deciding which providers can be used and when. As well, foregoing coverage of non-essential needs acknowledges that communal resources should not be used to remedy all healthcare problems. Despite these restrictions, most participants regarded this as appropriate for a basic plan and one they could accept for themselves.

The *Just Coverage* results – and the process that led to them – provide a provocative blueprint for more affordable healthcare coverage.¹



“Everyone needs some kind of coverage. You know, something to just get by until they hit the lottery.”



¹ Select findings of *Just Coverage* were first published in: M. Ginsburg, “Rearranging the Deck Chairs,” *Health Affairs* 25 (2006): w537-w539; 10.1377/hlthaff.25.w537; and M. Ginsburg, S. Goold and M. Danis, “(De)constructing ‘Basic’ Benefits: Citizens Define The Limits of Coverage,” *Health Affairs* 25, no. 6 (2006): 1648-1655; 10.377/hlthaff.25.6.1648.

INTRODUCTION

Throughout the country, policy leaders are exploring ways to provide healthcare coverage for the uninsured. Unfortunately, an employer-based health insurance premium usually costs more than is politically feasible for expansion programs financed with public and private monies. Consequently, the concept of “basic healthcare coverage” has emerged, an acknowledgement that a less expensive, more limited model must be developed.

Yet few policymakers have defined basic coverage, described its dimensions, or explained the rationale for what should and should not be covered.

In 2005-06, Sacramento Healthcare Decisions (SHD) conducted the *Just Coverage* project, engaging 800 Northern California residents in a small-group process to understand the trade-offs they would make in constructing a basic plan. SHD sought to identify:

- what healthcare needs should be met by insurance coverage and why,
- how essential coverage is distinguished from non-essential coverage,
- how consumers balance cost-sharing, provider choice and coverage restrictions, and
- whether consumers could develop a basic plan that they believed was acceptable for themselves and for others.

PROCESS FOR SETTING PRIORITIES

For this project, SHD set the basic premium at approximately 2/3 of the cost of the average employer-based premium in California. Although arbitrary, this dollar amount provided the framework for participants to weigh priorities and identify the relative importance of various characteristics of healthcare coverage.

While *Just Coverage* was intended to construct a coverage model for the uninsured, participants were also asked to consider in their deliberations the fundamental question: ***If everyone has healthcare coverage, what is the floor below which no one should fall?***

The *Just Coverage* decision tool was a computer-based program called CHAT[®], developed by the University of Michigan and the National Institutes of Health. SHD prepared the CHAT categories to represent various healthcare needs that coverage could address, as well as characteristics of the delivery system: choice of providers and levels of cost-sharing. CHAT also offered options that could reduce the cost of coverage, such as adhering to clinical guidelines, requiring least-costly alternatives and excluding marginally-beneficial treatments (see Appendix A). Participants were instructed to make decisions as citizens influencing health policy, not as patients deciding coverage for themselves.

USING CHAT

CHAT[®] (Choosing Healthplans All Together) was the centerpiece for a structured, interactive process that asked participants – in a 2.5-hour session with 9-12 people – to develop a basic health plan when there were more options than resources. This process did not pertain to Medicare, Medicaid or other public sector coverage.

Using individual laptop computers, participants considered various coverage choices, system characteristics and cost-sharing requirements that were represented on a pie chart. A model of the CHAT chart is shown on the inside cover of this report.

Participants had 50 “markers” to spend across the 76 available spaces on the pie chart. There were 14 categories to choose from, each having one to three tiers; higher tiers brought better benefits but cost more markers. The number of marker spaces assigned to each tier was based on actuarial costs determined in consultation with Milliman, Inc. a national healthcare consulting firm.

The CHAT process included four rounds: 1) on individual laptops, participants created their own version of a basic plan; 2) groups of three worked together to gain skill in creating a consensus plan; 3) the whole group worked with the facilitator to create one uniform plan; and 4) individuals created their own plan again. After the first two rounds, a health event “lottery” exposed participants to medical scenarios that illustrated how the plans they created would affect those with basic coverage (see Appendix B). Round 3 was tape recorded, transcribed and analyzed to identify the rationale for group decisions and to understand where there was particular agreement and disagreement.

Participants completed pre- and post-CHAT surveys which captured demographic information as well as attitudes and reactions. A total of 71 sessions were held in eight counties involving 798 participants.

The limitations of this project are noted in Appendix E.

SIX VALUES THAT INFLUENCED DECISIONS

The discussions in Round 3 exposed the reasons for many of the choices participants made as individuals and the issues they debated to reach group decisions. SHD identified six core values that most influenced these decisions. The comments included here are those of participants from various *Just Coverage* sessions.

1. AFFORDABLE FOR THE PATIENT

To most participants, basic coverage had to ensure that patient cost-sharing (such as premiums and co-payments) was affordable to lower and middle income families. They felt that high cost-sharing would preclude access to needed services, result in worsened health status and ultimately incur greater individual and taxpayer costs. Affordability also played a reverse role: at times, participants felt that individuals could afford to pay for lower-cost medical interventions out-of-pocket without relying on communal funds.

“The difference between \$300 a month [premium] and \$100 a month – that’s food on the table.”

