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Re-Designing Medicare

**Findings from the California
Medicare CHAT Collaborative**

September 2014

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The photos and quotes used in this report are those of participants from various MedCHAT sessions.

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INTRODUCTION

Medicare is one of the most pressing topics in the national dialogue on healthcare policy. The number of beneficiaries is expected to grow from 54 million to 80 million by the year 2030, and many are concerned about its long term financial health. Next year, Medicare turns 50 and while there is much to celebrate, policy leaders are debating how the largest health insurance program in the country should respond to the pressures it faces now and in the future.

The Center for Healthcare Decisions (CHCD) in partnership with LeadingAge California developed the California Medicare CHAT Collaborative ("MedCHAT") to encourage public input on Medicare. Its purposes were to: 1) promote individuals' interest in the Medicare debate as consumers and citizens; 2) improve understanding of the current components and relative costs of Medicare services; 3) expose the public to new policy and coverage considerations; 4) identify the priorities and trade-offs that surface when groups consider how Medicare could be improved; and 5) inform state and national leaders of the perspectives and values that are integral to considering the future of Medicare. More than 20 organizations became MedCHAT partners to help bring this civic engagement and research activity to their communities.

MedCHAT is an interactive, computer-based simulation, in which participants create a benefits package when potential coverage options exceed current Medicare funding. This simulation is an exercise in *public deliberation*,[1] a multi-step process that presents unbiased, factual information and exposes participants to a variety of options, each with its pros and cons. MedCHAT participants consider competing priorities, hear the perspectives of others, and negotiate as a group to find the best coverage components. Most important for a deliberative process, they talk about the reasons and principles that underlie their views when responding as citizens, not as individuals deciding coverage for themselves or family members.

For the past year, 82 three-hour MedCHAT sessions were conducted throughout the state involving 810 Californians: seniors, younger adults, healthcare professionals, community leaders and those working in senior services. Since this project targeted California residents, we hope the process and its findings will prompt other states and national organizations to engage their communities in discussions on the future of Medicare.

DESIGNING THE MEDCHAT PROCESS

MedCHAT uses the computer program called CHAT® (Choosing All Together) developed by physician-ethicists at the University of Michigan and the National Institutes of Health.[2] CHCD customized the CHAT software to show a spectrum of healthcare needs and services that Medicare currently covers, as well as potential new services. MedCHAT includes current policy topics, such as the use of evidence in medical decisions; the impact of unrestricted choice of providers; and the role of personal responsibility. However, Medicare is a complex, multi-faceted program, and fostering discussions requires a manageable volume of information. Thus, MedCHAT focuses only on re-designing Original Medicare, not Medicare Advantage or Part D.

Categories and tiers

Participants make their decisions using a pie chart that depicts 12 categories of coverage (see page 5 illustration). CHCD established these 12 categories, such as Early Chronic, Complex Chronic, Final Phase and Routine Care, because they are especially relevant to the population that Medicare serves. Describing the options in this fashion allows participants to think beyond "doctor visits" to a more holistic consideration of the purpose for which medical services are used.

Within the 12 MedCHAT categories are tiers: levels within each category that specify the extent of coverage. Offering new coverage categories or new tiers not currently provided by Medicare, as well as different types of coverage restrictions, allows individuals and groups to decide what in Medicare is worth retaining, what might be sacrificed and what compromises are worth making.
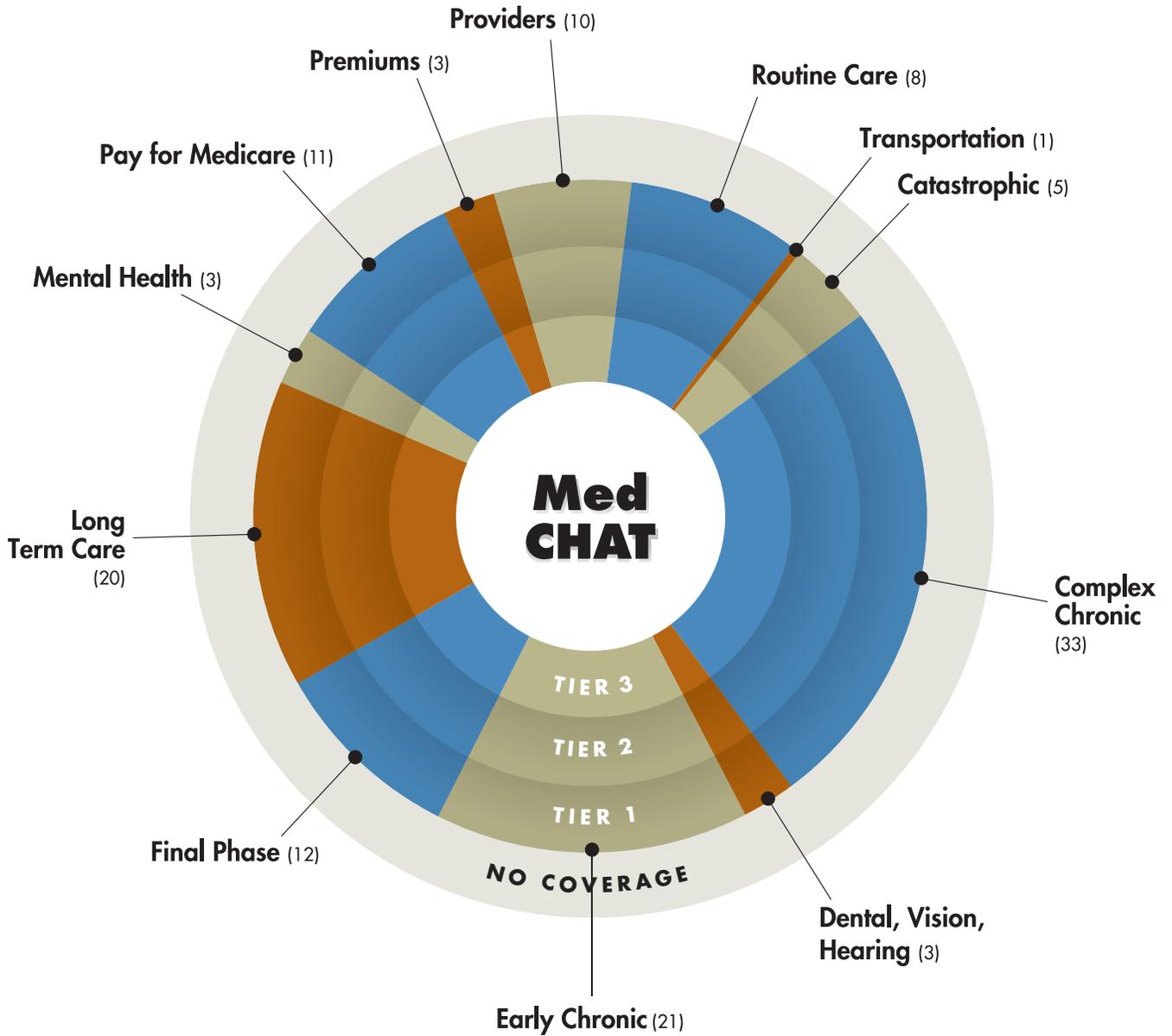
Since most people have little knowledge about the details of Medicare coverage, those tiers which represent existing coverage are identified as "current." This label helps participants recognize when they choose benefits that are more or less than existing coverage.

Markers and monetary calculations

The tiers within each category have a monetary value shown by the number of marker spaces, which represent the cost of that coverage relative to all Medicare expenditures. The actuarial firm Milliman calculated these monetary values to be as close as possible to the actual costs. Participants have a total of 100 markers to spend on the Medicare plan. The markers represent the average amount that the government currently pays for each beneficiary. There are 130 marker spaces on the pie chart; the 30 extra spaces represent additional benefits that can be added if current benefits are reduced. Seeing alternative coverage options allows participants to weigh the opportunity costs of current and potential benefits. Participants are also given the chance to dedicate some of their markers (Medicare dollars) to extend the program's financial security.

MedCHAT Options

The 12 MedCHAT categories are shown below; in parentheses are the number of "markers" needed to select the highest tier for that category. See Appendix A for a complete description of the categories, tiers and their monetary values.

Providers (10)

Premiums (3)

Routine Care (8)

Pay for Medicare (11)

Transportation (1)

Catastrophic (5)

Mental Health (3)

Long Term Care (20)

Med CHAT

Complex Chronic (33)

TIER 3

TIER 2

TIER 1

Final Phase (12)

NO COVERAGE

Dental, Vision, Hearing (3)

Early Chronic (21)

The 3-hour MedCHAT session:

Typically two trained facilitators conduct MedCHAT sessions in groups of 8–15 people. These sessions take place in a variety of community and professional settings (see Appendix E) using individual laptops or computer labs.

After group introductions, participants complete the pre-CHAT survey. Following a short introduction to Medicare, facilitators demonstrate the computer program. This is followed by four rounds of MedCHAT.

- *Round 1:* On individual computers, participants design a Medicare plan for themselves or a senior family member; they do not have to take into account the needs of others.

- *Round 2:* In groups of 2–3, participants work together on one computer to agree on a Medicare plan for the whole country.

- *Round 3:* Facilitators lead the entire group through an extended discussion to create one uniform plan for the country; participants are encouraged to give their rationale for their choices and to actively debate each other on the reasoning they use to justify trade-offs. Participants vote if the group cannot come to agreement on particular categories. This round is audio-recorded.

