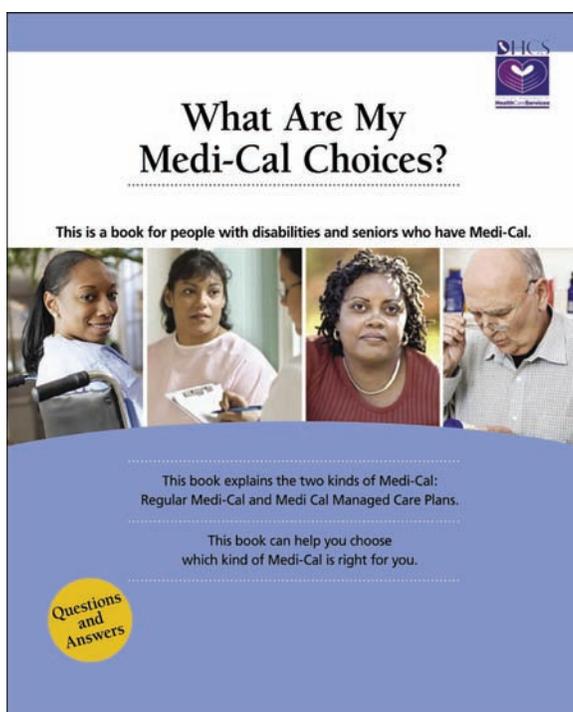# The Medi-Cal Access Project:

Increasing Awareness of Medi-Cal Managed Care and Promoting Voluntary Enrollment for Seniors and Persons with Disabilities

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Presented to California's Department of Health Care Services

What Are My Medi-Cal Choices?

This is a book for people with disabilities and seniors who have Medi-Cal.

This book explains the two kinds of Medi-Cal:
Regular Medi-Cal and Medi Cal Managed Care Plans.

This book can help you choose which kind of Medi-Cal is right for you.

Questions and Answers

Submitted by Health Research for Action
UC Berkeley School of Public Health

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August 15, 2007

The Medi-Cal Access Project:

Increasing Awareness of Medi-Cal Managed Care and Promoting Voluntary Enrollment for Seniors and Persons with Disabilities

Year One Report

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Executive Summary

The Project

Health Research for Action (HRA), a center in UC Berkeley's School of Public Health, was funded by the California Department of Health Care Services (DHCS) to conduct a four-year project to promote voluntary enrollment into Medi-Cal Managed Care for seniors and persons with disabilities. In year one of the *Medi-Cal Access Project,* HRA conducted extensive formative research to understand how seniors and persons with disabilities learn about their Medi-Cal delivery options and make decisions about those options. Based on these findings, HRA developed a consumer guide to increase awareness of Medi-Cal Managed Care and to promote voluntary enrollment.

This report summarizes the findings from the formative research, which focused on English-, Spanish-, Cantonese-, and Mandarin-speaking seniors and persons with disabilities in Alameda, Riverside, and Sacramento counties.

The Research

The research conducted in year one included:
- **24 consumer interviews**, conducted one-on-one, with seniors and persons with disabilities on Medi-Cal, to gather background information.
- **18 focus groups** with 105 seniors and persons with disabilities on Medi-Cal.
- **51 key informant interviews** with providers and advocates who are familiar with these issues.
- **36 usability tests**, conducted one-on-one, with seniors and persons with disabilities on Medi-Cal, to test specific chapters of the consumer guide.

The Advisory Group

HRA worked closely with a 24-member Advisory Group throughout year one. The Advisory Group includes advocates, managed care plan representatives, health care providers, policymakers, and Medi-Cal beneficiaries.

The Intervention

Based on findings from the formative research and input from the Advisory Group, HRA developed a user-friendly consumer guide. This guide will be mailed to beneficiaries with Regular Medi-Cal in the target population, starting in mid-2008. Based on findings from the formative research, additional interventions will be created in the remaining three years of the project.

The Findings

Main findings from the formative research are as follows:

- Consumers do not understand their options; they do not understand the differences between Regular and Managed Care Medi-Cal or how a medical group or clinic is different from a Plan.
- Consumers fear losing their benefits, not finding providers they need, and not getting the drugs they need.
- Consumers want more information and would like to receive it from a real person as well as in writing.
- Consumers do not trust HMOs or Medi-Cal.
- Consumers fear that if they join a Medi-Cal Managed Care Plan and are not satisfied, they cannot return to Regular Medi-Cal.
- Consumers want a tool to help them compare, side-by-side, the benefits of the Medi-Cal Managed Care Plans in their county and Regular Medi-Cal. They want phone numbers, information about costs, prescription drugs, and hospital choices.
- Providers are confused about consumers' options.
- Providers do not understand how Regular Medi-Cal and Medi-Cal Managed Care work.
- Providers would like more information about how to explain choices to consumers.

Background

California Department of Health Care Services (DHCS)

The mission of California's Department of Health Care Services (DHCS) is to protect and promote the health status of Californians through the financing and delivery of individual health care services. DHCS administers California's Medicaid program, which is called Medi-Cal. The Medi-Cal Managed Care Division administers the Medi-Cal Managed Care (MMC) delivery systems. It contracts for health care services through established networks of organized systems of care, which emphasize primary and preventive care.

Medi-Cal Managed Care (MMC) in California

Approximately 3.5 million Medi-Cal beneficiaries in 22 counties receive their health care through three models of health care plans: Two-Plan, County Organized Health Systems (COHS), and Geographic Managed Care (GMC). Medi-Cal providers who wish to provide services to managed care enrollees must participate in the managed care plan's provider network.

Of Medi-Cal beneficiaries, about 550,000 are seniors and persons with disabilities. Most of these are not in MMC, which is an optional choice for them in two-plan and geographic managed care counties.