2. MEETS THE NEEDS OF MANY

The number of people who benefited from a category greatly influenced participants’ views of its worth. Even less expensive categories like Vision and Dental were popular because so many people used them. For example, participants regarded expensive end-stage treatments used by a few as a lower priority than more common though less dramatic interventions. Thus, Restorative therapy was covered but not heart transplants for severe cardiac disease. They also tried to cover as many categories as possible, believing that this was the fairest approach to meeting the needs of different people.



3. EMPHASIZES PREVENTION

The theme of prevention arose in all discussions. Participants viewed prevention as the best way to forestall or reduce suffering of individuals and avoid higher healthcare costs in the future. This was particularly important as a rationale for including Dental care and for higher coverage for those in early stages of chronic illness. But participants were also discriminating. They rejected a higher tier of the Prevention category when it did not meet standards for effectiveness.

“What we are doing is controlling it longer in Maintenance so people aren’t morphing into Complex Chronic.”

4. PROVIDES GOOD VALUE

When people made decisions for themselves using their own money, “good value” was an individual judgment of cost relative to benefit. But when groups made decisions that applied to everyone, they were more likely to expect a standard of good value that was measurable and consistent. When resources were shared, maximizing the benefit to the entire population took precedence over the particular needs of individuals.

“But when we’re talking about the public money and the general plan for everybody, I don’t think it’s fair to ask the whole pot to make that huge extension for one individual.”

5. SERVES THE BEST INTEREST OF SOCIETY

Since participants were asked to respond as citizens making health policy, discussion often turned to the impact on the community. For example, although some objected to covering substance abuse or less severe mental health problems, others argued that treatment would help families stay intact, keep people from losing their jobs, and avoid the civic consequences of untreated substance abuse. Societal interests also played a role in rejecting coverage of such needs as infertility, impotence and athletic performance. These problems didn’t reach the same level of importance as, for example, enabling an individual to be healthy enough to earn a living.

6. SHOWS COMPASSION

This value was most evident in discussions about the End-of-life and Catastrophic categories. While participants recognized that relatively few would use End-of-life care (this plan was for a non-Medicare population), participants felt strongly that even a basic plan must include appropriate care for the dying and their families. Although participants rejected Tier 2 of Catastrophic (covering unproven treatment if nothing else was effective), it was difficult for many to do so, even when treatment was likely to be futile. “Doing everything possible” was a strong sentiment when otherwise healthy people faced devastating circumstances.

“I think it’s that tug between the heart and what science really can do for you.”

These values played a pivotal role in how groups prioritized among competing healthcare needs. It’s important to note, however, that these values reflect participants’ role as citizens making societal decisions, not as consumers choosing for themselves. This distinction is a significant one in healthcare policy, where shared decisions may be fair to the community at large but may not be optimal for individual patients.



“To some degree if you’re on this type of program you have to accept that you’re going to make those kinds of concessions.”

RESULTS: A MODEL FOR BASIC COVERAGE

The findings presented here reflect the majority decisions made during Round 3 of CHAT, when each of the 71 groups created a basic coverage plan together, rather than as individuals. Appendix A provides a detailed description of the categories and tiers and how the groups responded to each one.

In discussions about the relative importance of the categories and tiers, groups believed basic coverage was most important for meeting those healthcare needs that addressed life-threatening situations; prevented or delayed illness, disease, or disability; and enabled or restored vital functions. Two of the values listed previously – individual affordability and meeting the needs of many – were particularly important aspects of coverage design. With these attributes as its principal focus, basic coverage was then defined primarily by what was *excluded* from coverage.

Participants accepted the following limitations in defining the parameters of basic:

ELIMINATE COVERAGE OF HEALTHCARE NEEDS THAT ARE NOT CRITICAL TO ESSENTIAL HUMAN FUNCTIONING

Eighty-five percent of the groups excluded coverage for conditions that do not interfere with vital activities of living or those that are desirable but not considered medically essential. Examples were treatment of infertility or impotence, maximizing athletic functioning, expensive drugs for nail fungus, providing growth hormone for short children and circumcision. Most of these examples were included in the category called Quality of Life (QOL), a catch-all description of medical problems that are troublesome to individuals but have little impact on the most essential activities of living and whose remedies bring little benefit to the population as a whole.

“... it’s nice to have but it doesn’t affect your ability to go to work, it’s not going to shorten your lifespan, it’s a ‘nice to have’ ”.



EMPLOY STRICT LIMITS ON PROVIDER CHOICE AND USE OF SPECIALISTS

The Providers category stimulated the most debate; participants had difficulty compromising on broad provider networks and ready access to specialists. Nevertheless, most participants tolerated a very restrictive provider network with reduced access to specialists in exchange for reasonable levels of cost-sharing and assurance that critical healthcare needs would be covered. While 63% of the groups picked this restrictive Tier 1 of Providers, they felt strongly that limited choice must not translate to lower quality of care, reduced geographical access or long waiting times.

“I’d rather pay less out of pocket and only have three different doctors. I’m not necessarily getting worse healthcare; I’m just having less choice.”