- *Round 4:* Participants make their final decisions on their individual computers on what Medicare should look like for the country. Participants' most informed perspectives are reflected in round 4, and these data are central to the quantitative analysis. At the end of the session, they complete the post-CHAT survey.

- *Health event lottery:* After round 1, a computerized health event "lottery" exposes participants to randomly-assigned medical scenarios that illustrate how the plan they created would affect them based on the coverage decisions they made. All participants read their lottery cards aloud to give others a chance to recognize the impact of coverage decisions when applied to specific clinical situations. (See Appendix B for examples).

RESULTS

MedCHAT responses were analyzed both qualitatively and quantitatively. Qualitative analysis was based on audio-taped and transcribed group discussions from round 3, when all participants shared disparate views and experiences as they weighed the pros and cons of the options. CHCD staff reviewed the transcripts to identify prevailing and minority themes and to capture the reasoning and societal values that surfaced when groups debated the options for future Medicare benefits.

The Sutter Institute for Medical Research conducted the quantitative analysis, assessing the association between participant demographics and round 4 selections as well as demographic differences associated with select post-CHAT responses. The analysis used contingency tables, the Test of Independence, and Pearson Residuals.

While the decisions made in rounds 1, 2 and 3 of MedCHAT are important, the final round 4 data captured individuals' views after several hours of discussion had increased their understanding and broadened their perspective. Thus, for the purpose of reporting MedCHAT results, we used only the data from round 4. The qualitative narrative accompanying the results below was based on review of the round 3 transcriptions. We include verbatim comments from individual participants that illustrate how people talked about the issues that arose during these discussions.

Table 1 summarizes the Round 4 decisions of 781 participants for the 12 MedCHAT categories.

"You know, when you ask us to design something for the country as a whole, I guess I feel that part of my responsibility is to look at how to do the most good for the most people first."

Participants' final Medicare decisions

TABLE 1:

A summary of the 12 MedCHAT categories, in alphabetical order, with the coverage decisions of 781 participants in the final round of MedCHAT.*

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* While 810 individuals participated in MedCHAT, some participants did not complete the full session, some did not answer all pre- and post- questions and some data were lost through computer problems.

See Appendix A for complete descriptions of all categories, tiers, their monetary value, and the percent of participants that chose each tier.

- **Catastrophic Care:** For treating those faced with sudden devastating illness or injury. When conventional treatment fails, 53% included the use of "long-shot" treatments, even if they had only a small chance of working or the expected benefit was minimal; 47% did not cover long-shot treatments.

- **Complex Chronic:** For treating long-term chronic conditions like diabetes, heart or lung disease that require on-going treatment. 88% supported value-based coverage, meaning that if research showed that the benefit of a treatment was small, unlikely or more expensive than an equivalent, patients would pay at least half the cost.

- **Dental / Vision / Hearing:** Provides modest coverage for these three services. 85% supported adding all three as new Medicare benefits; another 11% added coverage for Dental only.

- **Early Chronic:** For controlling early chronic conditions like high blood pressure, diabetes, and obesity. 48% supported using incentives — both penalties and rewards — to motivate patients to comply with medical advice. Another 36% supported using penalties only.

- **Final Phase:** For care of those with long-standing incurable illnesses who are growing more frail and inactive, common in the last year of life. 65% supported coverage of palliative care/hospice but not coverage of treatments unlikely to make a meaningful difference; 31% covered palliative care/hospice as well as attempts to prolong life. 97% eliminated ICU coverage for patients who are dying.

- **Long-Term Care:** For those who need extended non-medical care (e.g., assistance with dressing, bathing, feeding, etc.) due to physical or mental impairment. 77% supported at least one year of coverage in a nursing home, supportive housing or person's home (with 10% co-insurance) as a new Medicare benefit.

- **Mental Health:** To increase the mental health services covered by Medicare, 69% added long-term (rather than short-term) counseling for less severe mental health problems with a lower co-insurance than the current benefit.

- **Pay for Medicare:** To assure that Medicare lasts at least another 50 years, 85% were willing to reduce Medicare spending on current and future beneficiaries.

- **Premiums:** 60% thought that those with incomes of $85,000/yr. and more should have higher monthly Part B premiums than they do currently. An additional 19% increased premiums for those earning $50K and more.

- **Providers:** 82% supported requiring the use of specific networks of doctors and hospitals, instead of the complete freedom of provider choice guaranteed in Original Medicare. Yet, most also included the proviso that a referral outside the network would be covered if approved by the primary care provider.

- **Routine care:** For services to treat short-term, episodic problems like the flu, heart burn, shingles, as well as preventive screenings and check-ups. 52% supported coverage of all tests and treatments that doctors order, even when there was little or no evidence of benefit; 47% did not include coverage when evidence showed little or no benefit.

- **Transportation:** For those who are unable to drive or use public transportation. 81% supported coverage of transportation to and from medical appointments as a new Medicare benefit.

Below is detailed discussion of the major findings that are indicated within the Table 1 results: limiting provider choice; reducing low-value care; adding new benefits; and addressing specific social values. Where applicable, data are included regarding differences by demographic characteristics.

Limiting provider choice

One defining characteristic of Original Medicare is unrestricted choice of any physician or hospital that accepts Medicare payment. The key decision before participants is whether to eliminate this freedom of choice and instead require everyone to use the network model. Of the 82% of participants that agreed to the network model, most included the flexibility of allowing the primary care provider to authorize out-of-network use. The remaining 17% chose to retain Medicare's current provider model. Cost was a major factor, since retaining the current Medicare benefit required nine more markers (of the 100 total) than the most restrictive network model.

Many participants noted that those under age 65 had grown accustomed to being in networks and anticipated that the next generation with Medicare may be even more amenable to receiving care this way. Some observed that with new emphasis on better coordination of medical services, unrestricted choice does not translate to better care for patients. They questioned the actions of some seniors who may use services indiscriminately or physicians who inflate their income with unnecessary prescribing.

"It's interesting that we want all the choice for beneficiaries to see any doctor they want but actually we as employees follow the network of our employers' plan. I don't feel like I'm under a hardship by having that."

"While I'm cool with relying on the research and what the research says, I want that doctor that I can trust. I don't want to be told what doctor I can go to and I don't want to be "allowed" by my doctor to maybe go see somebody outside…"

Such arguments were not persuasive for those who were staunch believers in unlimited provider choice. They feared the network approach would impose unacceptable restrictions on which doctors they could see and the type of care they would receive.

Participants' views were also captured via the pre/post survey questions regarding the actions they could support to reduce the impact of Medicare on the federal budget. Before the MedCHAT discussion, "requiring Medicare users to choose a specific provider network" was an option supported by 23% of participants. After MedCHAT, 34% supported this requirement (see Table 4, page 19). However, 82% of participants accepted a network model when it was presented as a trade-off for new Medicare benefits. Thus it appears that requiring use of provider networks was not as acceptable when the purpose was to reduce the federal cost burden. Nevertheless, this 11% absolute increase represents a meaningful change in participants' views.

The education level and age of participants made a difference in how they chose the provider option. Among participants with a high school education or less, 22% chose the current level of coverage compared to 11% of those with a four-year or graduate degree. The table below displays, by participant age range, acceptance of using provider networks as a requirement of Medicare. The younger age ranges were particularly accepting of the network approach, reinforcing the comments from the discussion groups that younger people have grown accustomed to the network model and would not be opposed to this change in Medicare.

"If you really want to pay for individual consumer ultimate choice, then it is going to be at the expense of some other things."

T A B L E 2 :	**Choice of physicians and hospitals: demographic differences by age in supporting various levels of coverage (n=779)**		
Age range of participants	**Tier 1:** *Must use a provider network*	**Tier 2:** *Must use provider network; outside referral possible via PCP*	**Tier 3:** *Unrestricted choice of provider (current under Original Medicare)*
• <= 39 years (n=121)	31%	62%	7%
• 40 – 64 years (n=339)	17%	70%	12%
• 65 – 80 years (n=251)	13%	60%	27%
• 81+ years (n=68)	12%	63%	25%

The relationship between age and acceptability of provider networks is statistically significant (p<0.05).

Reducing low-value care

"I mean, we know in medicine that nothing is really written in stone. So we are calling it now a low-value treatment. Who's to say?"

Value-based insurance design refers to determining coverage or cost-sharing rules according to the evidence of clinical effectiveness relative to the cost of the medical service. This concept is incorporated into four MedCHAT categories: Complex Chronic, Catastrophic Care, Routine Care and Final Phase. In all four categories, the choice for participants deals specifically with limiting coverage when care is low-value, e.g., when there is no evidence that treatment is effective or the effectiveness is minimal; when chances are unlikely that treatment will work; when treatment is more expensive but works no better than an alternative; or where benefit is minimal relative to cost. In each of the four categories, low-value care is currently covered by Medicare and participants could see the associated cost (number of markers) of covering it.

"I'm an engineer, I do numbers, I guess, and I'm a tight-wad. What still troubles me about this is how do we determine it's low-value and is it really done accurately? If it really can be done accurately then I clearly am supporting the tier 1 concept. If it's not accurate or if it's out of date, then that's troublesome and I don't know what the answer is."