DHCS has contracted with University of California, Berkeley's Health Research for Action (HRA) to develop, pilot, and disseminate a research-based consumer guide to choosing between MMC and Fee-For-Service Medi-Cal (FFS).[1] The goal of this project is to increase voluntary enrollment in Medi-Cal Managed Care Plans by seniors and persons with disabilities. Based on the research findings from this project, HRA will identify and draft interventions to complement such a guide.

The target group for the pilot project includes seniors and persons with disabilities in Alameda, Riverside, and Sacramento counties who speak English, Spanish, Mandarin, or Cantonese and have Regular Medi-Cal:[2]

Table 1 Seniors and Persons with Disabilities in Three Pilot Counties				
Target population	Alameda	Riverside	Sacramento	Total
Seniors	2,300	1,900	1,400	5,600
Persons with Disabilities	16,300	18,300	18,200	52,800
Total	18,600	20,200	19,600	58,400

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[1] Throughout this report, the terms Fee-For-Service Medi-Cal and Regular Medi-Cal are used interchangeably.
[2] DHCS supplied these numbers to HRA in 2006.

Health Research for Action (HRA)

Health Research for Action, a center in UC Berkeley's School of Public Health, has worked for more than 20 years with communities, foundations, and government agencies to conduct research and translate findings into resources to reduce health disparities. HRA has partnered with HMO consumers to develop, test, and disseminate information to more than 500,000 English- and Spanish-speaking families to help them make better health care decisions. HRA's bilingual Chinese-English *Wellness Guide* and *Parents Guide* were developed with the help of hundreds of Cantonese- and Mandarin-speaking professionals and consumers and have been disseminated to over 100,000 California families.

Literature Review

I*n the literature review, HRA examined a wide range of articles on managed care and Medi-Cal for seniors and persons with disabilities. The* summary *is divided into two sections: Communication & Decision-Making and Access to Health Care.* (See Appendix 1 for the literature review summary.)

The specific goals and parameters of this project limit the relevance of much of the literature reviewed by HRA. The barriers to communication for the project's target population are well documented. The complexities of health care decisions and the lack of decision-making tools are also well documented.

The review highlights the importance of access-to-care issues and provides a broad definition of access to care. As one study put it, access includes potential access (presence of a usual source of care), realized access (actual use of health care services), and the disabled individuals' assessment of their ease of access (Long, Coughlin, & Kendall, 2002).[3] This description can be adapted easily to apply to non-English speakers and other minority groups.

The literature review also reinforced many of the beneficiary concerns that Advisory Group members generated, such as access to providers who understand specific disabilities. The review also reinforced the need for easy-to-read information. As the project continues, HRA will conduct and report on additional literature searches as needed.

Advisory Group

In conjunction with the California Department of Health Care Services, HRA recruited 24 people to join the project Advisory Group. Advisory Group members represent a broad range of individuals,

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[3] Long, S. K., Coughlin, T. A., & Kendall, S. J. (2002). Access to care among disabled adults on Medicaid. *Health Care Financ Rev, 23*(4), 159–173.

groups, and organizations: Medi-Cal beneficiaries and providers; health, consumer, disability, adult literacy, ethnic, and language advocacy groups; health plans; and local initiatives. The main goal of the Advisory Group is to provide detailed input to the project and to help ensure that many perspectives are represented.

HRA conducted one-on-one interviews with each Advisory Group member prior to the first meeting, which was held in Berkeley on September 21, 2006. Following is a summary of themes from the one-on-one interviews.

Advisory Group members identified barriers to enrolling in MMC:
- Beneficiaries' long-standing relationships with providers, particularly with specialists. Beneficiaries have complex health situations and do not want to leave providers who they feel understand them and their health needs.
- Beneficiaries' fear of losing access to services, durable medical equipment, and medicines.
- The concern that managed care providers are not or may not be accessible.
- The complexity and high literacy levels of enrollment materials and other information.
- The lack of information in the beneficiary's language.
- An overall lack of understanding of MMC.
- Mistrust of managed care and the MMC system. Many people hold a negative view of managed care, believing that it means restriction of services and that the whole system is set up to keep people from providers.
- The belief that the MMC system is not ready for an additional influx; it does not have sufficient capacity, skilled administrators, or providers.

Advisory Group members suggested ways to help people make informed decisions about MMC:
- Recognize that seniors and persons with disabilities constitute many different groups, with differing needs.
- Provide one-on-one information.
- Keep information simple.
- Provide materials for caregivers and advocates.

Advisory Group members identified existing information and resources to help people decide about MMC (only two resources were mentioned):
- Inland Empire Health Plan's materials.
- HICAP (the Health Insurance Counseling and Advocacy Program) services for people on Medicare.

Advisory Group members identified groups they believed needed the most help to learn about MMC:
- Many people noted that there were many disability advocates but few advocates for seniors.
- Persons with mental health disabilities, developmental disabilities, AIDS, minimal education, limited literacy skills, limited English-skills, varying ethnic backgrounds, and/or reduced ability or inability to leave home without assistance (i.e., are homebound).
- People who are embarrassed to acknowledge that they need help.

Summaries of Advisory Group Meetings
In the first year of this project, there were three in-person Advisory Group meetings. Summaries of the meetings are below. (See Appendix 2 for full summaries of the Advisory Group meetings.)

Advisory Group Meeting Number One

The first Advisory Group meeting was held in Berkeley on September 21, 2006. There were two main goals for this meeting:
1. To define the roles of the Advisory Group and the UCB/DHCS team; and,
2. To introduce the Medi-Cal Access Project to the Advisory Group.

The facilitator for the Advisory Group began by explaining everyone's roles to the group. This explanation began by stating that the Advisory Group members will be expected and encouraged to offer detailed input throughout the duration of the project. The HRA team will be expected to then organize and incorporate feedback from the Advisory Group in conjunction with the information gained from research, and to develop materials for the Advisory Group to review. The DHCS team will be expected to listen to the feedback from the Advisory Group and HRA and make final decisions, based on state policy and regulations.

Following this discussion, HRA staff introduced the project, in detail, to the Advisory Group. This included information on the goals and parameters of the project. In this introduction, the HRA team also presented to the Advisory Group findings from each member's individual interview.