EXCLUDE COVERAGE OF UNPROVEN, INEFFECTIVE OR EXPENSIVE BUT MARGINALLY-BENEFICIAL TREATMENT

These criteria span several categories and some of the exclusions elicited greater debate than others. This was especially evident with catastrophic conditions when an otherwise healthy person had no other treatment option available. They also understood that these exclusions meant denying coverage in emotionally difficult circumstances – such as the family of a terminally ill patient when they are still hoping for a miracle. Nevertheless, participants did not support long-shot attempts when other coverage options presented better value for more people.

“If there is very little hope it is going to help, basic coverage doesn’t include the final ‘hail Mary’ pass....”

EXPECT ADHERENCE TO CLINICAL GUIDELINES AND, WHENEVER POSSIBLE, PRESCRIBE THE LEAST-COSTLY INTERVENTIONS

As citizens making decisions for health policy, participants saw the prudence of following clinical guidelines and starting with the least expensive treatment alternatives. Yet most agreed that a more costly alternative should be covered if that was the only option for maintaining good health status. The important message was that resources should be used judiciously, even if this conflicts with the preferences of patients and physicians.

EXCLUDE COVERAGE OF COSTLY TREATMENTS FOR CONDITIONS THAT COULD BE AVOIDED OR REMEDIED BY CHANGE IN PERSONAL BEHAVIOR

Participants supported reasonable coverage for treatment of behavioral health problems, such as smoking, substance abuse and obesity. But they did not support intensive, expensive interventions (such as in-patient drug treatment or bariatric surgery) for health problems that are a result of personal behavior they regarded as irresponsible. Many were also skeptical that extraordinary interventions for behavior-related problems provided effective long-term benefit.

Restrictions and exclusions were also probed on the post-CHAT survey. When asked to choose three of seven possible limitations to create basic coverage, participants were much more inclined to adopt higher standards for effectiveness than to increase patient cost sharing (Table 1).

TABLE 1: PARTICIPANTS’ PREFERENCES ON COVERAGE LIMITATIONS

Asked on post-CHAT survey: <i>“Insurance coverage could have a variety of limitations. Of those listed below, which THREE do you regard as the most acceptable in designing basic health coverage?”</i> (Listed here in order of preferences) n =779.*	
Restrict coverage of treatment that does not meet national standards for being effective.	61%
Restrict coverage of treatment that is not critical for patients’ basic functioning and long life.	57
Limit the use of expensive treatments that provide only a small benefit.	50
Require patients to pay higher rates if they do not follow medical advice that would keep them healthier.	41
Limit the choice of doctors and hospitals that patients use.	36
Except for emergencies, have longer waiting times for services.	35
Have patients pay a larger portion of the cost of health care.	10

* 798 people participated but 19 did not finish the session.

INDIVIDUAL vs. GROUP PRIORITIES

Whereas the purpose of Round 3 was to see how groups designed a uniform plan when participants worked together, Round 4 showed the final decisions of individuals when they were not required to negotiate with others. Round 4 also enabled SHD to determine the extent to which individuals changed their minds about coverage from their initial Round 1 decisions, as well as to assess if demographic characteristics were associated with the choices participants made.

While almost all categories and tiers shifted in varying degrees between Rounds 1 and 4, there were three categories whose changes were especially apparent or had clear demographic differences.

QUALITY OF LIFE (QOL)

When participants started the process, 57% selected the QOL category in Round 1. This dropped to 15% in Round 3 and rose again to 40% when participants made their last choices in Round 4. During the discussion phase, some groups rejected QOL with little disagreement while others debated passionately, especially the necessity of infertility coverage. Said one QOL advocate, “How many people can afford an infertility work-up? We owe them a chance.” The striking change from 57% to 15% to 40% suggests that when choosing on their own, participants are more inclined to provide coverage for interventions that have value to individual patients; but when deciding as a collective body, groups choose the categories or tiers whose benefits have more societal significance.



When the Round 4 results were assessed by demographic characteristics, one group varied dramatically: 71% of participants with both lower income and less education (under \$35K household; high school degree or less, some with minimal college; n=69) selected the QOL category, compared with 37% of all others ($\chi^2_1 = 29.85, p=0.000$). Higher-income African-American and Hispanic participants were also more inclined to choose QOL in Round 4: 59% and 55%, respectively, compared with 35% of other higher-income participants ($p<.004$).

PROVIDERS

This category also showed substantive change between the CHAT rounds. In Round 1, only 39% of participants selected the restrictive provider network of Tier 1, yet 63% of the groups selected this in Round 3. In the final round, 54% selected this coverage, which suggests a strong influence of the Round 3 discussion. There were some demographic differences but none were statistically significant; e.g., among African-Americans or those with lower income or lower education, 45% chose this Provider level in Round 4 ($p>0.05$).

“Well, I’m a PPO person myself. I like to go where I want. Tier 1 to me sounds like the health coverage from hell.”

VISION CARE

Unlike QOL and Providers, this category showed almost no change between Round 1 (56% selecting it) and Round 4 (51%). Yet just 42% of the groups included Vision care in Round 3. Interestingly, almost all participants indicated they supported Vision care for everyone – but they often excluded it because they felt that people could afford to pay out-of-pocket, compared with other needs that were prohibitively expensive.