Few participants were familiar with the meaning of value-based care, and many were surprised that Medicare pays for tests or treatments that met the definition of low-value. Though most had concerns about this current coverage, some were uneasy with the actions needed to curtail it. They were unsure about the accuracy of the research, the standards that constitute high-value care, and, most of all, worried that these coverage rules would over-ride a physician's judgment.

Interestingly, participants' views on reducing coverage of low-value care varied depending on the particular category under discussion. These differences are summarized below.

Complex Chronic

Complex Chronic is the one category that uses explicit language of high- and low-value care. Since this category also represents 33 of the 130 markers on the MedCHAT board, it elicited considerable discussion. Participants were well aware that this category applies to many seniors, yet by accepting limits to coverage of low-value care as many as 8 markers could be freed up for other uses. Consequently, only 11% of participants were willing to maintain Medicare's current coverage of both low- and high-value care.

Nevertheless, many were uncomfortable setting too strict standards for seniors to access low-value services. They felt it was unfair that the wealthy could afford whatever services they wanted, but average seniors would have to do without. Ultimately, most of those choosing to reduce coverage softened their decisions by choosing Tier 2. This required 50% co-pay for low-value care rather than no coverage at all.

Catastrophic Care

Unlike Complex Chronic, 53% of participants supported the current Medicare coverage that includes treatments that are not likely to work but are the only hope left. Many justified this choice because these patients were not chronically ill; rather, they were healthy but suddenly and unexpectedly felled by circumstances beyond their control. Many believed that Medicare should do everything possible for people in that situation. Though the chances of recovery may be slim, if treatment was successful, patients were more likely to return to a healthy, productive life than those with advanced illness (as in Complex Chronic). Taking a chance on a long-shot treatment seemed more appropriate in these situations.

Although it only required one marker to maintain this current Medicare coverage, a significant minority (47%) still preferred to eliminate coverage that had little or no hope for success. They used the same arguments as other value-based categories: if the odds of success were low, resources would be better spent elsewhere.

Routine Care

Like Catastrophic Care, this category was also closely divided with 52% supporting current Medicare coverage of low-value care and 47% rejecting it. Supporters showed a strong belief in preventive services, were skeptical about the research, and believed in the authority of the physician and patient to decide what was in the patient's best interest. Those opposed believed that eliminating coverage for low-value care was appropriate and necessary regardless of the type of medical problem. Some were familiar with the dangers of over-prescribing antibiotics or unnecessary screenings and they were especially outspoken (and sometimes persuasive).

Yet, it was a bigger stretch for many participants to forego Medicare's current coverage, because their perception was that routine screenings (and other forms of prevention) were always worth doing for individuals and for society. They also saw Routine Care, unlike the other categories, as affecting everyone on Medicare and that fact prompted greater leeway on coverage.

"So something that may be deemed "low-value" might in fact not be low-value. It just might not have won the horse race."

"Something like this is so catastrophic, I mean, if there's any chance at all to save someone, it's tough to say, 'No, I'm sorry we can't go for that.'"

"Well, if they've determined it's not going to be much benefit then why pull out all the stops? I think that's where costs get out of control and it may give peace of mind to the family member but for a national healthcare system it's not a sustainable perspective."

"If we're talking wellness then I think that it's important to cover our bases. I would agree if it weren't "Routine Care" but that's when you're usually at your healthiest. So, for me, I can't imagine all these tests being ordered for "Routine Care" unless there was a reason for it."

"Because I cannot imagine someone being in a situation where their loved one could possibly have their life extended and the only reason why the family chooses not to do it is because they can't afford it. I mean, would you want to do that to people?"

"No, it's not negating your [advance] directive! You've got to understand that. It's just saying that you're going to have to pay for it [ICU care]."

"I think it's too dramatic of a change, right now, to go from where we are (tier 3) down to 1. I think that maybe, eventually, we'll get to1 but for right now I would choose 2 because it would be a better transition for people to be able to accept that there's some finality to things and they would feel like they still had choices."

Final Phase

Like Complex Chronic, this category has considerable costs associated with current coverage of providing "last chance" treatments and ICU care for patients at the end of life. It is also a category where almost all participants had experience with loved ones. Consequently, almost two-thirds of participants wanted to reduce the coverage to only providing palliative care and hospice which they believed best served those near the end of life. They thought that offering the option of life-sustaining treatment and ICUs was a disservice to terminally-ill patients and their families.

Group discussions of Final Phase showed greater unanimity of viewpoint than any other category in MedCHAT. Even when participants saw that reducing current Medicare coverage meant taking final decisions away from patients/families (recognizing that by not paying for that type of care, Medicare was de facto restricting their ability to get it), this did not dissuade them. They believed that doctors who offer pointless treatments do their patients great harm, and at a time of emotional distress, families might make irrational decisions when they insist that "everything" be done.

In the 82 sessions, this was the only category where no group in round 3 opted to maintain the current Medicare coverage, and only 3% of all participants individually designated the current coverage in their last round of decisions.

The main debate within the groups was whether to support Tier 2 as a compromise; this meant that patients/families could opt for "last chance" treatment, but hospice, not the ICU, would be used when death was near. Some participants felt Tier 2 was a reasonable, politically-wise step towards a more responsible coverage policy. Others supported Tier 2 because they felt that it should be the patient and family making the decision about trying to extend life or not. Nevertheless, less than one-third included Tier 2 in their final Medicare plan.

Although very few participants argued for maintaining the current coverage, those who did were concerned about two issues: 1) since it is difficult to determine when a patient is terminally ill, some patients may have their lives shortened by removing the option of last-chance treatments; and 2) regardless of the hopelessness of treatments or of the possible suffering in the ICU, these decisions still belonged to patients/families and that Medicare should cover these costs.

"One of the problems that we have with the Medicare system is that so much money is spent on programs that have a snowball's chance in hell of doing anything and people want to cling on to this. And, I tell you, these programs where you get 1 in 100 that it has success, Medicare can't afford that."

"Researchers could be wrong in some cases. You know, it's the individual person that we're looking at and make sure that he or she receives proper treatment. The best way we can do it is through doctors."

Debating low-value care

A review of the discussions of these four categories suggests that the marker value played a role in groups' decisions of whether to cover low-value care. Both Catastrophic and Routine Care only require one marker to reach the current Medicare coverage; the other two categories are more expensive. It was not unusual in the round 3 discussions for participants to augment or reduce Catastrophic or Routine if they had an extra marker or needed one for another category; support for those two categories was more fluid than for Complex Chronic and Final Phase.

Across all discussions of low- and high-value care was the underlying theme of patient choice. For priority-setting that applied to all Medicare beneficiaries, participants wanted the best outcomes for the most people. But this was a struggle when that goal conflicted with their support for patients making their own treatment decisions. A common response was that individuals could choose to self-pay when Medicare would not. This reasoning was uncomfortable for others who noted that only wealthy people could maintain complete choice; others could not afford the low-value care even if they believed they needed it.

Demographic differences with low-value care

The level of support for maintaining Medicare coverage of low-value care varied according to some demographic characteristics. For all of the categories below, the association between the category and the demographic characteristics of interest was statistically significant at $p<0.05$.

In the **Complex Chronic** category, decisions varied depending on participants' profession, income level, ethnicity and education. Among those who identified as non-healthcare professionals, 14% wanted to retain coverage of low-value care in Complex Chronic compared to 7% of healthcare professionals. Regarding ethnicity, 23% of African-Americans chose to keep full coverage versus 7% of Caucasians. Among those who self-identified as lower/lower-middle income, nearly 20% chose to maintain full coverage compared to 6% of upper-middle/upper income participants. These same percentages pertained to those of lower and higher education levels.

With **Catastrophic Care**, differences were evident with age and ethnicity. Among those under age 40, 65% chose to maintain full coverage, compared to about half of participants aged 40 and over. Variation was also seen in racial and ethnic demographics: 65% of Hispanic participants chose full coverage as compared to 59% of African-American and 49% of Caucasian participants.

In **Routine Care**, age, profession and specific ethnic groups showed some differences. Fifty-three percent of those aged 40 – 64 chose to maintain the current level of coverage compared to 41% of participants under age 40. Among non-healthcare professionals, 59% chose the current coverage compared to 41% of healthcare professionals. Sixty-one percent of Asian participants chose the current level, as did 51% of African-Americans and 44% of Caucasian participants.

In **Final Phase**, 10% of African-American participants chose to maintain the current coverage of intensive healthcare services at the end of life, compared to the 2% of other ethnic/racial groups. Of those who reported having higher incomes, less than 1% chose to maintain the current coverage level.

Adding new benefits

Participants were presented with several categories where coverage could be improved or new benefits added to Original Medicare. The majority of participants opted to include all of them.

Long Term Care

Discussion about reducing coverage in Final Phase was almost matched in intensity by the discussion on adding long-term care coverage. Most participants (77%) chose to add one year of LTC coverage with a 10% co-insurance. Though they often preferred a three-year benefit, few could afford the required number of markers.

Many came to this decision through their own experience with family members or friends, as well as a general understanding of the demographics of the baby boomers, increased longevity and prevalence of dementia. Those knowledgeable about Medi-Cal debated if it would be preferable to transfer this obligation from the state to the federal government. They often noted that with reductions made in other MedCHAT categories (in particular Providers, Complex Chronic and Final Phase), a re-designed Medicare could afford to add a LTC benefit. Most important, they believed it was the "right thing to do" and were gratified to see that the LTC benefit included home-based care, not just care in a skilled nursing facility.