There were two main suggestions that advisors voiced during the first meeting:
1. To keep the guide simple so that beneficiaries will be able to read, navigate, and utilize it.
2. To include honest and unbiased information regarding Regular Medi-Cal and Medi-Cal Managed Care Plans, so that both sides are represented equally and fairly.

Advisory Group Meeting Number Two

The second Advisory Group meeting was held in Sacramento on January 24, 2007. The two main goals for this meeting were:
1. To present an update on formative research; and
2. To present the first draft of the guide to the Advisory Group and get feedback on content and design.

The HRA team began by presenting an update on the formative research. Since the previous meeting, HRA completed 20 consumer interviews and 23 key informant interviews. The main issue that had emerged from the formative research at that point was the barriers to making a choice between Regular Medi-Cal and Medi-Cal Managed Care. These barriers included lack of information, confusing information, limited health literacy skills, and consumer fatigue with the Medi-Cal system. The HRA team suggested these issues be addressed in the guide.

Following the presentation, the Advisory Group was asked to provide feedback on the first draft of the guide. Their first comments centered on the guide's design and readability; group members suggested making sure that the pictures used were representative of the target population and that the guide be user friendly. The next comments addressed content, and several members pointed out that the guide was biased toward Managed Care Plans. They also pointed out issues regarding costs, prescription drugs, DME, and state resources.

Overall, the two main issues that advisors voiced during the second meeting were:
1. To keep the guide unbiased and present Regular Medi-Cal and Medi-Cal Managed Care equally; and,
2. To present accurate information and create a guide that consumers can use to make an informed choice on their own.

Advisory Group Meeting Number Three

The third Advisory Group meeting was held in Berkeley on June 21, 2007. The two main goals of this meeting were:
1. To present the completed formative research and its impact on the guide; and,
2. To present the latest draft of the guide and county-specific inserts to the Advisory Group to get feedback.

Since the last meeting, HRA conducted a total of 24 consumer interviews, 53 key informant interviews, 18 focus groups (with 105 participants), and 36 usability tests.

There were several key findings from the research:
- Consumers do not understand their options; they do not understand the differences between Regular and Managed Care Medi-Cal or how a medical group or clinic is different from a Plan.
- Consumers fear losing their benefits, not finding providers they need, and not getting the drugs they need.
- Consumers want more information and would like to receive it from a real person as well as in writing.
- Consumers do not trust HMOs or Medi-Cal.
- Consumers fear that if they join a Medi-Cal Managed Care Plan and are not satisfied, they cannot return to Regular Medi-Cal.
- Consumers want a tool to help them compare, side-by-side, the benefits of the Medi-Cal Managed Care Plans in their county and Regular Medi-Cal. They want phone numbers and information about costs, prescription drugs, and hospital choices.
- Providers are confused about consumers' options.
- Providers do not understand how Regular Medi-Cal and Medi-Cal Managed Care work.
- Providers would like more information about how to explain choices to consumers.

Following the presentation and a short discussion, HRA presented the new guide. This guide takes into consideration the key findings from the formative research as well as previous suggestions from members of the Advisory Group.

The Advisory Group first commented on the county-specific inserts. Their comments were mainly about the fact that Regular Medi-Cal is not portrayed favorably, compared with the Managed Care Plans. They also spent time discussing how to make the information in each insert more accurate.

The Advisory Group also commented on the guide. They spent quite a bit of time discussing the chapters on nursing homes, prescription drugs, and costs; there was also a lengthy discussion on the lack of a chapter on mental health care (which HRA has since added).

The two main issues that advisors discussed during the third meeting were:
1. The need to present accurate information about Regular Medi-Cal and Managed Care Plans; and,
2. The need to create an easy-to-read guide that can be used as a community resource as well as by consumers and providers.

All three of the meetings were very well attended, and advisors came well prepared to discuss the items on the agenda. Based on feedback from the Advisory Group, HRA modified the content and layout of the guide.

Formative Research, Year One

The purpose of the formative research was to gather information to inform the creation of the Medi-Cal consumer guide. HRA collected data and input from the target population (seniors and persons with disabilities on Medi-Cal [SPD], excluding those with Medicare) and the individuals and organizations that serve and advocate for them. The formative research targeted three pilot counties (Alameda, Riverside, and Sacramento) and targeted three language groups (English, Spanish, and Chinese).

This report reflects the findings triangulated from a number of data sources, including:

- The California Department of Health Care Services
- The Medi-Cal Access Project Advisory Group
- 51 key informant interviews with professionals serving or advocating for the target population (representing all three pilot counties and statewide)
- 24 in-person interviews with SPD Medi-Cal consumers (in Alameda county only)
- 18 focus groups with SPD Medi-Cal users and caregivers (in Alameda, Riverside, and Sacramento counties)
- 36 one-on-one usability interviews with SPD Medi-Cal consumers (in Alameda county only)

The formative research was used to gather a variety of data that informed the creation of the consumer guide and the dissemination plan. Data were collected about a variety of topics including:

- The barriers SPD face in making informed decisions between MMC and Regular Medi-Cal.

- The unmet needs of SPD Medi-Cal consumers when it comes to information and decision support.
- Main decision points for SPD in the Medi-Cal enrollment process.
- The most effective sites, modes, and formats for delivering information about Medi-Cal choices to SPD.
- The advantages and disadvantages of MMC and Medi-Cal FFS.

Consumer Interviews

Methods and Recruitment
HRA conducted twenty-four in-depth, in-person interviews with seniors and persons with disabilities on Medi-Cal. To be eligible for an interview, individuals had to be Medi-Cal consumers who were seniors (age 65 or over) or persons with disabilities (enrolled in SSI). The study included both consumers enrolled in Fee-For-Service (FFS) Medi-Cal and those enrolled in Medi-Cal Managed Care (MMC). Consumers who were eligible for both Medi-Cal and Medicare were excluded from the study. Caregivers for eligible consumers were also eligible to be interviewed if they participated in health care choices and provided at least two hours of care to the consumer per week. To be eligible for the interview, consumers and caregivers had to speak one of the target languages: English, Spanish, Cantonese, or Mandarin. All participants were read and asked to sign a consent form. (See Appendix 3 for an example of a consumer consent form).