Support of Vision care was most evident among those who were uninsured (n=50). In Round 4, 72% of them included this in their basic plan, but only 49% of insured participants did so ($\chi^2_2 = 10.20, p=0.007$). Vision was also selected more frequently by African-Americans, of whom 69% selected it in Round 4 versus 49% of everyone else ($\chi^2_1 = 11.68, p=0.001$).

These selection differences raise an important question on whose perspective is most legitimate – the decisions made by groups, those made by individual participants, or ones made by consumers likely to be recipients of basic coverage?

SHD is reporting primarily on the results of Round 3, believing that group decisions take into account a variety of individual experiences, attitudes on risk-taking and perceptions of “what society owes its members.” Yet others might argue that it is only the individual perspectives from Round 4 that really matter, when people are free to express their preferences unhindered by group pressure. Still others would assert that the beneficiaries – in this case, the uninsured or lower-income participants who might need this coverage in the future – have legitimate claim to the decisions on plan design. Since basic coverage is most likely to be supported by public sector dollars, one could argue additionally that it is the taxpayers whose voice is most important.

While Quality of Life and Vision care were the only categories where demographic characteristics would have affected the actual plan design, these differences in values and priorities must be acknowledged.

ATTITUDES ABOUT BASIC COVERAGE

Pre and post-CHAT survey questions explored participants’ attitudes about basic coverage.

“Tier 2’s perfect. I’m not making that much money, that’s perfect for me. When I make more money, I’ll just upgrade it.”

In response to two questions (Table 2), 82% thought that the plan they developed in Round 4 adequately represented basic coverage and 85% would find this coverage definitely or probably acceptable if they personally needed it. When these two questions were analyzed by demographic groups, there were no meaningful differences in response rates by insurance status, income, education, ethnicity, gender or age.

TABLE 2: PARTICIPANTS’ VIEWS ON BASIC COVERAGE

Two questions from the post-CHAT survey (n=779*)	
<i>What do you think about the coverage plan you decided on today?</i>	
It is appropriate for basic coverage	82%
It is too low to be considered basic coverage	12
It is higher than is needed for basic coverage	6
<i>If you were to lose your current health insurance, would you consider the basic plan you created in Round 4 to be an acceptable plan for yourself?</i>	
Yes, definitely	36%
Yes, probably	49
Not sure	6
Probably not	8
Definitely not	2

* Not all of the 798 participants finished the session.

Most participants also believed that no one should be limited to basic coverage if they have the resources to buy more. This view was reflected in responses to a question on the right to health coverage. Half the participants answered this question before the exercise (pre-CHAT) and half the participants did so afterward (post-CHAT), to determine if the CHAT process had any influence on their views (Table 3).



TABLE 3: PARTICIPANTS' ATTITUDES ABOUT HEALTHCARE COVERAGE

<i>Which statement best completes the sentence, "Healthcare coverage should be like..."</i>	Pre-CHAT n=394	Post-CHAT n=380
The Fire Department: everyone receives the same level of protection, regardless of job or income.	34%	22%
Education: a basic level is guaranteed to everyone, but those who can pay for more may do so.	59	74
Housing: everyone has the responsibility to meet his or her own needs.	7	4

The results for all participants showed that modeling healthcare after Education, which is universally available but allows people to pay for more or “better,” had the strongest support pre-CHAT. This support increased considerably post-CHAT. When responses were analyzed by demographic groups, however, more than half of disadvantaged participants (those uninsured or with lower income or less education) preferred the single level Fire Department model pre-CHAT, with a slight shift towards the Education model post-CHAT.² Since these participants were most likely to be those without the resources to purchase “more” health coverage, it is not surprising that many would want a system that guarantees the same level to everyone.

The implications of a two-tier system, where some people explicitly receive less healthcare coverage than others, make many people uncomfortable. Yet while most Americans believe that healthcare coverage must be provided to everyone, they do not want to be limited to a standard they regard as minimal and do not want restrictions on what they can purchase with their own dollars.

“We are talking about a basic plan. I wouldn’t want it, but if that’s all I had, at least I’d have that.”

²These demographic results should be viewed with caution since the sample sizes for these groups were too small for statistical analysis.

CONCLUSIONS

Just Coverage’s emphasis on prioritizing healthcare needs (rather than focusing on services) was a strategy for exploring several fundamental questions about health insurance: What makes it most essential to people’s lives? What are the obligations of society to its members? What are the responsibilities of individuals? This project sought these answers in an effort to provide a viable approach to the inter-related problems of access and cost.³

Participants believed that reasonably comprehensive coverage with affordable patient cost-sharing was the foundation of basic healthcare, a level that should be provided to everyone. To satisfy these goals within a finite budget, they settled on a model that imposed formidable restrictions on which medical interventions are covered, how providers are used, and what healthcare needs are met. Defining basic meant identifying the limitations of coverage rather than its inclusions.

