
SHARING IN THE COST OF CARE

Perspectives from potential health plan users of the
California Health Benefit Exchange

June 15, 2012



Executive Summary	1
Background and Purpose	3
Cost-sharing categories	3
Capturing the public's views	4
Study Methodology	5
Using a deliberative process.....	5
Recruitment criteria and meeting logistics.....	5
The discussion process.....	6
Findings.....	9
Reactions to specific aspects of cost-sharing.....	9
Participants' rankings for 'least burdensome' cost-sharing	10
Rationale for participants' rankings	11
Demographic differences.....	13
Conclusions	15
Dominant themes	15
Implications for a cost-sharing model	16
Communicating about cost-sharing	17
Participants' response to this process	17
Limitations of this study.....	17
Appendices	
Appendix I: Case Studies on Preventive, Episodic, Chronic, and Catastrophic Care	A-2
Appendix II: Form for Ranking Health Care Needs.....	A-6
Appendix III: Post-Discussion Questionnaire and Results	A-7

All materials in the Appendices are available in Spanish upon request.

This report and other CHCD publications are available at www.chcd.org.

Prepared for the California Health Benefit Exchange by the Center for Healthcare Decisions, Inc., a nonprofit, nonpartisan organization whose purpose is to bring the public voice to complex health care policy decisions.

Authors: Marge Ginsburg
Kathy Glasmire
Tamar Foster

CHCD is grateful for assistance from Andrea Rosen with California Health Benefit Exchange; Pete Davidson of PricewaterhouseCoopers; Barbara Abbott of Milliman; Emily Cabrera and Margarita Rocha of Centro La Familia.

Participants' comments from various discussion groups are shown in italics throughout the report.



One of the important components of health care benefits under the national Affordable Care Act is cost-sharing. Cost-sharing is what the patient pays for care covered under a health benefit plan when care is used. Patient cost-sharing requirements are in addition to payment of the premium. The California Health Benefit Exchange (Exchange) is the state entity responsible for implementing some key requirements of the Affordable Care Act in California; among its responsibilities is developing cost-sharing models for new health plans offered through the Exchange in 2014.¹

To help inform its work, the Exchange contracted with the Center for Healthcare Decisions to design and conduct 10 discussion sessions with uninsured Californians who are potential customers of the Exchange. Since there are multiple ways to structure cost-sharing, the Exchange wanted to learn how potential health plan members would respond to the question, *What is the fairest way to structure cost-sharing when trying to meet the needs of many people?*

In seven locations from San Diego to Ukiah, 113 Californians participated in two-hour deliberative discussions which included two groups conducted in Spanish. The process included several didactic and discussion features: defining the common cost-sharing components; comparing three different cost-sharing models; reviewing different medical needs and their impact on individuals' use of health care; discussing case studies that illustrate the use of services and cost-sharing obligations; and, completing a ranking exercise to weigh the cost-sharing needs of those using their health benefits for preventive, episodic, chronic, and catastrophic care.

Participants' perspectives on the components of cost-sharing included the following:

- No-cost preventive services and excluding the first three office visits from the annual deductible were very well received, especially when faced with a high deductible. In general, high deductibles were viewed as a barrier to routine services.
- For most participants, reasonable co-payments for office visits and medications embodied accessibility – the cornerstone of fair coverage.
- Co-insurance was unfamiliar and confusing.
- Higher annual out-of-pocket maximum was more tolerable if deductibles and co-payments were reasonable.

The primary purpose of this project, however, was to identify the attributes of various health care needs that were deemed higher or lower priority in terms of affordable cost-sharing. Participants were asked to consider these decisions as if they were acting on behalf of all new Exchange health plan members, not just themselves.

¹ Other state entities with responsibilities for implementing the Affordable Care Act include the Department of Insurance, the Department of Managed Health Care and the Department of Health Care Services.

Conclusions from this study include:

- Cost-sharing design should impose the least burden on those who have the greatest medical needs. This view reflected concern for those needing chronic or catastrophic care.
- Cost-sharing design should encourage actions that reduce illness and disease. This was reflected in participants' interest in effective preventive services for long-term health promotion as well as assisting those now burdened with illness.
- Cost-sharing design should take into account – but not be driven by – individuals' responsibility to avoid or minimize unhealthy activities.

The difficulty of developing a fair cost-sharing model was not lost on the project participants. One participant observed, *"if these decisions were easy, we wouldn't be here."*



After Congress approved the Affordable Care Act in 2010, the California Legislature established the California Health Benefit Exchange (Exchange) to implement key aspects of the Affordable Care Act in this state. Congress specified many aspects of coverage required for health plans to be part of a state or federal Exchange, including the premium subsidies to be provided by the federal government for Americans at or below 400% of the Federal Poverty Level (FPL).

The Affordable Care Act permits the Exchange to establish cost-sharing structures of the benefit plans to be offered through the Exchange, in whole or in part. The Exchange currently is considering possible cost-sharing models for members who join health plans beginning January 2014.