The purpose of these interviews was to collect in-depth information about SPD consumers and their experiences with Medi-Cal enrollment and Medi-Cal choices. Consumers were interviewed in person, at a location of their choice, and were asked to tell their story about how they came to be enrolled in Medi-Cal. Interviews were open ended, recorded, and transcribed; a thematic analysis was conducted. Some of the consumer interview research questions included:

1) Where did SPD enroll in Medi-Cal?
2) What are the current experiences of SPD with written materials or other information aimed at assisting them in making choices about Medi-Cal?
3) What are the barriers preventing SPD from making informed choices about Medi-Cal?
4) What are the most common misconceptions and information needs about both FFS Medi-Cal and MMC?
5) What are the major unmet needs of SPD when it comes to making Medi-Cal choices?
6) What are the most effective ways of getting information to SPD about their Medi-Cal choices?
7) What information about Medi-Cal does SPD need to feel confident about making well-informed choices between FFS Medi-Cal and MMC?

To recruit participants, DHCS sent a letter to every fifth name on a list of Medi-Cal consumers in certain aide codes in Alameda County who fit into the target population. Consumers were invited to call if they were interested in participating in an interview or focus group. Approximately 4,960 letters were sent out and 326 consumers responded to the letter by calling HRA. Of those, HRA screened 275 for eligibility (via telephone); the remaining 51 were unreachable (via return phone call)

and therefore were not screened. Of those who completed the telephone screening, 249 were eligible for participation, and 24 were selected for a consumer interview. Consumers were selected for interviews based on purposive sampling techniques in an attempt to interview individuals with a wide range of disabilities and experiences. Those eligible consumers who were not selected for consumer interviews were invited to attend focus groups or were asked to complete a usability test at a later time. All consumers who participated in the consumer interviews were paid a $50 cash stipend.

At the beginning of each interview, each participant was verbally administered a short, quantitative pre-survey. The pre-survey collected basic background information, including Medi-Cal status and demographic information. These quantitative data were analyzed using SPSS.[4] After the pre-survey, consumers participated in an open-ended, semi-structured interview. (See Appendix 3 for the consumer interview screener and instrument.) These interviews were tape-recorded, transcribed, and, when needed, translated into English. Transcriptions were analyzed to ascertain dominant themes, using a qualitative data analysis program called Atlas.ti.[5]

Sample
Of the 24 in-person interviews completed, nine were conducted in English, five in Spanish, seven in Cantonese, and three in Mandarin. Six men and 18 women were interviewed. Three participants were African-American, five were Latino, three were white, ten were Chinese, and three were Other Asian/Pacific Islander.

Table 2 Ethnicity of Consumer Interview Participants		
Ethnicity	**Frequency**	**Percent**
African-American	3	12.5
Latino	5	20.8
White	3	12.5
Chinese	10	41.7
Other Asian/Pacific Islander	3	12.5
Total	24	100.0

Participants' ages ranged from 22 to 80, with the average being 56.8 years of age. Over one-third (nine) of the participants had completed less than a high school education or equivalent. Four had not completed elementary school.

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[4] SPSS for Mac, Rel. 11.0.4. 2005. Chicago: SPSS, Inc.
[5] Atlas.ti The Knowledge Workbench, Rel. 5.2.9. 2007. Berlin: Atlas.ti Scientific Software Development, GmbH.

Table 3		
Education of Consumer Interview Participants		
Highest Education Level	**Frequency**	**Percent**
Some Elementary/Primary	4	16.7
Completed Elementary/Primary	2	8.3
Middle School/Junior High	1	4.2
Some High School	2	8.3
Completed High School or Equivalent	7	29.2
Trade/Technical School	1	4.2
Some College	2	8.3
Completed College	2	8.3
Completed Graduate School	1	4.2
Don't Know/Missing	2	8.3
Total	24	100.0

Of the 24 consumers interviewed, 11 identified as a person with a disability on Medi-Cal. Five were caregivers for a person with a disability. Five identified as a senior on Medi-Cal, and three identified as a caregiver for a senior on Medi-Cal.

All participants, both seniors and persons with disabilities, were asked to describe their disabilities. About two-thirds of all participants identified as having a chronic or long-term disability. Fifteen of all participants identified as having a physical disability. Four participants had mental health disabilities, one had a sensory disability, three had developmental disabilities, two had cognitive disabilities, and three had other unspecified disabilities.[6] More than 40% of participants had two or more disabilities.

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[6] **The following definitions and parameters were used to categorize different disabilities for research purposes:**
PHYSICAL DISABILITIES were defined as a range of physical disabilities, as well as those in which the individual uses equipment such as a wheelchair, scooter, cane, or crutches. Examples include multiple sclerosis, muscular dystrophy, post polio, amputation, spinal cord injury, and arthritis.
SENSORY DISABILITIES include deafness, blindness, visually impairment, and hearing impairment.
DEVELOPMENTAL DISABILITIES include, but are not limited to, Down's Syndrome, mental retardation, cerebral palsy (may also be physical), autism, epilepsy, and child-onset brain injury.
COMMUNICATION DISABILITIES include disabilities, such as aphasia, where the individual uses an augmentative communication device (such as Easy Talk, Dynovox, or DynaMyte).
MENTAL HEALTH DISABILITIES include, but are not limited to, bipolar disorder, depression, panic disorder, obsessive compulsive disorder, schizophrenia, and adult-onset brain injury.
CHRONIC OR LONG-TERM CONDITIONS OR ILLNESSES include, but are not limited to, diabetes, congestive heart failure, HIV/AIDS, sickle cell disease (may also be listed as a physical disability), chronic obstructive pulmonary disease, chronic pain, and auto immune diseases (such as lupus).
COGNITIVE DISABILITIES include, but are not limited, to adult-onset traumatic brain injury or stroke, general non-developmental learning disabilities, memory impairment, dementia, attention deficit disorder [ADD], attention deficit hyperactivity disorder [ADHD], and dyslexia.