Not everyone agreed. Some participants opposed the addition of LTC because they believed that people had an obligation to save for the future and not expect others to take care of them. They also worried that this new benefit would soon be out of control, costing the government far more than it intended.

Dental, Vision and Hearing

These services are presented as one category across two tiers of coverage. Eighty-five percent of participants included all three services and another 10% included dental coverage only. Participants were most supportive of dental coverage with many comments on how good dental care helps to maintain personal dignity and quality of life, with a strong link to general health status. They believed all three services are integral to a person's well-being and ability to stay connected with the world around them, preserving their independence and preventing the isolation that can come with old age.

Those who objected to these new coverage categories felt that these services were affordable outside of Medicare; were not medical issues; and that the markers were needed for more important categories. Yet one participant pragmatically noted, *"If we're going to stop paying for all those low-value treatments, we'd better have something that seniors are going to want."*

"And so, for me, I think we have to address long term care. I think that we're putting our head in the sand if we're not addressing it."

"So I think it's really hard to pay for and it may require discussion about other categories but I think it's a really important benefit that makes a big difference to the people that need it."

"I thought tier 2 [one year LTC coverage] would give the family a little time to kind of get organized and get things settled and then, you know, find a place…"

"I think other things are more critical. I think this is when family members have to step in and help financially or bring a parent into a home and care for them in their own home."

"I know we're not supposed to think badly of Medicare but they don't help the mentally ill people and in everybody's lifetime we hit it sometime especially as we get older; you lose your spouse or you lose your job or you're by yourself or you have depression."

Mental Health

The 69% that augmented this category were adding long-term coverage for treatment of less severe mental health problems with a lower co-insurance than the current. Those who work in senior services or in healthcare were especially supportive. They regarded Mental Health as under-funded and under-utilized. Many expressed that even the augmented benefit seemed insufficient to meet the need, believing many seniors are affected by mild depression, anxiety and other mental health issues that keep them isolated from family and community and in poorer physical health.

Those opposed to expanding the current benefit were concerned that treatment for less severe problems might become a greater financial burden on Medicare than was intended. Some worried that the vagueness of "less severe" would expose Medicare and seniors to fraudulent providers and general abuse of the system.

Transportation

Except for ambulances, Medicare does not currently cover transportation services for medical reasons. A significant majority of participants (81%) felt that a transportation benefit would help those seniors without support networks keep medical appointments that were necessary for maintaining their health. They saw this as fiscally wise: helping seniors get to the doctor would keep them out of hospitals. Like dental, vision and hearing, maintaining independence required providing services where help was most needed.

Those who opposed this additional benefit believed that individuals should rely on friends, family and community services for this need. Some also felt that transportation services did not equate to a medical need and therefore should not be covered by Medicare.

Addressing specific social values

Emphasizing personal responsibility

Taking personal responsibility for maintaining one's health is often discussed in the healthcare reform arena. Although Original Medicare does not do so, employers and private insurers are experimenting with rewards and/or penalties to motivate people to take appropriate actions that are shown to improve health status and lower costs. To gauge the public's response, MedCHAT used the Early Chronic category for proposing the use of incentives to encourage patient compliance with medical management.

"There are people that don't take care of themselves but they're all part of our risk pool and if we want to bring them along and make them more healthy then I think incentives are better than sticks."

Eighty-five percent of participants included in their Medicare plan a mechanism for incorporating rewards and penalties. Most of the group discussions centered on which approach, penalties or rewards, would be more effective in encouraging compliance. Some objected to the idea of rewarding people for doing what they should be doing anyway. Others preferred a tier that only provides rewards (it was not available with MedCHAT), but chose the penalty/reward option because they believed it was better than doing nothing. Over all, there was strong sentiment that people needed to be more accountable for their health, especially since everyone else was helping to "pay the bills." Others believed this was too much intrusion into people's lives.

"I don't believe in penalizing people because I think that it disproportion-ately [punishes] the people who are most vulnerable."

A vocal minority of participants were uneasy about using penalties or rewards. They worried that many seniors were faced with obstacles in their lives, especially economic ones, and instituting any more financial barriers than they already had simply would make them less compliant, less healthy and less likely to use the healthcare system that they needed.

"I don't think we're here to take care of our brothers. I don't think it's any of our business whether you smoke or eat too much or drink too much or drive a car, which is the most dangerous thing you do in your whole life. We don't keep them from getting in their cars. I think it's totally inappropriate."

Having higher-income seniors pay more

The Premium category pertains to the monthly amount that seniors pay for their Part B coverage. The size of the premium currently increases according to an individual's monthly income, from $105/mo. for those earning under $85,000 per year to up to $336 for those earning more than $214,000. Since the vast majority of seniors pay the lowest premium amount, this MedCHAT category did not have many markers at stake.

"We're talking about the general population. We want to focus on that. Because 99% of the people would not be able to [pay more]. But the 1% or 2%, it would not really hurt them to pay a couple of hundred dollars for care because they have so much more money."

Nevertheless, 79% of participants believed it would be appropriate to charge higher-income seniors more than they now pay. Most of the participants (60%) would raise the rates for those at and above the $85K/yr. income level, and 19% applied an increase to those earning as low as $50K/yr. This was not a very controversial category and there were few heated debates over whether the current arrangement was fair enough.

Reducing Medicare spending

With concern about the long-term financial health of Medicare, MedCHAT is structured to assess whether participants were willing to reduce Medicare expenditures now in order to provide some financial stability for the future. The category Pay for Medicare gives participants the option to contribute eight of their 100 markers to relieve the financial worries for 50 years; eleven markers brought 75 years. Eighty-five percent of participants contributed their markers, with the vast majority opting for the 50 years.

Participants often responded to this in terms of meeting the future needs of their children and grandchildren. There were remarkably few comments about their own entitlement to all the "markers" they were owed. While there was cynicism about government, in general they did not openly blame government for letting the spending get out of hand. Much of the discussion was on deciding what level to fund (50 vs. 75 years), not on whether to do so. The dominant choice of 50 years was not only because it was a less expensive option; participants offered pragmatic reasons why 75 years is unnecessary (see comments on the left).

Yet most groups also had participants arguing against this approach to bailing out Medicare. They saw so much waste in health care or in other government programs that they didn't think it was necessary for current seniors to make this sacrifice.

"So the question is should we sell out the next generation?"

"In 50 years…we'll have fewer people going into Medicare 'cause you've done away with the Baby Boomers."

"Don't forget there will be other voting groups. I mean, in 20 years it's going to be a whole different group of people voting and they'll change whatever we have decided."

"Because 50 years from now that should be enough for us to try to take care of. I think 75 should take care of its own self."

"I just don't think that we should be using 8 markers to save for the future when it's already a restricted budget. I don't know, I just feel like there are other ways that the federal government could… reallocate funding."

"We shouldn't be contributing ANY of our markers towards the extension of Medicare. Where the extension of Medicare should come from is from big pharma and the device companies and the hospitals."

ATTITUDES AND BELIEFS

Participants completed several pre- and post-CHAT survey questions to see if their views changed over the course of the session. Other post-CHAT questions assessed their reactions to the MedCHAT process. Below are results that reflect two content areas: views on Medicare reform and the impact of MedCHAT as a deliberative process. As noted previously, the number of responders often varied because participants could choose to skip questions.

Views on Medicare reform

As shown in Table 3, there was a meaningful increase — from 54% to 75% — in the belief that Medicare needs significant changes but not a complete overhaul.

TABLE 3:   Participant's views on changing Medicare
"There is a concern that this county cannot afford today's Medicare program without some changes. What is your view about this?"

Possible Responses	Pre-CHAT (n=791)	Post-CHAT (n=771)
• Medicare needs a total overhaul	9%	10%
• It needs some significant changes, but not a complete overhaul	54%	75%
• It needs some minor changes	17%	11%
• It does not need to be changed	2%	2%
• Not sure	19%	2%

After completing MedCHAT, participants also re-visited a question on specific ways to reduce the impact of Medicare on the federal budget. Most of the options shown on Table 4 were ones they had discussed as part of their MedCHAT coverage decisions (e.g., requiring use of provider networks). We looked at whether participants changed their minds about any of the options they had discussed and if those changes were consistent with their round 4 MedCHAT choices.

T A B L E 4 :   **Views on ideas for reducing impact on federal budget**
"There are a variety of ideas for reducing the impact of Medicare on the federal budget. Of those listed below, check any that you might support."

Possible Responses	Pre-CHAT (n=802)	Post-CHAT (n=780)
• Have wealthier Medicare users pay more	48%	62%
• Require Medicare users to choose specific networks of doctors and hospitals	23%	34%
• Reduce coverage for ineffective treatments	46%	65%
• Do not cover expensive treatments if less costly ones are just as good	49%	64%
• Charge patients more if they don't adopt healthier lifestyles	29%	50%
• Require patients to use hospice when dying, not ICUs	30%	59%
• Lower the amount that Medicare pays doctors	13%	14%
• I do not support any of these	10%	2%

The first six options were topics that were integral to the MedCHAT categories, and there was a significant increase in support from pre- to post-CHAT, consistent with their coverage decisions in round 4. While these pre/post changes were meaningful, the post-CHAT level of support was not as great as that shown in round 4. For example, the two responses in Table 4 that dealt with low-value care (reduce coverage for ineffective treatments and do not cover expensive treatments if less costly treatments are just as good) were supported post-CHAT by 65 and 64%, respectively, increased from pre-CHAT figures of 46 and 49%. Yet in round 4, 88% of participants supported higher cost-sharing for low-value care in the Complex Chronic category.