Cost-sharing categories

Cost-sharing refers to a variety of ways that patients pay some portion of the expense of the health care services they use when they are members of a health plan. The most common cost-sharing categories are:

- **Annual deductible:** The amount an individual pays when using certain health care services for each enrollment year. Once the entire deductible has been paid, the individual then is responsible solely for co-payments and other per-service charges.
- **Co-payments:** A fixed dollar amount that an individual pays per unit of service, regardless of the actual cost of the service. Co-payments generally apply to office visits, drug prescriptions, and sometimes daily charges for in-patient hospital stays.
- **Co-insurance:** A percentage of the cost of service that an individual pays for those services that are not subject to a co-payment. Services that are typical for co-insurance include lab tests, procedures, x-rays and scans, and medical equipment.
- **Annual maximum:** The most an individual is required to pay out-of-pocket each year. If an individual requires extensive medical care, this dollar amount serves as a safety net, assuring that once this maximum amount is paid, the plan pays for 100% of all covered services for the balance of the year.

Currently, employer-based and individual health plans vary in how much patients are charged in each of these cost-sharing categories. For example, one plan may require a \$20 co-payment for an office visit, while another may require \$35. In developing a structure that fits the requirements of the Affordable Care Act, the Exchange may choose different values for the cost-sharing categories.

Depending on an individual's health status and services used, individuals can be affected financially to a greater or lesser extent by cost-sharing requirements. For example, a person who expects to use medical care extensively may be more accepting of a high deductible in exchange for lower co-payments once the deductible has been met. A person who rarely uses services may prefer a lower deductible, anticipating that higher co-payments will not be a frequent burden. Since there is not a single approach to cost-sharing that serves all individuals equally, this raises the question, *What is the fairest way to structure cost-sharing when trying to meet the needs of many people?*

Capturing the public's views

In March 2012, the Exchange contracted with the Center for Healthcare Decisions (CHCD) to develop, conduct and analyze the results of 10 small-group discussion sessions across the state. CHCD designed these sessions to help identify key principles for establishing a fair cost-sharing structure given the diverse health care needs and wide variation in when and how Californians use health care services.

While town-hall meetings and other open forums for stakeholder input provide valuable opportunities to capture the views of disparate groups, those events are not typically designed to elicit decisions that require trade-offs. In this study, CHCD employed a deliberative process to capture participants' choices when the options necessitate priority-setting.



Using a deliberative process

Unlike focus groups that ask for individual experience or opinion, a deliberative process asks participants to wrestle with a dilemma. Deliberation has several distinguishing elements:

- **Concepts and facts:** Participants are given unbiased information to help them make more informed choices.
- **Trade-offs:** Participants weigh the pros and cons of different options.
- **Reason-giving:** Participants talk about why they make their choices, providing a basis for identifying individual values.
- **Discussion and debate:** Through facilitated, interactive discourse, participants clarify for themselves what is most important when the most desirable choice is not available.
- **Social decision-making:** Participants are asked to give their perspectives as members of society, articulating the priorities that will serve many people, not just themselves.

This research is qualitative, designed to understand why people respond as they do and their rationale for how they weigh competing interests.

Recruitment criteria and meeting logistics

The Exchange staff, PricewaterhouseCoopers and CHCD defined the recruitment criteria for the approximately 120 participants expected to attend these 10 two-hour discussions. Participants would be those who are:

- without health insurance for at least one year;
- between 200-400% of the FPL (eligible to qualify for some premium support, but not cost-sharing assistance);
- legal residents of California;
- between ages 30 and 64 (those under 30 would qualify for catastrophic coverage only); and,
- able to read and write English (eight groups) or speak Spanish as their first language (two groups).

Each participant was paid a stipend ranging from \$75 to \$100 depending on location. The 10 sessions were held between April 26 and May 22, 2012 in:

<i>Bakersfield (1)</i>	<i>Encino (1)</i>	<i>Fresno (2 in Spanish)</i>	<i>Oakland (2)</i>
<i>Sacramento (1)</i>	<i>San Diego (2)</i>	<i>Ukiah (1)</i>	

EXHIBIT 1
Demographic Characteristics
of Discussion Group Participants
(N=113)

AGE	PERCENT
30-34	15
35-39	19
40-44	10
45-49	17
50-54	18
55-59	12
60-64	9

EDUCATION LEVEL COMPLETED	PERCENT
Some high school	2
High school graduate or GED	25
Some college	27
College graduate	37
Post graduate	9

GENDER	PERCENT
Male	47
Female	53

ETHNICITY	PERCENT
African-American	25
Asian	5
Caucasian	30
Latino/Hispanic	33
Multiple	4
Other	3

For the English-language sessions, professional firms recruited participants and CHCD staff facilitated the groups. Seven sessions were held in focus group houses and one was held at the Mendocino County Public Health Department. A community organization—Centro La Familia—recruited and facilitated the two Spanish-language sessions held in Fresno. A note-taker was present at all sessions, which also were audiotaped. CHCD staff reviewed notes and transcriptions as part of the qualitative analysis.