Table 4		
Type of Disability of Consumer Interview Participants		
Type of Disability	**Frequency**	**Percent**
Chronic/Long-Term	15	62.5
Physical	8	33.3
Mental Health	4	16.7
Developmental	3	12.5
Cognitive	2	8.3
Sensory	1	4.2
Other Disabilities	3	12.5

Medi-Cal status. Nineteen participants had FFS Medi-Cal and five had MMC (two had Alameda Alliance and three had Blue Cross). The length of time participants had been on Medi-Cal at the time of the interview ranged from one month to more than 35 years. About 70% of participants had been on Medi-Cal for five years or less.

Awareness of choices/information received. Slightly more than half of the participants (13) reported that they were aware they could choose between different types of Medi-Cal. Of these, nine had received a packet in the mail explaining their choices, two had heard from providers such as social workers or benefits counselors, and two had received information from other sources. Eleven of the participants had not heard that they could choose between different kinds of Medi-Cal.

Table 5			
How Consumers Learned about Medi-Cal Choices			
	Frequency	**Percent**	**Valid Percent**
Received Packet in the Mail	9	37.5	69.2
Provider	2	8.3	15.4
Other	2	8.3	15.4
Subtotal	13	54.2	100.0
N/A – Did Not Know About Choices	11	45.8	
Total	24	100.0	

Why consumers stayed on FFS. Consumers on FFS were asked to state the primary reason they did not choose to switch to MMC. Of the 19 consumers who were on FFS Medi-Cal, 12 said they did not choose a Medi-Cal Managed Care Plan because they did not know they had a choice, three said they did not have enough information about MMC to feel confident in making a choice, two were worried about having to change doctors, and two were worried that their prescriptions would not be covered.

Why consumers enrolled in MMC. Of the five people who chose Medi-Cal Managed Care, two had defaulted previously under a different aide code, two chose MMC because a family member was enrolled in it, and one chose it because of a previous positive experience with the MMC Plan when she was enrolled while working as an IHSS provider.

Experiences with Medi-Cal. While 54.2% said that Medi-Cal was currently meeting their needs, 70.8% said that they had experienced some problems with their Medi-Cal. Some of the problems listed included difficulty getting prescriptions covered, long waits for appointments, problems with language services, and being denied treatment due to lack of coverage.

Usability Tests

Methods and Recruitment
Usability tests are one-on-one interviews with members of the target population. The purpose of these interviews is to measure out how well SPD consumers could read, use, and understand specific parts of the guide. During usability tests, consumers were given specific parts of the guide to read and then were asked very detailed questions to ascertain their comprehension of the subject matter.

HRA conducted thirty-six usability tests with seniors and persons with disabilities on Medi-Cal. In a usability test, a participant may be tested on up to two different chapters of the guide. To be eligible for a usability test, individuals had to be Medi-Cal consumers who were seniors (age 65 or over) or persons with disabilities (enrolled in SSI). The study included consumers with Fee-For-Service (FFS) Medi-Cal only. Consumers who were eligible for both Medi-Cal and Medicare were excluded from the study. Caregivers for eligible consumers were also eligible for usability tests. To be eligible for the interview, consumers and caregivers had to speak one of the target languages: English, Spanish, Cantonese, or Mandarin.

To recruit participants, HRA contacted consumers who had previously completed the telephone screening, were eligible to participate, and had not been invited to participate in a consumer interview. Some of the 36 consumers had already participated in a focus group and others had not. All consumers who participated in the usability tests were paid a $30 cash stipend.

The usability tests were semi-structured, interactive interviews where participants were asked to read certain segments of the guide and respond to direct questions. Participant responses were recorded in interviewer notes and summarized by topic. These results were then used to directly inform the content, wording, and layout of the guide.

At the end of each test, each participant was administered a quantitative survey. This post-survey collected basic background information, including demographic information. The quantitative data from the post-survey were analyzed using SPSS. (See Appendix 3 for a sample of a usability test instrument and post-survey.)

Sample
Of the 36 one-on-one usability tests completed, 23 were conducted in English, six in Spanish, and seven in Cantonese. Seventeen participants were African-American, seven were Latino, seven were Chinese, four were White, and one was American-Indian. Twenty-six participants were female and ten were male. Of the 36 consumers interviewed, 35 were with consumers with Regular Medi-Cal; one was in a Medi-Cal Managed Care Plan.

Table 6		
Ethnicity of Usability Tests Participants		
Ethnicity	**Frequency**	**Percent**
African-American	17	47.2
Latino	7	19.4
White	4	11.1
Chinese	7	19.4
American Indian/Alaska Native	1	2.8
Total	36	100.0

The age of the participants ranged from 30 to 83, with an average age of 54. Among participants who reported their highest level of education, 41.7 % did not complete high school. Seven participants completed high school, nine had some college education, four completed college, and one participant never attended school.

Table 7		
Education of Usability Tests Participants		
Highest Education Level	**Frequency**	**Percent**
Some Elementary/Primary	1	2.8
Completed Elementary/Primary	2	5.6
Middle School/Junior High	7	19.4
Some High School	5	13.9
Completed High School or Equivalent	7	19.4
Some College	9	25.0
Completed College	4	11.1
No School	1	2.8
Total	36	100.0

The majority of participants (63.9%) were persons with disabilities. Seven participants (19.4%) self-identified as seniors, three participants identified as caregivers for persons with disabilities, and three identified as a caregiver for a senior.