We interpret this difference (65% versus 88%) as a reflection of participants' motivation: seeking greater fiscal stability for Medicare was important but not as compelling as being able to create a better benefits package (the goal in round 4). Despite these differences, the significant pre/post changes suggest that the MedCHAT process had a meaningful impact on participants' views about these cost-containment strategies.

The seventh response — lower the amount that Medicare pays doctors — did not change from pre- to post. This was the one option that was not discussed as part of the MedCHAT process.

Demographic differences

Responses to Table 4 post-CHAT questions show that participants' income levels were a statistically significant factor in most of the options (p < 0.05). While 25% of participants who self-reported as lower/lower-middle income indicated that they might support use of provider networks, 39% of those who reported middle and upper incomes did so. The majority of participants in all income categories supported reducing coverage for ineffective treatments, but 54% of those in the lower income ranges chose that option versus 77% of those in the higher income ranges. These were the same percentages for the option of "not covering expensive treatments when less costly options were available." Financial penalties for patients who do not adopt healthier lifestyles were least acceptable (36%) to participants in the lower income ranges, compared to 59% of people who reported upper income. Finally, persons who reported lower income were evenly split in regards to reducing ICU services at the end of life, while 72% of persons of upper income ranges chose to restrict that coverage. Analysis by education levels closely paralleled income levels.

Based on these responses, it appears that those of lower income or education levels had greater reservations about requiring provider networks, reducing coverage of low-value care, the use of financial penalties, and restricting the use of ICUs at the end of life compared with participants in higher income and education levels. Nevertheless, these demographic differences did not show this same degree of variation in participants' round 4 choices where the trade-offs (improved benefits) were more tangible.

Impact of the deliberation process

In addition to assessing participants' convictions about strategies to sustain Medicare, post-CHAT questions also helped determine if the MedCHAT process was effective as a tool for public deliberation. As described in the Introduction, deliberation offers a depth of engagement not found in traditional focus groups or surveys. Various MedCHAT questions probed how participants responded to the process and what they found most beneficial.

Table 5 shows participants' responses to the group decisions made in round 3 when all participants had to come to agreement (often by having to vote on various categories) on what Medicare should cover.

T A B L E 5 :	Satisfaction with the group's changes to Medicare
	"If this process today had been real, would you be willing to accept the group's coverage decisions in Round 3?" (n=767)

Possible Responses	Percentages
• Yes, definitely	26%
• Yes, probably	61%
• Probably not	10%
• Definitely not	1%
• Not sure	2%

"Do we get the prize for the best plan in the nation?"

Given the significant Medicare changes that were proposed in most of the round 3 sessions, the 87% that indicated yes probably/definitely for accepting those decisions is a strong indication that participants felt that the results were a reflection of their priorities. While consensus is usually not a goal of deliberation, accepting the trade-offs at stake shows an understanding about compromise and social decision-making that are characteristics of deliberation.

A deliberative process also has certain features that can distinguish it from other forms of public input. Table 6 shows what participants valued most in the MedCHAT process. While there was fairly even distribution of their responses, the top choices — having a chance to think about what is important and discussing our choices as a group — are distinctive components of a deliberative process.

T A B L E 6 :	Most worthwhile aspect of MedCHAT
	"Which aspect of MedCHAT did you find most worthwhile?" (choose only one) (n=770)

Possible Responses	Percentages
• Having a chance to think about what is important	25%
• Discussing our choices as a group	25%
• Learning details about Medicare coverage	19%
• Hearing what others think	16%
• Knowing our opinion will be shared with policy leaders	15%

Another feature of successful deliberation is its potential to have an impact on participants beyond the session. The final questions in Tables 7 and 8 were to gauge the effect of MedCHAT on their knowledge now and, perhaps, their thinking about Medicare in the future.

T A B L E 7 :	**Impact of MedCHAT on knowledge**
	"Has MedCHAT improved your knowledge about Medicare coverage?" (n=766)

Possible Responses	Percentages
• Yes, I now understand a lot more than I did	51%
• Yes, I now understand somewhat more	34%
• Yes, now I understand a little more	10%
• No, it has not improved my knowledge	5%

T A B L E 8 :	**Over-all impact of MedCHAT**
	"Which statement most closely represents your view about participating in MedCHAT today?" (n=770)

Possible Responses	Percentages
• This will make a difference in the way I consider Medicare	44%
• It's given me something to think about	50%
• No new information, but it was enjoyable	4%
• It was not a good use of my time	2%

Participants also commented in an open-ended question on what they valued with MedCHAT. Typical responses:

- It made me think about what is important to me vis-a-vis thinking about the cost.
- Working through the sticky issues in a group setting.
- Being challenged by the difficult questions about individual v. national health needs/solutions.
- Talking it over with other people who have different opinions than my own.
- Hearing other arguments (especially those that differed from mine) on the way money should be spent.
- Listening to people and having people listen to me.
- There were so many other viewpoints that made sense after hearing other perspectives
- Opened my eyes more to the hard choices and compromises to be made.

IMPLICATIONS

If Medicare reflected the discussions and decisions of the majority of California MedCHAT participants, it would have these features:

1. All beneficiaries would choose a network of physicians and hospitals to provide their medical needs. They would have more than one network to choose from; the networks would have sufficient numbers of physicians and hospitals to access local, high quality providers. In some situations, a referral outside the network would be covered with approval of the primary care provider.

2. Medical services would be covered that meet established criteria for high-value care. If patients or physicians want services — tests, treatments, procedures, devices, etc. — that research has found to be low-value for chronic conditions, patients would pay half the cost. There would be greater coverage flexibility for low-value preventive and routine care and for services pertaining to catastrophic situations.

3. Medicare would now include a modest long-term care benefit. As an individual's frailty and dependence increases, this benefit would cover most of the cost of in-home services or other community living arrangements for one year.

4. New Medicare benefits would contribute to better quality of life and independence, such as dental care, vision, hearing and transportation for medical visits, as well as more coverage for common mental health problems.

5. Medicare would provide palliative and hospice care for those in the final phase of life. If patients or families wanted life-sustaining interventions that had little hope for a meaningful benefit, they would pay for those services themselves. Additionally, spending the last days or weeks in the ICU would not be covered by Medicare unless essential for symptom relief.

6. Strategies would promote the personal responsibility of individuals to stay healthy and comply with medical recommendations that help avoid complications in health status. Rewards and penalties would be used judiciously and effectively.

7. The formula for determining Medicare premiums based on income would be restructured to increase the financial obligation of upper-income seniors.

8. The resources saved by establishing this new version of Medicare would be used to strengthen the long-term solvency of the program.

While this model differs considerably from Original Medicare, several of these features are topics in today's healthcare policy discussions.

Requiring the use of provider networks

Unrestricted choice of provider, a hallmark of Original Medicare, is based on a fee-for-service payment system. As the cost of health care has increased, healthcare systems have changed, and in the private insurance market, traditional fee-for-service indemnity plans are now rare. Preferred Provider Organizations (PPOs) are now the option for those who want the greatest flexibility. This new norm likely contributes to California MedCHAT participants offering relatively little push-back to the option of having Medicare only offer provider networks. The reaction might be quite different if MedCHAT were conducted in states where discrete provider networks and integrated healthcare systems are not as prevalent.

In recent years, national policy analysts have also become more concerned about fee-for-service medicine rewarding volume of services, rather than value. Increasingly, higher costs, poorer quality and greater inefficiencies are associated with providers who are paid to deliver more services, rather than paid to deliver higher quality care.[3] A recent report to The White House from The President's Council of Advisors on Science and Technology notes that "the primary barrier to greater use of systems methods and tools is the predominant fee-for-service payment system, which is a major disincentive to more efficient care."[4]

The majority of MedCHAT participants were willing to accept the network approach, but they did so knowing that the quid pro quo was additional Medicare benefits. Medicare Advantage plans are examples of the network approach, but they currently are optional, not required. If the government moves towards a network model, policymakers must involve Medicare beneficiaries in discussions on ways to assure sufficient provider choice and quality.

Using value as a basis for coverage

"I don't like the idea that these decisions are made by some group of people somewhere, but on the other hand I think that in many instances [researchers] can be a little more objective than your personal doctor who's trying to keep you happy."

Most value-based insurance design in the private sector has concentrated on high-value interventions: encouraging the use of services proven to be beneficial for patients relative to costs by reducing or eliminating patient cost-sharing.[5] Attention to low-value care also is strong, reinforced by an Institute of Medicine report, which states that at least 30% of all medical care is wasteful.[6] In the first national effort to reduce low-value care, the Choosing Wisely campaign is supported by dozens of medical associations, alerting physicians and consumers to medical care that is ineffective and unnecessary.[7] Some research, however, suggests that simply listing low-value services is insufficient and proposes "testing of approaches to reduce their use, ideally through a combination of benefit design, physician payment policies, and social and professional guidance."[8]

MedCHAT participants demonstrated their interest in reducing low-value care through benefit design by limiting Complex Chronic to Tier 2, where patients would pay half the cost of a low-value service. This sacrifice was not made in a vacuum; they limited coverage with the expectation that they could use those Medicare dollars for something "better."