The discussion process

The topic of cost-sharing can be complex and often confusing. The goal of this project was to identify how participants viewed health care needs in terms of the impact those needs have on what individuals pay out of pocket for their care. To merge the two concepts – cost-sharing and health care needs – CHCD developed the discussion in two parts:

- 1) to demonstrate and explain different cost-sharing models so participants could understand the financial impact each one represents; and,
- 2) to present various health care needs that typify how different people use health care services and show the impact of those needs on patients' out-of-pocket obligations. The resulting discussion process followed sequential steps, detailed on page 7.

The discussion process

1. **Introductions.** Facilitator introduced the project: the topic; the role of CHCD; the sponsor (the Exchange) and its relationship to the Affordable Care Act; and, explained why these sessions would help the work of the Exchange. Participants were told their identities would be kept confidential and their comments would be attributed anonymously. Participants introduced themselves, mentioning their work status or daytime activities.
2. **Cost-sharing terms.** Using PowerPoint, the facilitator provided definitions of key terms: annual deductible, co-payments, co-insurance, and annual maximum. Participants recounted their own experiences with the different forms of cost-sharing. Most, but not all, participants previously had health insurance as an adult at some time in the past.² The monthly premium also was explained as being separate from the cost-sharing obligation, and participants were told that their income levels would qualify them to receive some federal subsidy to assist with the monthly premium.
3. **Three cost-sharing models.** As shown in Exhibit 2 on page 8, participants were each given a chart depicting three theoretical models (Plan A, Plan B, and Plan C), each with different rates for the various categories of cost-sharing.³ The facilitator pointed out the differences to make sure the variations between the three models were clear. Participants were told about the Affordable Care Act's requirement to include no-cost preventive services. These models also included the first three office visits with co-payment only (no deductible applied).
4. **Individual choices and discussion.** Each participant was asked which of the three plans they would choose for themselves or their family as part of the new insurance program starting in January 2014. Participants indicated their choice with a tent card and then discussed their reasons. This provided opportunity to verify their understanding of the terms and clarify any confusion. Participants sometimes changed their minds after hearing the logic or experience of others.
5. **Different health care needs.** Next the facilitator and group discussed the different reasons that people use

health insurance: for preventive services only, episodic care, chronic illness, and catastrophic situations. The facilitator gave common examples of each, and participants often mentioned their own or other's experience with these types of medical problems.

6. **Case studies.** The facilitator then presented scenarios about four fictitious patients' use of health insurance over an entire year. Each scenario illustrated one of the four general reasons (preventive, episodic, etc.) that patients use health care services, and concluded with a table depicting the actual total cost of services used that year and the patient's share of those costs under each plan (Appendix I).⁴
7. **Prioritizing by health care needs.** The final discussion was the most relevant to the central purpose of this project. Participants were asked, If there were just one cost-sharing model, how should the Exchange prioritize health care needs in terms of their cost-sharing burden on individuals?

At this point, participants were asked to make decisions as if they were representing ALL uninsured Californians in their same income bracket, not only themselves.

- Individually, each participant ranked on a scale of 1 (highest) to 4 (lowest) the needs: preventive, episodic, chronic, and catastrophic. (Appendix II)
- With a show of hands, the note-taker recorded on a flipchart the number of participants who selected higher (1 or 2) and lower (3 or 4) rankings for each need.
- Participants then discussed the rankings and their rationale for their selections.

During the discussion, the facilitator provided two additional facts:

- About 7-8% of adults under age 65 are hospitalized each year.⁵
- Nearly half of all adults under age 65 have one or more chronic conditions.⁶

8. **Post-discussion survey.** Participants completed a short written survey at the conclusion of the discussion (Appendix III).

² The one exception to this was one of the Spanish-language groups where no participant had ever had health insurance as an adult.

³ The three models used figures provided for this study by PricewaterhouseCoopers and were developed as actuarial equivalents or close to it. The participants were told that these were possible models the Exchange might use, but that no decision had been made.

⁴ The cost summaries shown on these four examples of yearly costs are based on California's average medical costs of the total events referenced in each case study. The individual cost figures were provided to CHCD by Milliman (under contract with the Exchange); CHCD totaled the figures and applied the cost-sharing specifics for each model.

⁵ Source: Communication with Peter Davidson at PricewaterhouseCoopers, April 2012.

⁶ Source: Centers for Disease Control and Prevention citation of Wu SY, Green A. "Projection of chronic illness prevalence and cost inflation." Santa Monica, CA: RAND Health; 2000.

EXHIBIT 2
Three Cost-Sharing Models

FEATURE	PLAN A (amount you pay)	PLAN B (amount you pay)	PLAN C (amount you pay)
ANNUAL DEDUCTIBLE	\$1,500	\$2,000	\$3,000
CO-PAYMENTS			
Office visits	\$40	\$20	\$35
Medications	\$15 (generic) \$45 (brand)	\$10 (generic) \$30 (brand)	\$20 (generic) \$45 (brand)
In-patient hospital stay	\$400/day	\$200/day	\$350/day
CO-INSURANCE	40% of all other services	30% of all other services	35% of all other services
ANNUAL MAXIMUM	\$6,000	\$7,000	\$4,500

Note for all three plans:

Annual exam, certain preventive care: NO cost-sharing.

First three office visits: co-payments only.



"I don't know if they'd expand that any further than three [visits] or not. But at least make sure that that part of it stays in the plan."