Table 8		
Usability Tests Participants: Seniors, Persons with Disabilities, or Caregivers		
Participant	**Frequency**	**Percent**
Person with Disability	23	63.9
Senior	7	19.4
Caregiver for Senior	3	8.3
Caregiver for PwD	3	8.3
Total	36	100.0

All of the participants reported having a disability. The most common disabilities identified by the participants were physical, mental health, and chronic.

Medi-Cal Status. The great majority of the participants were in Fee-for-Service (FFS) Medi-Cal (97.2%). One participant was in Alameda Alliance. Participants' length of time on Medi-Cal ranged from five months to 30 years. Approximately 31% of participants had been on Medi-Cal for five

years or less, while 20% percent had been on Medi-Cal for five to ten years. About 25% enrolled more than ten years ago, and 22% enrolled over 20 years ago.

Focus Groups

Methods and Recruitment

HRA conducted a total of 18 focus groups with Medi-Cal consumers in Alameda, Riverside, and Sacramento counties. A total of 105 consumers and caregivers attended these groups. To be eligible to participate in a focus group, individuals had to be Medi-Cal consumers who were seniors (age 65 or over) or persons with disabilities (enrolled in SSI). Consumers who were eligible for both Medi-Cal and Medicare were excluded from the study. Caregivers for eligible consumers were also eligible for focus group participation if they participated in making health care choices for the consumer and provided at least two hours of care to the consumer per week. To be eligible for the focus groups, consumers or caregivers had to speak and read one of the target languages: English, Spanish, Cantonese, or Mandarin.

A variety of different recruitment methods were used. In Alameda county, a random selection of consumers were mailed letters and invited to participate (see Consumer Interviews: Methods and Recruitment, above). Those who were not selected for consumer interviews were invited to participate in focus groups or other research testing. All consumers who participated in the focus groups were paid a $50 cash stipend. Focus group participants were also recruited through community-based organizations who served SPD populations in the three target counties and who agreed to host focus groups at their site.

The focus groups had two main purposes. The first was to gather background information about Medi-Cal consumers, similar to the information gathered in the consumer interviews (see the list of consumer interview research questions under Consumer Interviews: Methods and Recruitment, above). Second, each of the 18 focus group discussions specifically targeted one or two topics that were to be covered in the guide. For instance, a focus group discussion might concentrate on prescription drug coverage information or access to language services. In later focus groups, which met when versions of guide chapters were available, participants were asked to look at anywhere from one to three chapters of the guide and to give feedback about whether those sections answered their questions about the topics.

Before the focus group began, each participant was administered a short pre-survey. The pre-survey collected basic background information, including Medi-Cal status and demographic information. These quantitative data were analyzed using SPSS. The subsequent focus group discussions were open-ended and facilitated using a script (See Appendix 3 for examples of focus group scripts and pre-survey.) The discussions were tape-recorded, transcribed, and, when needed, translated into English. Transcriptions were analyzed to ascertain dominant themes, using a qualitative data analysis program called Atlas.ti.

Sample

Language and Ethnicity. Of the 18 focus groups completed, ten were conducted in English, four in Spanish, two in Cantonese, one in Mandarin, and one in Sign Language.[7]

Table 9		
Language of Focus Group Participants		
Language	**Frequency**	**Percent**
English	59	56.2
Spanish	25	23.8
Cantonese	12	11.4
Mandarin	3	2.9
Sign Language	6	5.7
Total	105	100.0

Of the 105 total participants, 23 were African-American (21.9%), 30 were Latino (28.6%), 29 were White (27.6%), 16 were Chinese (15.2%), one was American Indian/Alaska Native, and one was Other Asian/Pacific Islander. The remaining five participants (4.8%) were of multiracial descent.

Table 10		
Ethnicity of Focus Group Participants		
Ethnicity	**Frequency**	**Percent**
African American	23	21.9
Latino	30	28.6
White	29	27.6
Chinese	16	15.2
American Indian/Alaska Native	1	1.0
Other Asian/Pacific Islander	1	1.0
Multiracial	5	4.8
Total	105	100.0

Age and Gender. One-third of focus group participants were male and two-thirds were female. The age of the participants or the people for whom they provide care ranged from 12 to 83, with an average of 52.9 years.

Medi-Cal status. The study included consumers enrolled in Fee-For-Service (FFS) Medi-Cal and consumers enrolled in Medi-Cal Managed Care (MMC). Five focus groups included FFS consumers only, three included only MMC consumers, and the remaining six focus groups were mixed.

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[7] Of the six Deaf focus group participants, two were fluent in American Sign Language (ASL) while others were bilingual in both ASL and Mexican Sign Language, Spanish Sign Language, Hong Kong Sign Language, or Chinese Sign Language.

Table 11
Type of Medi-Cal of Focus Group Participants

Type of Medi-Cal	Frequency	Percent
FFS or Regular Medi-Cal	79	75.2
Alameda Alliance	11	10.5
Inland Empire	8	7.6
Blue Cross Alameda	2	1.9
Blue Cross Sacramento	5	4.8
Total	105	100.0

Participants' length of time on Medi-Cal ranged from as little as two months to over 30 years. Roughly 44% of participants had been on Medi-Cal for five years or less, while 20% had been on it for five to ten years. About 36% enrolled more than ten years ago and 17% enrolled over 20 years ago.

Disabilities. Most focus groups included both seniors and persons with disabilities. Four groups included only seniors (or caregivers for seniors), twelve groups included only persons with disabilities, and the remaining two groups were mixed including both seniors and persons with disabilities. All of the disability only groups included persons with a variety of disabilities except one group that targeted people identifying as Deaf.

The majority of focus group participants (59%) were persons with disabilities or caregivers for persons with disabilities (6.7%). Thirty-two participants (30.5%) identified as seniors or caregivers for seniors (3.8%).