They also identified some of the difficult issues that make differentiating low from high value care so controversial: Who determines if the medical treatment is good enough? What happens when research results change over time? Isn't the individual doctor the one most qualified to decide if someone needs a certain test or treatment?

Among the various choices made by MedCHAT participants, putting teeth into a process for reducing low-value care may be the most challenging of this new model. Currently, most programs that limit coverage of low-value care are used within Medicaid.[9] In developing a model for Medicare, it may be more applicable to consider the experience of private or public sector employees. For example, the Washington State Health Care Authority has a Health Technology Assessment process in place to make determinations about the effectiveness and value of new technologies.[10] Those that are not approved by the expert panel are not covered by health plans that serve various state agencies. In Oregon, two public employee benefits boards have adopted a process of higher co-payments for overused or preference-sensitive services of low relative value.[11]

Even with reputable models to consider, the topic of low-value care is far from settled. While MedCHAT participants made well-reasoned decisions about their priorities, this subject is rife with conflicts about standards of evidence, degrees of effectiveness, and professional authority. Far more needs to be explored with the public on identifying the principles for defining and steps for reducing low-value care.

Changing end-of-life care

"I think we're using an awful lot of resources on tier 3 which we shouldn't be. We're encouraging people to try things which are not effective and prolonging their lives with low quality and I think we ought to cut that off."

Although tremendous efforts have been made in the past 20 years to promote advance care planning, palliative care and hospice, evidence suggests that what is being delivered is still not commensurate with what individuals say they want.[12]

Unique to this category was the passion participants brought to changing end-of-life care through coverage policy. Although the public believes that individuals have a right to make their own healthcare decisions, they do not believe that society is always obligated to pay for those decisions. Participants mused about "death panels" and the controversy that limiting this coverage would raise. Yet at the end of the sessions a near unanimous 97% of participants would not cover ICU care for dying patients. They made these decisions with the assumption that all the services associated with high quality end-of-life care — pain control, supportive services at home, a focus on quality of life — would be available and accessible.

"I'm just saying we got away from "Final Phase" tier 3 and we're going to take that money and use it some place for quality of life rather than keep giving them open ended choices until they're 97."

"I think that if Medicare is not covering these treatments, it's going to force us as a nation to realistically face the issue of death and dying. We need to be doing that."

Despite participants' strong convictions, there are few existing models on which to base this change in policy. One health plan (possibly the only one) that explicitly denies coverage for unwarranted end-of-life treatment is the Oregon Health Plan that serves Medicaid members. OHP coverage is based on lists of conditions/treatments, ranked in order of their evidence of effectiveness, congruence with social values and other factors.[13] Depending on the state budget, the higher the condition/treatment pairs are on the list, the more likely they are covered. OHP covers palliative care and includes in its guidelines this statement:

> *Treatment with intent to prolong survival is not a covered service for patients who have progressive metastatic cancer with: 1. severe co-morbidities unrelated to the cancer that result in significant impairment in two or more major organ systems… OR, 2. a continued decline in spite of best available therapy.*[14]

Similar to the discussion earlier about putting teeth into denying coverage of low-value care, end-of-life care raises the same issue: that it may not be enough to educate doctors and patients about the virtues of palliative care and hospice. Participants recognized that the pressures to over-treat are many and that the most effective way to reduce inappropriate care would be for Medicare to stop paying for it. This is reinforced by the nature of the CHAT process, where participants see how those saved resources can be used in ways they regard as more beneficial to patients and society.

Adding a long-term care benefit

For many years, healthcare and senior service leaders have sought new approaches for providing long-term services and supports (LTSS) for those with severe cognitive and physical limitations. Many efforts have not come to fruition, such as when the CLASS Act (Community Living Assistance Services and Supports) was not deemed financially viable under the Affordable Care Act. The extraordinary cost of LTSS, the number of Medicare beneficiaries who need these services, and the challenges of private financing are well-known. Given the financial status of Medicare, however, the odds of adding this as a new benefit seem long.

Last year, a Commission on Long-Term Care was convened to report to Congress the state of LTSS with specific recommendations to improve access to services. Although the Commission did not recommend adding LTSS to Medicare per se, it listed in the report an "alternative approach" to a limited LTSS benefit within Medicare.[15] Interestingly, this model was remarkably close to the intent of MedCHAT participants' decision to include one year of LTC coverage. Like the Commission's model, participants could not financially justify a more extensive benefit, and many felt that patients/families have some responsibility to help finance or provide this care. But participants recognized that average families cannot handle this financial burden without assistance.

While the Commission offered suggestions for public funding of this limited benefit, MedCHAT participants felt that they could "afford" this new benefit by modifying existing Medicare benefits — in particular, by requiring use of provider networks and/or by reducing coverage of low-value care.

The suggestion that Medicare dollars are not being spent in ways that frail seniors would want was expressed clearly by Dr. Joanne Lynn, a long-time advocate for seniors. In a 2012 JAMA article she writes, "Medicare's open-ended entitlement to medical interventions contrasts with the limited and often inadequate safety-net programs to support personal needs, and this mismatch complicates development of a coherent and efficient service delivery system."[16]

One option would be a voluntary approach suggested by Dr. Arnold Milstein during an interview several years ago.[17] Dr. Milstein, Director of the Clinical Excellence Research Center at Stanford University and a respected thought-leader in healthcare policy, proposed that when people sign up for Medicare, they be offered the following option: "if I fall below a pre-defined level of functioning despite best medical efforts over at least 3 months and I am no longer able to care for myself due to severe mental or physical impairment, I will waive further inpatient hospital care in exchange for an expanded Medicare benefit that will (a) provide me with ongoing supportive and skilled services that allow me to remain in my home as long as possible, and (b) provide more personalized and individual companionship and care if institutional care is needed."

Dr. Milstein brands this as a "TLC option" that seniors could elect when they enroll in Medicare. In trade for the enhanced benefit, once they remain at the pre-defined level of functioning for 3 months despite best medical efforts, they would waive all inpatient care. He proposes that the pre-defined level of functioning be calibrated by Congress to be either budget-neutral or budget-favorable for federal and state governments. He believes that the advantages to beneficiaries of offering this option would outweigh its disadvantages such as subsequent regret among those whose preferences change as the aging process unfolds.

This model closely mirrors the trade-offs proposed by MedCHAT participants: to forego coverage of intensive medical interventions near the end of life in exchange for a reasonable LTC benefit.

Balancing competing priorities

Eight hundred California residents — a mix of seniors, younger adults, senior services and healthcare professionals — do not represent the country. It is entirely possible that 800 Iowans, Texans or New Yorkers would re-design Medicare with different priorities and other features that should be retained, added and eliminated. Regardless of where these discussions occur, at the heart of the task — how to distribute Medicare resources to best serve its beneficiaries — lie a number of social values that need to be reconciled, such as:

- Preserving patient choice while stressing the communal good
- Supporting physician authority while committing to evidence-based practice
- Reinforcing individual responsibility while establishing safeguards for those at risk
- Allocating resources for medical needs while helping seniors maintain their highest level of functioning and quality of life.

None are necessarily conflicting, but each represents values that compete for priority. MedCHAT fosters these values-based discussions, because its structure does not allow for open-ended wish-lists: it requires decisions within the limits of a specific budget. An individual cannot simply argue for adding LTC without suggesting what would have to be sacrificed as a result. In discussing these trade-offs, individuals discover where their own values lie and how far they are willing to go to put those values into action. Participants also recognize (through exercises like the health event lottery) that individual patients may not tolerate coverage limits with the same equanimity as they demonstrate when making societal decisions. That is the invaluable attribute of CHAT: the realization that coverage decisions apply to everyone, including "the future me."

Including the public's voice

"But I think that's what this is all about; making some decisions and seeing what plan we can come up with. And whenever you devise something that's new or different then you add, you change, you delete."

Bringing the public's voice to the Medicare debate is not easy. National policy discussions about changing Medicare are often highly politicized, and consumer surveys are quite narrow in scope and offer little opportunity to probe individuals' thinking. In contrast, deliberative methods like MedCHAT provide opportunities for individuals to wear their "citizen hat" and wrestle with some of the conflicting priorities faced by policymakers.

Overwhelmingly, MedCHAT participants valued their contribution to the Medicare debate and brought perspectives that reflected a thoughtful balancing of core values. Most participants volunteered their time for MedCHAT, demonstrating that the public is both willing and able to be active players in the world of healthcare policy. Changes in Medicare are inevitable; asking the public to help resolve complex issues is necessary in a fully functioning democracy. We hope that California's experience will prompt other states to ask their own residents to join in.

PROJECT LIMITATIONS

1. **The complexity of Medicare required limiting the options for discussion.** Medicare is a complicated benefits package. To create a coherent 3-hour simulation exercise, we could not include all possible ways to "re-design" the program. Although we aimed for aspects that were particularly important in contemporary policy discussions, others (such as improving Medicare solvency by increasing the Medicare payroll tax) were not included. Other components of Medicare, e.g., Medicare Advantage plans or Part D coverage, were not part of the discussion because the volume of detail would have been too much for the general public to absorb. The results, then, must be viewed with full recognition that other MedCHAT options would have generated additional findings.