"If I just didn't have any money, I could call my mom, my friend's son. Someone would give me \$20 to go to the doctor. But, 'hey, you got \$40?' I mean, people that I know aren't just free with 40 bucks."

Reactions to specific aspects of cost-sharing

Although the primary interest of the Exchange was to understand principles of fairness as they pertain to the burden of cost-sharing, participants' responses to the cost-sharing categories and models may be useful to the Exchange.

Annual deductible

- Excluding the first three office visits from the annual deductible and subject only to the co-payment was seen as an important enticement and, in part, mitigated the sticker shock of the annual deductible.
- The annual deductible was difficult for many to fully grasp; repeated explanations were sometimes needed, particularly as it related to the annual maximum. For those who had never before experienced a deductible, its presence was disconcerting.
- The four case studies proved useful in illustrating the impact of the annual deductible. The episodic case study showed that the patient had to pay about 75% of the total cost for the year because of her deductible; while a somewhat out-of-control diabetic in the chronic illness case study paid about 50% of the total cost of his care. The case studies illustrated how the value of insurance coverage increases dramatically when medical services are used extensively.

Co-payments

- Participants tended to focus on those aspects of cost-sharing with which they were familiar. During the 'choose your cost-sharing plan' discussion, nearly 80% of participants in each group chose Plan B because of its reasonably-priced co-payments for office visits and medications – services participants most often used.
- Regardless of the annual deductible, participants still viewed the co-payment as the key to their ability to access health care. The primary concern for many participants was being able to afford to see a doctor when they needed one.

Co-insurance

- Almost all participants were unfamiliar with this type of cost-sharing and did not give it much attention in their discussion and decision-making.
- As it was presented on the three cost-sharing models chart (Exhibit 2), co-insurance was often misunderstood, even after the facilitator gave a specific example of how it might apply.
- The different rates of co-insurance (30/35/40%) did not raise concerns; participants viewed the differences in co-payments as much more meaningful.

"I'm not even thinking about the big picture right now. I'm thinking about 'OK, let's take it a day at a time.'"

Annual maximum

The annual maximum was reassuring, but the actual dollar amount seemed less important to participants as a feature of cost-sharing. When reviewing the case study of the 'catastrophic' patient, participants recognized the annual maximum as relatively small compared to the total cost of the medical care received. They were relieved that there was a 'cap,' but were less inclined to quibble over the amount (even when considering differences between \$4,500, \$6,000, and \$7,000), than they were with the different out-of-pocket costs of common, routine medical care.

Consequently, many participants seemed willing to accept a higher annual maximum if it meant a lower deductible and lower co-payments. Not everyone agrees that a higher maximum is acceptable:

"The other things, I can look on Google, do my own research. I can eat healthy, exercise. I can take care of myself on the low level. It's the high level that I have to worry about. That's why I'm going with the lowest annual maximum above all else."

Choosing among the three cost-sharing models

- Participants who said they were healthy and anticipated using health care services infrequently were more likely to pick Plan A because it included the lowest deductible. Advocates for Plan C (with the lowest annual maximum) cared primarily about an unexpected catastrophic event and saving money at 'the ceiling' rather than 'the floor;' they also did not anticipate using medical services frequently and were more risk-averse. Most participants saw themselves 'in the middle' with Plan B, and wanted those 'middle' features – the three components of co-payments – to be as reasonably priced as possible.
- When reviewing the case studies of fictitious patients, a number of participants observed that there was very little difference between the three cost-sharing models in terms of the patient's out-of-pocket obligations. Despite these comments, no one expressed doubt that the different models had enough variation to be meaningful.
- When participants were told that approximately 7-8% of all adults under age 65 are hospitalized each year, most were surprised by the low number. This was especially relevant for those few people who chose Plan C (with the lowest annual maximum) since the statistic suggested that the likelihood of reaching the annual maximum was small. Most changed to Plan B.
- Conceptually juggling these four types of cost-sharing – and the three subsets of co-payments – was not easy for most participants. One proposed that a visual image be used to make it clearer, particularly to explain how the annual deductible and annual maximum worked.
- Some participants noted that it was difficult to choose among the cost-sharing options without knowing how much their monthly premium would be.

Participants' rankings for 'least burdensome' cost-sharing

As anticipated, the final exercise to rank health care needs stimulated the most discussion and debate among participants. Participants were highly engaged in the topic and often changed their rankings as the discussion progressed.

EXHIBIT 3
Ranking Health Care Needs on a
Scale of 1 (highest) to 4 (lowest)

“And if they [those with chronic conditions] knew their community will cover them, they could go and get the right things. Maybe they would look up some more things about nutrition and prevention. Maybe they would be able to tell their family members, ‘This is something our family has to watch out for, so we should do this, that, and the other.’ So it may be those ongoing costs would end up being reduced because people would get the care they need, and they would get the information to manage their diseases more effectively.”

“There are things with the chronic that, if you’ve got it and it wasn’t your fault, I mean there’s nothing you can do about it. But you can make it better. My wife didn’t go out and sign up for asthma. But she figured out how to take care of it.”

Exhibit 3 below displays the summary rankings of all 113 participants, based on the form shown in Appendix II.