Participants did not accept these restrictions easily. If resources had been unlimited, *Just Coverage* participants would have included everything on the CHAT pie chart. They saw value in meeting all healthcare needs with as few restrictions as possible and allowing patients to determine what is in their own best interest regardless of clinical efficacy or cost-effectiveness. Yet the increasing cost of healthcare and the growing number of uninsured are now common knowledge, and most participants recognized that limit-setting is inevitable.⁴ With six values dominating their perspective, they sought compromises that they believed did the most good and the least harm for those with basic coverage.

Crafting a basic plan would be much simpler if participants had instead supported high patient cost-sharing and/or eliminated certain well-delineated categories like Maternity, Dental or Restorative which are far easier to carve out of a benefits package. The model they propose would require considerable commitment and creativity to translate to a benefits package. Although challenging, it is not impossible.

While other public engagement efforts may elicit different results than those of *Just Coverage*, it is time for policymakers to take the lead in asking citizens what society owes its members and, as importantly, what it does not.

³While this project focused on the fundamentals of coverage, it was not designed to seek answers on who should provide the financial support for basic coverage.

⁴This conclusion is based on the results of a pre- and post-CHAT survey question. See Appendix D.

CREATING A BASIC PLAN

Communities interested in adopting these findings to a coverage plan could start with the three main facets of *Just Coverage*'s version of basic:

USE WELL-FUNCTIONING, COST-CONSCIOUS PRIMARY CARE PROVIDERS

Finding the marriage between high quality and fiscally-responsible practice patterns – including the discriminating use of specialists – is the centerpiece of this basic coverage plan. While it may appear that there are few current models to emulate, some communities have begun developing discrete provider networks that are aiming for this standard.

DENY COVERAGE FOR LESS ESSENTIAL NEEDS

This restriction acknowledges that some healthcare needs are more deserving of coverage than others. Most participants saw the difference between a knee replacement to enable an arthritic patient to walk again and knee surgery to enable long-distance biking, but translating this distinction into coverage design would need further elaboration. The Quality of Life category has boundless capacity for new interventions that address personal healthcare needs and desires; establishing guidelines for defining “less essential” would be a continual work in progress.

EXCLUDE HIGH-COST, LOW-VALUE INTERVENTIONS

This delves into coverage restrictions that are especially relevant in two arenas: 1) using cost-effectiveness explicitly as a criterion for coverage decisions when the benefit is small and the cost is high (e.g., “last-chance” cancer drugs)⁵ and 2) providing hospice and palliative care for patients who are terminally ill, while not covering very expensive interventions that can, at best, delay the inevitable. Both these arenas are fraught with ethical and emotional significance. The challenge is to respect the desire for compassion – the urge to “do everything possible” – without diverting resources from interventions that can save and improve more lives.



⁵SHD recently completed *Getting Good Value*, a project that asked consumers to consider whether cost vs. benefit should be a consideration in coverage criteria. Project results are available at www.sachealthdecisions.org/docs/ggv_report.pdf

APPENDIX A

COVERAGE CATEGORIES AND GROUPS' DECISIONS

Below are descriptions of the *Just Coverage* categories and their tiers with the percentage of the 71 groups that selected each tier in Round 3. The coverage level chosen by the majority of groups is in red italics.

<i>Healthcare needs</i>	<i>Descriptions of coverage</i>
<p>CATASTROPHIC CARE</p> <p>selected by 96% of groups</p> <p>4%</p>	<p>Treatment of unexpected, severe illness or injury, such as sudden liver failure from food poisoning or massive injuries from an accident.</p> <p>TIER 1: <i>All emergency remedies are covered to try to save the person's life and establish basic functioning. Treatments are those proven to be effective. If these treatments do not work or no such treatment exists, supportive care is covered.</i></p> <p>TIER 2: If the customary treatments do not work, insurance also covers unproven treatments that are not likely to help but are the "only hope" left.</p>
<p>COMPLEX CHRONIC</p> <p>32%</p> <p>58%</p> <p>10%</p>	<p>Treatment of serious long-term conditions – such as diabetes, heart failure, arthritis – if they have worsened over time and require extensive medical care to keep patients as functional as possible.</p> <p>TIER 1: Doctor is required to follow established guidelines for the least costly ways to manage complex chronic illness. Though the covered tests, treatments and drugs are effective for most people, they may not work quite as well as more costly alternatives.</p> <p>TIER 2: <i>Besides Tier 1, also covers very costly treatments that may improve patients' health or functioning, like knee replacement if arthritis makes walking impossible.</i></p> <p>TIER 3: Besides Tier 2, for those at the end stage of their disease this also covers extraordinary interventions (such as heart transplants) that might extend life.</p>
<p>DENTAL / VISION</p> <p>3%</p> <p>55%</p> <p>42%</p>	<p>For preventing and treating dental problems; testing and correcting for problems with eyesight.</p> <p>(NO COVERAGE)</p> <p>TIER 1: <i>Dental care only. Cleanings and x-rays yearly without co-payment. Basic dental services are 80% covered; maximum coverage is \$1,000 yr.</i></p> <p>TIER 2: In addition to Dental Care in Tier 1, covers Vision Care, which includes vision testing (refraction) once a year, if needed. Covers \$75 towards glasses every 2 years but not contact lenses.</p>
<p>END-OF-LIFE CARE</p> <p>4%</p> <p>96%</p> <p>0%</p>	<p>For patients who have a terminal condition, when medical treatment is no longer effective and who are expected to die within the next few months.</p> <p>(NO COVERAGE)</p> <p>TIER 1: <i>Hospice is covered in the home or hospital to provide good pain control, treat other symptoms, and give emotional and spiritual support. Coverage is not provided for further medical attempts to delay a patient's death from the terminal condition.</i></p> <p>TIER 2: Hospice care is covered, but if the patient or family wants, measures will be covered that might help delay death for a few days, weeks or months, such as hospital intensive care, CPR and breathing machines.</p>
<p>EPISODIC CARE</p> <p>94%</p> <p>6%</p>	<p>Treatment (office visits, tests, drugs, etc.) for common problems, such as a sore knee, constipation, recurrent cough, heart burn, persistent skin rash, etc., and short-term urgent problems like appendicitis.</p> <p>TIER 1: <i>All emergencies and urgent care are dealt with quickly. When the problem is not urgent, patients may wait several weeks or LONGER for medical appointments, tests or surgery.</i></p> <p>TIER 2: All emergencies and urgent care are dealt with quickly. When the problem is not urgent, patients wait several weeks or LESS for appointments, tests or surgery.</p>