2. **Designing categories around needs, not services, is less precise.** The CHAT® software allows complete flexibility in how benefits are described. In deciding to include such descriptive categories as Complex Chronic, Catastrophic and Routine Care, we created categories with somewhat indistinct boundaries. As a result, our actuarial consultant Milliman could not guarantee the same level of precision for their monetary value that the standard categories used by health plans have. Since participants were influenced by the number of markers available, small errors in cost assignment might have affected participants' choices.

3. **This report does not address ways to implement changes.** Virtually all changes in healthcare coverage, financing and service delivery have complex political, professional and organizational obstacles. MedCHAT's intention was to consider significant aspects of coverage changes at a conceptual policy level, but the implementation of these changes was outside the scope of this project.

4. **Relying on volunteer participants skewed the representation.** With few exceptions, MedCHAT session sponsors recruited participants from within their work sites, from among their constituents and from the community groups they know. Hence, participants were mainly self-selected, as evidenced by the higher-than-average educational levels. Consequently, the demographics are not fully representative of the state at large.

5. **MedCHAT re-design focused on seniors but not on the disabled.** The needs and preferences of the disabled population are likely distinct from that of seniors, and it is expected that their views about coverage would be different. With more time and resources, MedCHAT would have targeted this subset of the Medicare population and compared how their needs differed from those of seniors.

6. **MedCHAT participants were all Californians, not a national sampling.** As a national issue, Medicare policy would be best informed with deliberative input from a broad spectrum of the American public.

ENDNOTES

1   There are many references to using public deliberation in healthcare policy. The Institute of Medicine devoted a chapter to it in its 2012 report: Essential Health Benefits: Balancing Coverage and Costs. See chapter 6 on Public Deliberation at http://www.nap.edu/openbook.php?record id=13234&page=103

2   For more information about using CHAT®, see http://www.usechat.org/console/CHAT-resources/

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17 This interview was conducted by CHCD in 2010 on behalf of the Alzheimer's Association and its development of a 10-year plan for California. Dr. Milstein was responding as a key informant to the question "what should be done to meet the financial needs of Alzheimer's Disease patients and their caregivers?"

APPENDIX A:

MedCHAT Categories, Tiers and Final Decisions

Below are descriptions of the MedCHAT categories and tiers, as well as the % of the 781 individuals that chose each tier in round 4. At the end of each tier description is the number of markers required to choose that tier; where "current" is written indicates the tier that Medicare now covers.

Categories	% that selected each tier	Descriptions of tiers and the markers required
• **Catastrophic** Treatment of unexpected, severe injury or illness. Examples: a fast, deadly form of cancer; massive injuries from an accident; a sudden irreversible stroke.	1%	No Coverage
	46%	**Tier 1** — All emergency remedies are covered to try to save the person's life. However, even if the doctor orders it, treatments are not covered if the benefit is minimal or if it has only a small chance of working. In that case, supportive care is covered. (4 markers)
	53%	**Tier 2** — If the customary treatments do not work and if the doctor orders it, Medicare also covers treatment where the benefit is minimal or has only a small chance of working. (*Current;* 5 markers)
• **Complex Chronic** Treatments for long term conditions (diabetes, heart failure, lung disease, etc.) that need ongoing medical care. Coverage may require that treatments are proven effective AND least costly (called HIGH-value care).	1%	No Coverage
	34%	**Tier 1** — Low-value care is not covered. Example: even if the doctor suggests a certain heart treatment, if research shows that the likelihood of benefit is very small, patient pays the full cost of $10,000. (25 markers)
	54%	**Tier 2** — Low value care is partially covered. Example: Even if the doctor suggests a certain heart treatment, if research shows that the likelihood of benefit is very small, patient pays half of the cost of $5,000. (30 markers)
	11%	**Tier 3** — If the doctor orders it, Medicare covers it even if the likelihood of benefit is very small and the cost is high. Thus, patient pays the same co-insurance whether it is HIGH-value or LOW-value care. (*Current;* 33 markers)
• **Dental, Vision, Hearing** For preventing and treating dental problems. May also include testing and correcting for vision and hearing.	5%	No Coverage *(Current)*
	10%	**Tier 1** — Dental care only. Covers cleanings and x-rays yearly plus dental services such as oral surgery, crowns, bridges, dentures. Maximum coverage is $1,500 yr. (2 markers)
	85%	**Tier 2** — Besides dental, also covers vision (refractions) and hearing test once a year, if needed. Covers glasses prescription and $250 of the cost of frames; covers $1,000 towards the cost of a hearing aid. (3 markers)

(continued)

APPENDIX A:	MedCHAT Categories, Tiers and Final Decisions

Categories	% that selected each tier	Descriptions of tiers and the markers required
• Early Chronic High blood pressure, diabetes, obesity and other conditions when newly diagnosed. These can become very serious; patient self-care is needed to prevent worsening. In each tier, all necessary medical care is covered.	1%	No Coverage
	37%	**Tier 1** — Care coordinators will teach patients how to control their condition. If patients do not follow medical advice, some co-payments will be higher than the usual Medicare rates. (17 markers)
	48%	**Tier 2** — Same as tier 1. If patients do not follow medical advice, some of their co-payments will be higher. But if patients do comply, their co-payments will be lower than the usual Medicare rates. (20 markers)
	14%	**Tier 3** — Care coordinators may be available; if so, patients are encouraged but not required to use them. There are no penalties or rewards for patients following medical advice. (***Current;*** 21 markers)
• Final Phase For those with long-standing incurable illness who are growing more frail and inactive. This is common in the last year of life. Patients may be in the hospital frequently as their illnesses worsen.	1%	No Coverage
	65%	**Tier 1** — Care Management is provided for supportive services and palliative care to manage medical flare-ups, control pain and improve quality of life. Attempts to extend life, like surgery, are not provided. When death is near, patient is in hospice, not ICU. (5 markers)
	31%	**Tier 2** — Care Management, like tier 1, is provided if patients want it. Other attempts to extend life, such as surgery, are offered even if there is little chance they will help. When death is near, patient is in hospice, not ICU. (8 markers)
	3%	**Tier 3** — Same as Tier 2. When actively dying, patient can choose any services available from palliative care and hospice to hospital intensive care, CPR, and breathing machines. (***Current;*** 12 markers)
• Long Term Care (LTC) Medical and non-medical care (such as assistance with dressing, bathing and using the bathroom) for people who have chronic physical or mental impairment and require services or support on a long-term basis.	<1%	No Coverage
	23%	**Tier 1** — Although no LTC is covered, does cover the first 100 days in a skilled nursing facility if services needed for short-term rehab after hospital care. There is a daily copayment after day 20. (***Current;*** 5 markers)
	62%	**Tier 2** — Besides Tier 1, LTC is covered in a nursing home, supportive housing or the person's home for up to 1 year with 10% co-insurance. (12 markers)
	15%	**Tier 3** — Besides Tier 1, LTC is covered in a nursing home, supportive housing or the person's home for up to 3 years with 10% co-insurance. (20 markers)

(continued)

A P P E N D I X A:	MedCHAT Categories, Tiers and Final Decisions

Categories	% that selected each tier	Descriptions of tiers and the markers required
• **Mental Health** For detecting and treating mental illness and improving mental health.	2%	No Coverage
	29%	**Tier 1** — Covers clinic therapy, medicines for severe mental illness, such as bipolar disease; also hospital stay up to 190 days lifetime. Covers short term counseling, medicines for less severe problems like mild depression with 45% co-insurance. (***Current;*** 2 markers)
	69%	**Tier 2** — Besides Tier 1, also includes long-term counseling for less severe mental health problems. 20% co-insurance applies to all outpatient services. (3 markers)
• **Pay for Medicare** National experts say that Medicare will greatly increase the national deficit and the Medicare Trust Fund will run out of money by the year 2024.	15%	**Tier 1** — Medicare rules and coverage should not change regardless of the impact on the economy. This country must keep its promise to seniors! (1 marker)
	76%	**Tier 2** — Medicare needs to change in some way to make it available for seniors today and the next generation. At this tier, Medicare Trust Fund will be intact for 50 years. (8 markers)
	9%	**Tier 3** — Medicare needs to change significantly to make it secure for the long term (75 years). At this tier, the Medicare Trust Fund will be in good shape for all those who follow us. (11 markers)
• **Premiums** What Medicare users pay for coverage of doctors and outpatient services (Part B). Those earning less than $85,000 per year now pay $105 each month; those earning more than $85,000 pay $147 or more.	19%	**Tier 1** — Those earning between $50,000 and $85,000 will now be charged the higher premium of $147 each month. (1 marker)
	60%	**Tier 2** — Higher premiums will still only affect those earning $85,000 and more. But rather than paying a minimum of $147 each month, they will have to pay at least $191. (2 markers)
	21%	**Tier 3** — Premiums will increase a small amount each year for everyone, as they usually do. (***Current;*** 3 markers)
• **Providers** These are the professionals who provide all the medical services, such as routine check-ups, chronic illness, specialty care, emergencies, and hospital care.	17.5%	**Tier 1** — All services are provided by a specific group of doctors, nurses, therapists and hospitals. All medical care must be provided by them; patient pays the entire cost if using a provider outside of this network. (1 marker)
	65%	**Tier 2** — Same provider network as Tier 1. But in certain situations, if the primary care doctor states that it is necessary, the patient can go to a doctor or hospital outside of their network. (5 markers)
	17.5%	**Tier 3** — Patient can go to any doctor or hospital, anywhere, any time without approval from another doctor. (***Current;*** 10 markers)