Of the four health care needs, how would you prioritize them in terms of the importance of affordable cost-sharing? (N=113)

Health care need	% who ranked it higher priority (1 or 2)	% who ranked it lower priority (3 or 4)
Chronic	78	22
Catastrophic	50	50
Preventive	47	53
Episodic	27	73

Rationale for participants’ rankings

Many participants mentioned how difficult it was to rank health care needs; they felt that all needs had high priority for affordable cost-sharing. Nevertheless, they took this task seriously and most had compelling and deeply-felt arguments on why one category of need was more important than another for reasonable cost-sharing.

CHRONIC CARE

Most groups ranked chronic illness as the highest priority. When presented with the rates of chronic illnesses among America’s adult population, participants were not surprised by the high number based on their personal experience or that of family members. The reasons for the higher ranking included:

- These patients have the highest overall cost burden, incurring routine medical costs year after year.
- It is stressful having a chronic illness; adding money concerns on top of health problems will add stress.
- Chronic illness affects many people, not just a few.
- These medical problems can have a devastating effect on families, not just individuals.
- Most health care dollars go to chronic illness, so these patients should be a priority.

Those who ranked it lower gave such reasons as:

- It is predictable; patients can plan for the services they will need.
- It is controllable if people take better care of themselves.
- These are not curable conditions; it is better to focus on preventing and curing illness.

"I feel if you're at the catastrophic stage, you're fighting for your life. That is your main goal."

"If you know it's a catastrophic event in your life, you can handle that financial arrangement somehow. Your life has been saved. You've been able to work through it. You can handle it. You're an adult; take care of it."

"But also with catastrophic you're most likely to get help. Like, nobody's going to have a car wash for my kid when she falls off her bike and breaks her arm."

"We're all fat and lazy, and now we have these chronic issues. But maybe somebody could've made me wake up long before this, and then I would've never gotten it."

"Being preventive is a personal choice. You know, I understand that part of this model is that we all want to be healthier people. Because if we're all sharing the cost, then we should all try to be healthier. But then again, you know, part of that – it's human nature to not give a shit sometimes. And so that's kind of built in. So that's why I gave it that [low] number. You know, you want to participate, but we're only willing to go so far."

CATASTROPHIC CARE

Concern about financial devastation prompted high priority for this health care need. To summarize:

- It does not happen often but when it does, the costs are extraordinary.
- Huge debt can ruin families.
- It is unpredictable; people cannot plan for it.
- Patients should not have to deal with money issues while also trying to recover from a major illness or accident.

Those who ranked it lower gave such reasons as:

- It does not happen very often.
- Hospitals are willing to set up a payment plan to help with the financial burden.
- Because of the serious nature of the incident, there are ways to get financial help from the community.

PREVENTIVE CARE

Participants were particularly divided on this category with more than a third giving it the lowest ranking of the four. Those who ranked prevention higher, however, were adamant since they viewed the value of preventive care as much more than just routine screenings:

- Reduces costly use of services by preventing illness, disease.
- Helps people who do not understand the importance of maintaining a healthy lifestyle; it can be effective in educating and empowering individuals.
- Everyone can take advantage of prevention; it is not limited only to those with certain health problems.
- Making preventative services free encourages people to use them.
- More important to be proactive, rather than reactive.

Those ranking prevention lower saw it in a different light:

- Some prevention is already free in these models, so there is no reason to do more.
- It is relatively inexpensive and is not needed that often; many people will not take advantage of it even when it is free.
- Maintaining a healthy lifestyle is an individual obligation, not a societal one.
- There is no agreement on what constitutes 'prevention' and it does not always work to prevent illness.

"I mean, there's just a lot of people that are only going to use episodic care anyway. So I just don't think that they should have to pay as much as, say, someone who has a chronic disease – who you know is going to need a lot of care."

EPISODIC CARE

Although everyone was personally familiar with episodic care – even more so if they had children – it ranked the lowest of the four. Those who gave it a higher ranking did so because:

- These problems happen frequently, particularly with children.
- The need is unpredictable and everyone experiences these problems.
- Just because the needs are less than with chronic illness, it is unfair to discriminate against healthier people.
- Episodic events are 'curable' – it is important to get people back to work quickly.
- Addressing them keeps problems from becoming chronic.

Those that ranked it lower did so because:

- These are small events, not big ones, and do not usually keep people out of work.
- They are temporary problems; once dealt with, they are over.
- Episodic events are easier to recover from financially, compared to chronic and catastrophic problems.
- Many of these problems can be self-managed and do not always require a higher level of care.

Demographic differences

CHCD conducted some basic statistical analyses to see if there were any demographic differences in how individuals ranked health care needs. In fact, there were minimal differences between the rankings of men and women, as well as between the age groups of 30-44 and 45-64. The limited sample size of this project – and its qualitative design – precluded additional analysis.