<p>MENTAL & BEHAVIORAL HEALTH</p> <p>25%</p> <p>62%</p> <p>13%</p>	<p>For detecting and treating mental illness. May also cover Behavioral Health problems such as smoking and substance abuse, and unhealthy conditions like obesity.</p> <p>TIER 1: For severe mental health disorders (such as bipolar disease, severe depression and anorexia) covers inpatient and outpatient therapy and drugs. Does not cover Behavioral Health problems.</p> <p>TIER 2: <i>Besides Tier 1, covers less severe mental health problems, as well as behavioral health problems, with out-patient therapy and medications.</i></p> <p>TIER 3: Besides Tier 2, also covers hospital in-patient substance abuse treatment programs and bariatric surgery (stomach-stapling) for obesity.</p>
<p>MAINTENANCE</p> <p>34%</p> <p>66%</p> <p>0%</p>	<p>For regular monitoring and treatment of chronic conditions (such as asthma, high blood pressure, diabetes) when they are newly diagnosed or uncomplicated, to maintain good health and avoid worsening of condition.</p> <p>TIER 1: Doctor is required to follow established guidelines for the least costly ways for managing chronic illness. Though these tests, treatments and formulary drugs are effective for most people, they may not work quite as well as more costly alternatives.</p> <p>TIER 2: <i>If Tier 1 treatment is not sufficient, also covers more expensive tests, procedures and formulary drugs. Doctor is required to follow established guidelines for using these treatments.</i></p> <p>TIER 3: Doctor can order any tests, procedures and drugs that he thinks will help the patient, without having to follow established guidelines.</p>
<p>MATERNITY</p> <p>99%</p> <p>1%</p>	<p>For care of women during pregnancy and childbirth; includes care of the newborn.</p> <p>TIER 1: <i>Covers routine pre-natal and post-natal office visits, tests, drugs and procedures that meet national standards for preventing, detecting or treating problems. Covers childbirth, any complications, and the first day of hospital stay for normal birth.</i></p> <p>TIER 2: Besides Tier 1, also covers other services that patients request such as several prenatal “photos” of the baby; newborn circumcision; two-day hospital stay after normal delivery.</p>
<p>PREVENTION</p> <p>92%</p> <p>8%</p>	<p>To help prevent many diseases or illnesses and to identify medical problems as early as possible. There are no co-pays for preventive services.</p> <p>TIER 1: <i>Covers wellness exams, screening tests and immunizations. These must meet national standards for being most effective, such as flu shots, PAP tests at a certain age, colon exam at age 50, cholesterol screening and others.</i></p> <p>TIER 2: Besides Tier 1, also covers screening of those who are low-risk where chances are small that they have the disease – such as mammograms for women under 40. Also covers screening for uncommon conditions, such as testing all newborns for very rare diseases.</p>
<p>QUALITY OF LIFE</p> <p>85%</p> <p>15%</p>	<p>For problems in function, appearance or comfort that are not seriously disabling but impact personal quality of life. Examples: Injuries affecting athletic performance; infertility; impotence; nail fungus.</p> <p><i>(NO COVERAGE)</i></p> <p>TIER 1: Covers all medications, medical and surgical treatment necessary to correct the problem.</p>
<p>RESTORATIVE</p> <p>1%</p> <p>62%</p> <p>37%</p>	<p>For restoring or improving ability to do basic daily activities such as walking, speaking, personal care and critical work-related functions. Often needed after strokes, joint replacements, amputations, etc.</p> <p><i>(NO COVERAGE)</i></p> <p>TIER 1: <i>Covers all necessary rehab services (such as physical therapy) to improve essential functioning. Covers artificial limbs but not in-home patient equipment.</i></p> <p>TIER 2: Besides Tier 1, covers basic equipment that is needed for rehabilitation (crutches, wheelchairs, back braces, shoe orthotics, etc.). Covers 50% of the cost of expensive equipment, such as electric wheelchairs.</p>