(continued)

APPENDIX A:	MedCHAT Categories, Tiers and Final Decisions *(continued)*	
Categories	**% that selected each tier**	**Descriptions of tiers and the markers required**
• **Routine Care** Services (MD visits, tests, medicines, etc.) for the flu, heart burn, shingles and other common short-term problems, including joint surgery in a healthy person. Also covers preventive screenings and check-ups.	1%	No Coverage
	47%	**Tier 1** — Covers diagnosis of all medical problems. But will NOT cover medical care that experts say is unnecessary, such as antibiotics for a virus, screening for colon cancer over age 85 or doing routine tests that have no proven benefit. (7 markers)
	52%	**Tier 2** — Covers all diagnoses, tests and treatments if ordered by the doctor or other provider. (*Current;* 8 markers)
• **Transportation** For those who are unable to drive or use public transportation, yet want to continue living as independently as possible.	19%	No coverage *(Current)*
	81%	**Tier 1** — Transportation services are available to get to and from medical appointments. There is no co-payment. (1 marker)

A P P E N D I X   B :

Health Event Lottery Examples

Randomly- selected computerized lottery cards are used after participants design a Medicare plan for themselves in round 1. With the lottery, participants can see how their benefits package responds when common or uncommon health events occur. The level of benefit that the participant chose for that category is highlighted so the actual coverage is shown. If the participant didn't choose that category for their plan, the card will indicate the cost that the patient would have to pay.

All participants read their cards aloud, indicating the tier they had picked and commenting briefly on whether or not they are satisfied with the outcome. This process helps inform their decisions on future rounds of MedCHAT. Below are examples of these health events.

Category: Long Term Care	Category: Complex Chronic	Category: Final Phase
TOO MANY STROKES.	*FORGETFUL.*	*LIFELONG SMOKER.*
You are quite frail and have had one too many strokes and cannot live at home. You refuse to live with your children so it is time for a nursing home.	**You have had Alzheimer's for 10 years. Though it progressed slowly, your memory is getting much worse. Your doctor suggests a new drug, Cognimax, that may slow the dementia.**	**You started smoking at 14. But many years later, you haven't stopped and lung disease is killing you. The doctors say another operation is not likely to help.**
• **Tier 1** Since you were not in the hospital, Medicare won't cover a short term skilled nursing facility. You will have to pay about $60,000 a year for a nursing home.	• **Tier 1** Cognimax is LOW-value because it is very costly for a very small impact on your dementia. If you want it, you pay the full cost of $500 per week.	• **Tier 1** You aren't ready to give up and want the operation. Medicare will cover supportive care services to make you comfortable but will not cover this operation.
• **Tier 2** Though you were not in the hospital, Medicare will cover 90% of the first year in a nursing home. You will pay about $6,000 but this does not cover year two.	• **Tier 2** Cognimax is LOW-value because it is very costly for a very small impact on your dementia. If you want it, you pay $250 per week, which is half the cost.	• **Tier 2** You aren't ready to give up and want the operation. Medicare will cover this if your doctors agree. When death is near, you go into hospice, not into the ICU.
• **Tier 3** Though you were not in the hospital, Medicare will cover 90% of three years in a nursing home. You will pay about $6,000 per year.	• **Tier 3** Cognimax is LOW-value: it is very costly for a very small impact on your dementia. But if your doctor orders it, Medicare covers it with the same co-payment as other meds.	• **Tier 3** You aren't ready to give up and want the operation. Your doctors agree to do it. If this fails, you can stay in the ICU, hoping for a miracle. Medicare covers it all.

APPENDIX C:

Demographic Characteristics of Participants (N=810)

Gender
(n=810)

Male	29%
Female	71%

Age
(n=800)

18 – 39	16%
40 – 64	44%
65 – 80	31%
81+	9%

Race/Ethnic Group
(n=802)

Asian	25%
Black/African American	12%
Hispanic or Latino	11%
Native American	2%
White	50%
Other	2%

Education Level
(n=794)

8th grade or less	0%
Some HS, did not graduate	1%
HS graduate or GED	6%
Some college/2-year degree	23%
4-year college degree	29%
Post-graduate degree	40%

Economic level
(n=792)

Lower income	14%
Lower-middle income	14%
Middle income	41%
Upper-middle income	25%
Upper income	6%

Work in health care
(n=791)

Yes	39%
No	61%

APPENDIX D:

Project Partners

Many organizations worked with CHCD and LeadingAge CA, contributing their time and resources by:

- Volunteering professional staff to become trained MedCHAT facilitators

- Hosting MedCHAT sessions with their staff and/or constituents

- Recruiting community members to participate in MedCHAT sessions; and/or

- Communicating project information to community, state and national leaders.

Funding Support

In addition to the in-kind support from MedCHAT partners, several organizations provided direct funding for the project:

- Blue Shield of California
- Dignity Health
- LeadingAge California
- Sutter Health

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Project Consultants

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MedCHAT Partners

- ACC Senior Services
- Alzheimer's Association, Northern California/Northern Nevada Chapter
- American Society on Aging
- California Department of Aging
- California Health Advocates
- Episcopal Communities & Services
- Episcopal Senior Communities
- Eskaton
- Huntington Hospital Senior Care Network
- Institute on Aging
- Keiro Senior HealthCare*

- Legal Assistance for Seniors/ Alameda HICAP
- Navigage
- Northern California Presbyterian Homes and Services
- Partners in Care Foundation
- Plymouth Village Retirement Community
- SCAN Health Plan
- TELACU

*Keiro Senior HealthCare merits particular recognition for bringing MedCHAT to so many of its communities.

Steering Committee

Joanne Handy, *President and CEO, LeadingAge California, CHAIR*

Dianne Belli, *Chief Administrative Officer, Keiro Senior HealthCare*

Tom Briody, *President and CEO, Institute on Aging*

Marge Ginsburg, *Executive Director, Center for Healthcare Decisions*

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Melanie Weir, *SCAN Health Plan*

APPENDIX E:

Session Sponsors

We are grateful to the individuals and organizations that convened and hosted the MedCHAT sessions listed below.

Community members/organizations

Sponsoring Organization	Location
ACC Senior Services	Sacramento
Alicia Broadous Duncan Multipurpose Senior Center/TELACU	Pacoima
Congressman Ami Bera's District Office Sacramento	Rancho Cordova
CSUS Retirees Association	Sacramento
East San Gabriel Valley Japanese Community Center	West Covina
Fontana Community Senior Center/TELACU	Fontana
Foothills Congregational Church	Los Altos
Gardena Valley Japanese Cultural Institute	Gardena
Hompa Hongwanji Buddhist Temple	Los Angeles
Huntington Hospital Senior Care Network (4)	Pasadena
Keiro Senior HealthCare (4)	Los Angeles
Orange County Buddhist Temple	Anaheim
Oxnard Buddhist Temple	Oxnard
Placer Independent Resource Services (PIRS)	Auburn
Rotary Club of Sacramento	Sacramento
San Fernando Valley Japanese Community Center	Arleta
San Francisco Village/SF Senior Center-Aquatic Park	San Francisco
SCAN Senior Resource Center	Ventura
Venice Japanese Community Center	Los Angeles
Wintersburg Presbyterian Church	Los Angeles

County programs

Sacramento Co. Foster Grandparent Program (2)	Sacramento
Sacramento Co. Senior Companion Program	Sacramento
San Joaquin Co. Foster Grandparent Program	Stockton
San Joaquin Co. Senior Community Services Employment Program	Stockton
Santa Cruz Foster Grandparent/Senior Companion Program	Aptos

Faith communities

Christian Fellowship Ministry Church (2)	Rio Linda
Grace Bible Fellowship of Antioch	Antioch
Holy Cross Lutheran Church	Rocklin
Next Level Living Christian Center	Sacramento
Parkside Community Church	Sacramento
St. Robert Catholic Church	Sacramento

(continued)

APPENDIX E: Session Sponsors *(continued)*

	Sponsoring Organization	Location
Healthcare/senior service providers	Alzheimer's Association, Orange County Chapter	Irvine
	Alzheimer's Association, No. California/No. Nevada Chapter	Lafayette
	California Department of Aging	Sacramento
	California Health Advocates	San Diego
	Centers for Medicare & Medicaid Services (4)	San Francisco
	Episcopal Communities & Services	Pasedena
	Episcopal Senior Communities	Oakland
	Kaiser Permanente Ethics Committee (2)	Woodland Hills
	Kaiser Permanente Ethics Committee (2)	Irvine
	Legal Assistance for Seniors/Alameda HICAP	Oakland
	Passages Health Insurance Counseling and Advocacy Program	Chico
	SCAN Health Plan (4)	Long Beach
	TELACU (2)	Los Angeles
	UCSF Medical Residents Program (3)	San Francisco
Senior residences	Eskaton Village	Carmichael
	Fern Lodge (2)	Redlands
	Lytton Gardens	Palo Alto
	Palm Village Retirement Community	Reedley
	Piedmont Gardens	Oakland
	Pilgrim Place (2)	Claremont
	Spring Lake Village	Santa Rosa
	St Paul's Towers	Oakland
	The Canterbury	Rancho Palos Verdes
	The Covington	Covington
Other	CSUS Executive Fellowship Program	Sacramento
	Opinions of Sacramento (2)	Sacramento

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