However, the two Spanish-language groups (n = 23) were distinctive in several ways:

- In one of the Spanish-language groups, none of the 11 participants had ever had health insurance. Though some ran their own businesses or had high levels of education, the lack of familiarity with health insurance terms and concepts made this a challenging discussion. Participants had no frame of reference for the various types of cost-sharing, so comparing them was not a productive way to identify their concerns.
- Both groups expressed considerable skepticism for preventive care. Participants thought it was over-rated and not useful in terms of designing an affordable cost-sharing arrangement. This was reflected in the ranking exercise where these two groups gave prevention a much lower priority than had all the other groups.
- Episodic care was ranked low because participants tended to use home remedies for minor medical problems, rather than go to the doctor.

"People don't go to the doctor unless they are dying."

With such a limited sample size, these findings do not necessarily represent the Latino/ Hispanic Spanish-speaking populations in California. Nevertheless, if there are in fact many people with scant knowledge of health insurance terminology, then carefully designed outreach and enrollment activities will be especially vital. Despite this challenge for the discussion process, the priorities of these 23 individuals were oriented toward chronic and catastrophic needs for the same reasons as participants in other groups: these are the most costly for individuals to manage without meaningful financial help.



Determining a fair cost-sharing structure is essentially a resource allocation decision. As such, this decision requires trade-offs, compromising one or more ideals in order to prioritize others. The project participants were not new to the concept of trade-offs or allocating resources. Many had been without health insurance for years, and they had first-hand experience with weighing the benefits and costs of seeking medical treatment or doing without. Living with these types of limits may well have sparked the dynamic and highly interactive discussions that ensued.

Dominant themes

Regardless of which health care needs participants ranked higher or lower, several themes emerged in the group discussions:

Cost-sharing should be least burdensome for those who have the greatest medical needs.

While 'greatest' medical needs had somewhat different meanings to different participants, recurrent views included:

- Helping those who need medical services the most consistently, over time.
- Providing benefit to a large number of people.
- Protecting individuals from financial devastation.

The majority of participants identified chronic illness as the health care need that was most deserving of reasonable cost-sharing because the medical needs were continuous and so many people were affected. Participants acknowledged that such a cost-sharing structure would be less advantageous to individuals who are rarely sick or whose medical problems are short-term and not terribly costly.

In the same vein, participants understood the necessity of trade-offs as evidenced in their prioritization of catastrophic care. Ranking this category second overall indicated their strong concern about protecting individuals from a devastating financial impact; however, catastrophic 'failed' another important criterion, that of providing benefit to a large number of people.

Cost-sharing should encourage actions that reduce illness and disease.

Participants wanted cost-sharing to be structured in ways that positively influenced the health of the population:

- Helping chronically ill patients become healthier.
- Investing in prevention programs that can have an impact on health.
- Enabling everyone to benefit, not only those who are currently sick.
- Allowing people to continue working.

"On the other hand, if you focus on preventive care, then you can eliminate many people having high blood pressure, high cholesterol, and that trickles up as far as saving money."

“And so I guess I’m thinking about the whole picture for California. I mean, academically, preventive [is highest]. You know we should all be striving for that. But to help everyone in the state, I’m thinking catastrophic and chronic.”

“Like if you know it’s raining outside, and you don’t have something covering your head, or you don’t have the right shoes on and stuff...it’s a possibility that you’re going to get sick. So preventive maintenance, or preventive care, it starts basically with yourself, you know. Use a little common sense and have a little self-preservation.”

“Diabetes is one thing a lot of people are going through. And sometimes because of financial issues, they can’t see the doctor all the time. So it would be nice to have something that they can go to and the cost would be included less than average. Then, that way, they don’t stress as much and they can be more comfortable going more often.”

While this was a universal theme, the greatest divide arose in how to achieve it. The ‘prevention-oriented’ participants wanted to use cost-sharing mechanisms to instill preventive activities into everyone’s lives for the long-term purpose of reducing the burden and cost of poor health.

The ‘chronic illness-oriented’ participants felt California did not have the luxury of investing resources for long-term benefit when many people need help dealing with their current health problems. These participants felt that the higher duty was to help address immediate needs, not long-term ones.

The discussion of chronic illness frequently evoked concerns about people being able to work; for many, losing one’s job because of poor health was a real threat.

Cost-sharing should take into account – but not be driven by – individuals’ responsibility to avoid unhealthy activities.

Many participants discussed the degree to which medical problems are or are not ‘within our control,’ although there was very little discussion of ‘blame’ (e.g., that those who have not taken good care of themselves do not warrant affordable cost-sharing). From their own experiences, some participants thought episodic events were more personally ‘controllable,’ while others thought the same about chronic or catastrophic. They conveyed the perspective that the more random the health care problem (i.e., there was nothing the individual could do to avoid it), the higher priority it should be for affordable cost-sharing.

When participants explicitly raised the issue of personal responsibility, it was usually in reference to prevention, when maintaining a healthy lifestyle was viewed as an individual’s duty rather than an obligation of society.

Implications for a cost-sharing model

CHCD makes the following recommendations based on the reactions participants had in discussing their own cost-sharing preferences as well as the themes that arose from their broader discussions of priorities:

- Ensure that the preventive services available with no cost-sharing required is well understood by future enrollees.
- Consider excluding the first three office visits from the annual deductible with only a co-payment requirement.
- Keep co-payments for office visits and prescriptions at a ‘typical’ rate and within price ranges that people recognize.
- Keep the annual deductible as low as possible, even if doing so results in a higher annual maximum.