APPENDIX A (CONTINUED)

<i>Features of the delivery system</i>	<i>Descriptions of coverage</i>
<p>CO-PAYMENTS</p> <p>13%</p> <p>86%</p> <p>1%</p>	<p>These are the amounts that individuals pay when they use healthcare services. Co-payments are not required for basic preventive services, routine screening tests and wellness classes.</p> <p>TIER 1: There are co-payments for most services, such as \$30 for doctor or therapist visit; \$15 (generic) and \$30 (brand-name) for drugs; \$100 for expensive tests; \$150 for ER visit; and \$1,000 for a hospital admission.</p> <p>TIER 2: <i>Co-payments are lower than Tier 1. Doctor or therapist visit is \$15; drugs are \$10 (generic) and \$25 (brand-name); \$100 co-pay for ER visit; \$500 for hospital admission. These are typical amounts now used with private insurance.</i></p> <p>TIER 3: Co-payments are lower than Tier 2. Doctor or therapist visit is \$5; drugs are \$5 (generic) and \$10 (brand-name); there is \$25 co-pay for ER visit; and \$100 for a hospital admission.</p>
<p>PREMIUM</p> <p>11%</p> <p>77%</p> <p>11%</p>	<p>In Calif., health insurance averages \$300 per month for an individual; \$835 for family. Most is paid by employer. This category sets the amount that an individual must pay for his or her portion of the total.</p> <p>TIER 1: Each person pays \$60 per month (up to \$300 for family) towards the cost of the health insurance premium.</p> <p>TIER 2: <i>Each person pays \$40 per month (up to \$200 for family) towards the cost of the health insurance premium. These are the average amounts now paid by those with private insurance.</i></p> <p>TIER 3: Each person pays \$20 per month (up to \$100 for family) towards the cost of the health insurance premium.</p>
<p>PROVIDERS</p> <p>63%</p> <p>37%</p> <p>0%</p>	<p>Refers to the healthcare system available to those who have basic coverage.</p> <p>TIER 1: <i>Services are provided by a specific group of primary care doctors who deliver most of the patient care. Referrals to specialists are given sparingly. Choice of doctors and hospitals is limited.</i></p> <p>TIER 2: Services are provided through an HMO. Choice of doctors (primary care and specialty) and hospitals is greater than Tier 1 but limited. Primary doctor must make referral for first specialist visit; follow-up visits do not require referral.</p> <p>TIER 3: There is wide choice of doctors and hospitals in the community, though patients have higher co-payments for some doctors and hospitals. Referral from primary doctor is not needed to see a specialist.</p>



APPENDIX B

HEALTH EVENT LOTTERY

To help participants understand the meaning of the categories – and the consequences of the choices they make – they experience a computerized health event lottery after Rounds 1 and 2. These medical events are assigned at random, allowing them to see how their health plan choices would impact someone who had basic coverage. Below are two of the 80 possible health events in *Just Coverage*.

CATEGORY: MAINTENANCE

Your neighbor has been diabetic for several years, using standard insulin injections. He is doing well but has learned that the insulin pump is probably better at keeping him in good control with the disease.

TIER 1: Though an insulin pump might be useful, this \$5,000 device is not covered at this level. If he wants to switch from shots to pump, your neighbor has to pay the total cost himself.

TIER 2: If his doctor determines that your neighbor meets the clinical guidelines for needing a pump, then his health plan will pay for the \$5,000 device.

TIER 3: If his doctor believes that the insulin pump would be useful, his plan will pay the \$5,000 for it, even if your neighbor doesn't meet the clinical guidelines for needing the pump.

CATEGORY: CATASTROPHIC

You read about a local resident who was swimming in the river, hit by a floating log and almost drowned. She was rushed to the hospital and was there for many weeks at a cost of \$350,000.

TIER 1: Though her care was paid by her health plan, she is still unconscious and the possibility of recovery is very slim. The only chance is an unproven \$50,000 therapy, which her health plan will not pay for.

TIER 2: Though her care was paid by her health plan, she is still unconscious and the possibility of recovery is very slim. Nevertheless, her health plan will pay for the unproven \$50,000 therapy since it is the only hope left.

APPENDIX C

DEMOGRAPHIC CHARACTERISTICS OF PARTICIPANTS

(n=798 unless noted otherwise)

Age (n=797)		Education	
18-29	27 %	8th grade or less	0 %
30-39	19	Some high school but did not graduate	1
40-49	20	High school graduate or GED	6
50-59	22	Some college	14
60 and up	12	Two-year college graduate	6
Gender		Four-year college graduate	42
Male	35 %	Post-graduate degree	31
Female	65	No response	0
Ethnicity		Income	
Asian	11 %	Less than \$20,000	16 %
Black or African American	10	\$20,000 to less than \$35,000	13
Hispanic or Latino	10	\$35,000 to less than \$60,000	17
Native American	2	\$60,000 to \$90,000	17
White	69	More than \$90,000	36
Other	5	No response	1
<i>(does not total 100%; could select more than one category)</i>		Have health insurance (n=795)	
		Yes	93 %
		No	6

APPENDIX D

VIEWS ON THE LIMITS OF HEALTH INSURANCE

Agree or Disagree: Given the rising cost of healthcare today, it is reasonable to limit what is covered by health insurance.