Table 12
Focus Group Participant: Senior or Person with Disability

Participant	Frequency	Percent
Senior	32	30.5
Person with a Disability	62	59.0
Caregiver for Senior	4	3.9
Caregiver for a Person with a Disability	7	6.7
Total	105	100.0

Both seniors and persons with disabilities were asked to identify any disabilities they had. Caregivers were asked to identify the disability of their Medi-Cal consumer care recipient. Participants were allowed to identify as many disabilities as applied. The most common types of disabilities identified by participants were physical (43.8%), chronic conditions (34.3%), and mental health (23.8%). Among those who reported disabilities, 40% had two or more disabilities, and 10% had three or more.

Table 13 Focus Group Participant Type of Disability*		
Type of Disability	**Frequency**	**Percent**
Physical	46	51.7
Chronic illness	36	40.4
Mental health	25	28.1
Sensory	15	16.9
Developmental	9	10.1
Cognitive	5	5.6
Communication	2	2.3
* Both seniors and persons with disabilities were asked to report type of disability. This table includes seniors who reported having a disability.		

Health Status. Using a measure of self-rated health, over 66% of focus group participants rated their health as either fair or poor, 18% rated their health as good, and 3% rated it as excellent. There was no significant difference between how FFS and MMC participants rated their health.

Table 14 Focus Group Participant Self-Rated Health		
Self-Rated Health	**Frequency**	**Percent**
Poor	21	20.0
Fair	59	56.2
Good	19	18.1
Excellent	3	2.9
Total	102	97.1
N/A	2	1.9
Don't Know	1	1.0
Total	105	100.0

Education. Over one-third of focus group participants (36.6%) did not complete a high school education, with 10% not having completed an elementary education. About 20% completed high school only, and 7% completed technical or trade school. Roughly 25% of participants completed some college, while 10% graduated from college or higher.

Table 15 Education of Focus Group Participants		
Highest Education Level	**Frequency**	**Percent**
Some Elementary/Primary	11	10.5
Completed Elementary/Primary	7	6.7
Some or All Middle School/Junior high	8	7.6
Some High School	11	10.5
Completed High School	21	20.0
Trade/Technical School	7	6.7
Some College	25	23.8
Completed College	6	5.7
Some Graduate School	1	1.0
Completed Graduate School	2	1.9
No School	2	1.9
N/A	1	1.0
Don't Know	3	2.9
Total	105	100.0

Cross-tabulations showed that English-speakers were more likely to have a higher education level than non-English speakers (p<.001).

Decision support. Less than half of all participants (43.8%) reported that they received no help in deciding whether to stay in Regular Medi-Cal or switch to a Managed Care Plan. When the participants did get assistance, a social worker or benefits counselor was most frequently (26.6%) the one who helped participants make decisions. Other participants sought advice from family members or friends (9.6%), their primary care doctor (3.8%), or SSI/Medi-Cal eligibility worker (2.9%).

Use of technology. All participants were asked about their use of the internet, DVD players, and CD players. About 40% of focus group participants said they use the internet. Of this subgroup, 24.3% said they used the internet often to look up health-related information, and 37.8% said they used it sometimes. Cross-tabulations showed that English-speakers were significantly more likely to use the internet than non-English speakers (p < .05). Only five non-English speaking participants (12%) said they use the Internet.

Roughly 70% of participants use a DVD player. While English-speakers were more likely to use a DVD player (p < .05), the majority of non-English speakers (60%) also reported that they used one in their homes.

Cross-tabulations showed that English-speakers were also more likely to use a CD player in their home (p <.001), with only 13% of English speakers reporting that they did not use a CD player, compared to 42% of non-English speakers.

Findings from Interviews and Focus Groups with Consumers

All consumers and caregivers who participated in the consumer interviews and focus groups were asked questions about their experiences with Medi-Cal. The purpose of this was to determine what areas were problematic for consumers and what areas consumers need clarification about.

Prescription Drugs

Experiences with prescription drug coverage. Participants reported the experience of being told that their prescription medication wasn't covered. This was one of the most common problems faced by those who participated in the research. Some consumers paid out-of-pocket to get the denied medication, others went without needed medication.

> *I was in a similar situation as her at one point. I had really bad allergies, and the doctor prescribed some pills for me, but they would not give it to me because I had had too many medications from Medi-Cal. I had to wait until the next month to get it...Since I really needed it, I just paid for it. I felt like I could not breathe.*
> —Spanish-speaking FFS Consumer

If they charge, I just say I don't want the drug.
                                                    —Cantonese-speaking FFS Consumer

Many participants reported that the $1 co-payment for prescriptions that can be charged to consumers on regular Medi-Cal was of great concern to them. One consumer said that he choose MMC because he did not have to pay the $1 co-payment associated with Regular Medi-Cal prescription drugs.

My sister once told me about the co-payments. Like, for every bottle, it's a dollar that you pay for. But I get mine free. Because most offices say you have to pay a co-payment… a dollar for prescription. But I'm able to get mine free, so [laughs] I'm just kind of fortunate, you know.

                                                    —English-speaking MMC Consumer

Information needs about prescription drug coverage. Consumers wanted specific information about prescription drug coverage in both kinds of Medi-Cal. They wanted to know if their particular prescriptions were covered, if there were limits on the number of prescriptions they could get, and whether or not there were co-payments required. They were concerned about formularies changing and wanted to know if the formulary would change less often with an MMC Plan. They were interested in what they could do about it if they were told their prescription medication was not covered by Medi-Cal. And they wanted to know about non-prescription drug coverage in different types of Medi-Cal and how they could find out about what was covered.

[I want to know] the number of drugs that would be covered, like she was saying. Regular MediCal only covers five. So what are the limitations? Does Inland Empire cover 15 and Molina cover 12? That is a big consideration for all of us. I take a lot of medication. That would definitely change my mind.
                                                    —English-speaking MMC Consumer

Do these [Managed Care Plans] cover non-prescription drugs? You know? Because sometimes the doctor will order, like, over the counter iron. OK? Is it covered? Is vitamins, are they covered? Is prenatal vitamins, are they covered?
                                                    —English-speaking Caregiver of MMC Consumer

Costs/Out of Pocket Expenses

Experiences with Medi-Cal expenses. Many consumers were concerned about out-of-pocket costs associated with Medi-Cal. Many had the experience of getting billed for doctor visits, hospital stays, or other procedures they thought would be covered.