Participants’ concerns about the financial burden on patients for managing chronic illness suggests there may be support for value-based insurance design – where patients with chronic medical needs benefit from reduced cost-sharing to help improve their health status. This may be an area for the Exchange to explore in greater depth.

Communicating about cost-sharing

The chart of three cost-sharing models was necessary to set the stage for the various ways to structure cost-sharing differences, but as a decision tool, it was not particularly helpful. Participants tended to focus on what they knew and dismissed details that were foreign to them.

The case studies in this project seemed useful in giving participants a good sense of how insurance coverage can be most helpful in different types of health care situations. The catastrophic example had the greatest impact when participants saw that the actual annual cost of care had been \$44,500, but the individual's share was a fraction of that. Case examples also personalized the discussion by using profiles of 'people like me,' with health care events and medical costs that are realistic.

When participants reviewed and discussed the case studies, several noted that there was actually a fairly small difference in the cost-sharing obligations in Plans A, B, and C (except for the catastrophic case where the annual maximum had been met). Nevertheless, there was still the perception that co-payment amounts, in particular, have a meaningful impact on an individual's ability to access affordable health care. Regardless of whether this is statistically valid or not, this perception is a strong one and may well influence how potential plan members make decisions about cost-sharing options.

This project was not designed to test materials for teaching about cost-sharing; nevertheless, it is apparent that many people have minimal numeracy skills and little patience for wading through voluminous figures. If the Exchange (or others) will be using individual case studies to illustrate how cost-sharing works, it appears that the simpler the description, the better.

Participants' response to this process

Each session concluded with a short written questionnaire, mainly about participants' experience in the session. Participants expressed a high level of comfort with the decision-maker role and strong enthusiasm for their involvement in policy decisions. Survey results are shown in Appendix III.

Limitations of this study

The subject matter for this project was complicated, evidenced by how some participants struggled to understand the discussion. Additionally, the discussion process itself was multi-faceted, requiring participants to pay close attention. While the majority of participants were fully engaged, perhaps 10% (based on the facilitator's subjective observations) had more limited insight into what was being asked of them.

This study was conducted within a short timeframe, so testing of materials was limited to one pilot session. Time constraints also meant that it was difficult to achieve a fully-representative demographic mix. There were too few Asian participants, and it would have been useful to conduct several more sessions, including ones in Chinese and other languages that reflect California's diverse population. As well, Ukiah was the only rural location and the recruitment firm had great difficulty finding eligible participants to fill that group. One or more additional rural sites would have brought greater representation of the population.



APPENDICES

**Appendix I: Case Studies on Preventive, Episodic, Chronic,
and Catastrophic CareA-2**

Appendix II: Form for Ranking Health Care NeedsA-6

Appendix III: Post-Discussion Questionnaire and ResultsA-7



Appendix I

Case Studies on Preventive, Episodic, Chronic, and Catastrophic Care

**CASE STUDY:
PREVENTIVE CARE**

JOHN

John is a 45 year old single man who works for a small carpentry business. When younger, John had many trips to the doctor for sprains and broken bones from his often risky outdoor activities and contact sports. While he still enjoys those activities, he has become more careful because he can't afford to miss work when he is injured.

This past year, John used his health insurance for preventive care services recommended by his health plan for a man his age. He had an annual exam by his doctor, including lab tests for high blood sugar and cholesterol (both problems run in his family). He also received his flu shot. Since John is African-American and his father had prostate cancer at a young age (African-Americans have higher rates than other men), John also gets a prostate screening test each year. During the year, John also saw his doctor for a mild sinus infection.

The health care that John received this year cost a total of:

\$416

For the whole year, John paid a total of:

**Plan A
\$40**

**Plan B
\$20**

**Plan C
\$35**



Case Studies on Preventive, Episodic, Chronic, and Catastrophic Care

**CASE STUDY:
EPISODIC CARE**

JANET

Janet is a 37 year old married woman with two pre-teen children. Janet is healthy and athletic and works hard to keep herself in good shape. She has used her health insurance mainly to cover regular wellness exams and screenings. However, this year she has used her insurance several times for unexpected injuries and minor illnesses.

Her biggest problem happened when she was trying out her son’s rollerblades. He forgot to tell her how to stop if she is going too fast. Janet crashed into a brick wall, breaking her wrist, dislocating her shoulder and getting a nasty cut on her forehead. She was really embarrassed by this accident and went to her urgent care center. There she received x-rays, pain medication, stitches in her forehead, tetanus shot and antibiotics, cast for her wrist and a sling for her arm. Janet got appointments for physical therapy and follow-up visits with her doctor. Four weeks later, she was pretty much back to normal. She sold the roller blades on Craig’s List and bought her son a tennis racket.

Janet had two other short-term medical problems this year that also brought her to the doctor. She had a bad case of strep throat requiring a lab test and antibiotics, and later that year she found a couple spots on her nose that worried her and had to get skin lesion tests to make sure they were not cancer (they weren’t). And of course, she had routine screening tests that are recommended for women her age.