	<i>Pre-CHAT response (n=403)</i>	<i>Post-CHAT response (n=383)</i>
Strongly agree	8 %	26 %
Agree	43	49
Not sure	21	11
Disagree	21	11
Strongly disagree	7	3

APPENDIX E

PROJECT LIMITATIONS

Just Coverage was both a quantitative and qualitative process and each aspect had limitations. By designing CHAT categories around healthcare needs (rather than healthcare services), actuarial estimates of the value of each category and tier were less precise. Since participants were influenced by the number of markers (i.e., dollar amount) required for each category or tier, even small errors in cost assignment might have affected their choices.

Project participants were mostly recruited as volunteers; thus, our sample did not sufficiently represent the population of the participating communities. Those with higher education and income were over-represented while those who would be likely recipients of basic coverage were under-represented: the uninsured, those with lower education level and Hispanics, who comprise a disproportionate percent of California's uninsured. A more representative sampling would have strengthened our ability to isolate the preferences and values of those most affected by these coverage criteria.

Most important, *Just Coverage* dealt with certain types of trade-offs but not with all possible ways to reduce the cost of healthcare. Other cost-drivers (such as the market-driven prices of drugs and devices, administrative costs, profit margins and unnecessary duplication of services) represent formidable obstacles to an efficient system. If strategies to address these cost-drivers were implemented and effective, there is no doubt that consumers would prefer them to restrictions on coverage.

APPENDIX F

PARTICIPATING ORGANIZATIONS

We are grateful to the organizations, institutions and individuals who sponsored and participated in *Just Coverage* sessions.

COMMUNITY ORGANIZATIONS/GROUPS

Action Network, Gualala
California Fndn. for Independent Living Centers
Community Services Planning Council
Eskaton
Housing Coalition
Interfaith Power & Light
Mendocino County Cover the Uninsured
Opinions of Sacramento focus groups
Sacramento Enriches
Shingle Springs residents
Sierra Health Foundation
Turning Point
UCDMC Community Advisory Board
Yolo Adult Day Health

FAITH COMMUNITIES

Cornerstone United Methodist Church
Fremont Presbyterian Church
Holy Cross Lutheran Church
Mercy Faith Community Nurse Support Group
Parkside Community Church
St. John's Lutheran Church
Trinity Episcopal Church

EDUCATIONAL SETTINGS

Samuel Merritt College RN students
UC Berkeley graduate students
UCDMC Clinical Pastoral Education students
UCDMC medical students
USC Sacramento

GOVERNMENTAL AGENCIES

California Department of Health Services
California Department of Insurance
California Department of Managed Health Care
CalPERS
IHSS Public Authority
State Assembly, Executive & Senate Fellows

APPENDIX F (CONTINUED)

BUSINESS/HEALTHCARE LEADERS

American Leadership Forum, Sacramento
Center for Health Improvement
Community Leadership San Jose
Executive Forum
Healthcare Leadership Forum
Leadership Sacramento
Metro Chamber Health Committee

WORKPLACES

Blue Shield of California
CAL Insurance & Associates
El Dorado County businesses
Marshall Medical Center
Nugget Markets
PacAdvantage
PRIDE Industries
Sacramento Municipal Utilities District
SureWest Communications
Western Health Advantage
Woodruff-Sawyer & Co.

APPENDIX G

ADVISORY COMMITTEE

Scott Bain
Consultant, Assembly Appropriations
Suzanne Chammout, RN, JD
*Chief, Sacramento Licensing Branch
California Department of Managed Health Care*
Nettie Hoge
*Deputy Commissioner, Policy and Planning,
California Department of Insurance*
Mike Johnson
Senior Public Policy Advisor, Blue Shield of California
Olivia Kasirye, MD
Sacramento County Department of Public Health
Deborah Kelch
Consultant, Assembly Health Committee
Lee Kemper
*Administrative Director,
County Medical Services Program*
Garry Maisel
CEO, Western Health Advantage
Shawn Martin
*Senior Fiscal & Policy Analyst,
Legislative Analyst's Office*
Tom Moore
*Senior Policy Consultant,
California Health Care Coalition*
Shelley Rouillard
Program Director, Health Rights Hotline
Seren Taylor
Principal Consultant, Senate Republican Fiscal Office
Lucien Wulsin
Project Director, Insure the Uninsured Project, UCLA

PROJECT CONSULTANTS

Marion Danis, MD, *National Institutes of Health*
Susan Goold, MD, MHSA, MA, *University of Michigan*
Arthur Baldwin, *Milliman, Inc., Seattle*
Carol Parise, PhD, *Sutter Institute for Medical Research*

STAFF

Marjorie Ginsburg, *Sacramento Healthcare Decisions*
Kathy Glasmire, *Sacramento Healthcare Decisions*



SACRAMENTO
 Healthcare Decisions

3400 Data Drive
Rancho Cordova, CA
95670

www.sachealthdecisions.org