In the past year, Janet did not need to use her health insurance for any chronic or catastrophic care; rather, most was for episodic care.

The health care that Janet received this year cost a total of:

\$2,089

For the whole year, Janet paid a total of :

Plan A	Plan B	Plan C
\$1,589	\$1,659	\$1,659



Appendix I

Case Studies on Preventive, Episodic, Chronic, and Catastrophic Care

**CASE STUDY:
CHRONIC ILLNESS**

ROBERT

Robert is 29 years old, married with one child and is employed as a sales clerk. He has had diabetes since childhood because his diabetes is a genetic condition that he was born with. This means that he must take several injections of insulin every day of his life and test his own blood regularly with special equipment. He also visits his primary care doctor every 3 months and needs lab tests every so often to check on his diabetes. To avoid complications, Robert must see his foot doctor and eye doctor once each year. He also gets education about nutrition and other ways to help him manage his diabetes.

Robert is careful to keep up with other screenings and tests that will help find any early medical problems and each year gets a flu shot.

But this year has been particularly hard on Robert and he had great difficulty managing his condition. He had one trip to the ER and then needed to see his doctor six more times than he usually required and get more blood tests to help adjust his insulin dose.

The health care that Robert received this year cost a total of:

\$8,912

For the whole year, Robert paid a total of :

**Plan A
\$4,426**

**Plan B
\$4,044**

**Plan C
\$4,500**



Case Studies on Preventive, Episodic, Chronic, and Catastrophic Care

**CASE STUDY:
CATASTROPHIC CARE**

SALLY

Sally is a 52 year old single woman with two grown children. She has mild asthma which is controlled with medicine. Other than a few other minor medical problems, Sally has been quite healthy. She always gets the preventive care exams and tests recommended by her doctor and health plan.

One day, Sally started to notice numbness in her arms and legs. Over the next few days she felt she was growing weaker, so she saw her primary doctor. Quickly a specialist examined her, and a scan showed that she had a tumor pressing on her spine. She had surgery which successfully removed the tumor (not cancer), but after several days in the hospital she still had considerable weakness in arms and legs. She couldn't hold a fork to feed herself and could not walk on her own. She was transferred to an in-patient rehabilitation center for intensive physical and occupational therapy. With therapy, over the next two weeks she grew stronger and regained control of her hands and the ability to stand and walk on her own. Three weeks later, Sally was back home and received several weeks of out-patient physical therapy. Three months later, she was able to return to her job.

The health care that Sally received this year cost a total of:

\$44,596

For the whole year, Sally paid a total of:

Plan A	Plan B	Plan C
\$6,000	\$7,000	\$4,500



Appendix II Form for Ranking Health Care Needs

Imagine that you are helping the Exchange design the cost-sharing model that would apply to all uninsured Californians in the same income range as you.

As you know, there are different cost burdens depending on each person's health status and how each uses health care services. Of the four categories of health care needs listed below, which one do you think should be the highest priority for affordable cost-sharing?

Please rank the four categories below, with #1 being the highest priority and #4, the lowest.

For example, if you think that the most affordable cost-sharing should apply to catastrophic care, mark it #1. The next most affordable, mark #2, etc.

PREVENTIVE CARE

Generally includes exams, tests and health education intended to monitor patients and help them prevent diseases and maintain good health. Also includes treating diseases early before they cause significant health problems.

Example: Blood pressure tests or the flu shot. Reminder: Preventive care does not require cost-sharing.

EPISODIC CARE

Treatment for a particular problem that does not require ongoing care. Emergency departments provide some episodic care but most is provided in the regular doctor's office.

Example: Strep throat or breaking an arm.

CHRONIC ILLNESS

Treatment for long-term or ongoing health problems, that generally have to be controlled, but can't be cured.

Example: Diabetes or asthma.

CATASTROPHIC CARE

Treatment that involves intensive, highly-specialized medical care of a seriously ill patient.

Example: Motorcycle crash, major heart attack.



Appendix III

Post-Discussion Questionnaire and Results

*Post-Discussion
Questionnaire and
Results (N= 113)*

1. This discussion presented a lot of information about ‘cost-sharing.’ Was this information difficult to understand?

- 2%.....It was difficult.
- 29%It was somewhat difficult.
- 70%It was not at all difficult.

2. We asked you to imagine that your decisions about cost-sharing could affect many people, not just yourself. How comfortable were you in having that task to do?

- 13%I was very uncomfortable.
- 17%I was somewhat uncomfortable.
- 71%I was quite comfortable.

3. How would you rate this discussion today? On a scale of 1 (not at all) to 5 (definitely yes):

	1	2	3	4	5
Discussion leader was open to hearing all viewpoints.	-	-	-	12%	88%
I had the opportunity to give my opinion.	-	-	1%	8%	91%
I appreciated the chance to contribute to this topic.	-	-	6%	6%	88%
I learned things today that might be helpful to me in the future.	1%	1%	4%	17%	78%

4. How important is it for the Exchange to get the views of people like you – potential health plan users – when they are developing new health insurance programs?

- 97%It is very important.
- 3%It is somewhat important.
- 0%It is not important at all.