I went to Alameda Hospital, and I was there for five days. And I guess my Medi-Cal paid for some of my stay, but then I got a bill for $3,000…so I don't understand why I have a bill now for $3,000, that I can't pay for, you know?
                                                    —English-speaking FFS Consumer

I would like to know why it's so expensive to get necessary tests done?
                                                    —Spanish-speaking FFS Consumer

Others had been put in a position of not getting required treatment because the treatment was not covered by Medi-Cal. When consumers were satisfied with the coverage they were getting with FFS Medi-Cal, they did not want to switch to MMC for fear that MMC would not cover all of their expenses.

Information needs about costs. Due to the fear of increased health care costs, consumers reported they would not feel comfortable switching to MMC until they knew exactly what sorts of fees would be required and whether MMC would cover their prescriptions, doctor visits, hospital stays, tests, and procedures. They also wanted to know whether MMC required a premium to join.

> *I would like to know the costs associated with the new plan?*
> —Spanish-speaking FFS Consumer

> *If I switch from Medi-Cal to Blue Cross, then do we have to pay an insurance premium?*
> —Cantonese-speaking FFS Consumer

Access to Providers and Specialists

Experiences accessing providers. While most consumers who participated in the formative research were satisfied with their experience of finding a primary care provider, many experienced difficulty finding a specialist. Their experiences with specialists included not being able to find specialists who worked nearby, being referred to specialists who no longer took Medi-Cal, and attempting to make appointments only to find that the specialist had a months-long waiting list for Medi-Cal recipients. Both FFS and MMC consumers reported trouble accessing specialty care.

> *Now [on MMC] I have to wait months for a doctor to refer me [to a specialist].*
> –English-speaking MMC consumer

> *Oh, I could not find [a provider who took FFS Medi-Cal]. And I called. When I called Alameda county, they told me, 'Well, use the phone book.'*
> —English-speaking FFS consumer

Information needs about access to specialty care. There were two primary concerns that consumers had about the effects of MMC on access to providers. First, for those who have a physician they like, they wanted to know whether they would be able to keep their current doctor. Second, participants, especially those who had trouble finding specialists, were interested to know if MMC would provide them with easier access to specialists, including those who provided good quality care and timely appointments and had offices comparatively close to the participants' homes.

Understanding of Medi-Cal Choices

Experiences with Medi-Cal information. Most consumers and caregivers who participated in the research did not understand the differences between Regular Medi-Cal (FFS) and Medi-Cal Managed Care (MMC). Even for those who had heard there were two kinds of Medi-Cal, or had heard of one of

the MMC Plans in their county, the information they had received was often meaningless because they did not understand how different types of Medi-Cal would affect their experiences, ability to access care, and costs of care.

Information needs about Medi-Cal choices. Most consumers, whether they had seen information about MMC or not, felt that they still needed more specific information about the differences between the Plans.

> *And any HMO literature that I've received has not done a comparison with any of the other insurance plans. So if they want me to switch to an HMO, they're going to have to say what your standard Medi-Cal is giving you now. And this is what you're going to get if you go to an HMO.*
>
> –English-speaking FFS consumer

Consumers also wanted to know about the enrollment process and exit strategy. They wanted to know if they would lose their benefits while waiting to be enrolled in MMC. They also wanted to know if there was a way to switch back to Regular Medi-Cal.

> *Let's assume I switch to another plan and it's not working out for me or something. Can I go back to the one I had? And they won't cancel it? You know, sometimes when they're changing the paperwork or something and by the time this and that it's sent back, they cancel Medi-Cal.*
>
> —Spanish-speaking FFS Consumer

Language Services

Experiences accessing language services. Many of the non–English-speaking participants have encountered difficulties accessing interpreter services. Participants reported requesting services and many times not having an interpreter or a doctor that speaks their language. Participants recalled being told to bring their own interpreters or improvise by using hand signals.

> *Sometimes they [provide interpreters] and other times they don't. For example, specialists have always told me that I need to provide my own [interpreter]. So I have to pull my daughter from school, and I take her.*
>
> —Spanish-speaking FFS Consumer

When interpreters were provided, several participants reported that the interpreter did not relay information to their doctor accurately or did not relay it at all.

> *My doctor…he has to bring someone who speaks Cantonese every time he saw me. But sometimes I feel the [interpreter] was not [interpreting] accurately, including what the doctor diagnosed about my illness. I am not sure if she could always convey the doctor's words to me precisely.*
>
> —Mandarin-speaking FFS Consumer

Deaf participants had an especially difficult time getting services during appointments and other health services and procedures outside the clinic, such as at pharmacies. Many were frustrated with their inability to find providers equipped to accommodate their communication needs.

> *It's been really frustrating going to the pharmacy, going to the lab for the mammogram, um —you know. Communicating with the doctor has been very frustrating because there have not been interpreters. That's important to know.*
> —Deaf FFS Consumer

Despite these problems, a few participants said they were satisfied with their ability to communicate with their providers.

> *I went to the bone specialist and they did provide someone to interpret for me.*
> —Spanish-speaking FFS Consumer

Information needs regarding language services. Participants wanted to know why some physicians' offices provided interpreters and translators while others did not. They wanted to know what they were entitled to as far as interpreters and translators were concerned. They were frustrated with the lack of services available to them but did not know what their rights were or how to go about filing a complaint.

Reasons for Not Wanting to Switch to Medi-Cal Managed Care

Stigma of managed care. There were many consumers who participated in the formative research who felt very negative about managed care or health maintenance organizations (HMOs). Some of the consumers who felt this way had had negative experiences with HMOs in the past. Others had no experiences with HMOs but had heard from others or from the media that the purpose of HMOs was to cut costs and, thus, HMOs would cut back on the services provided to patients.

> *I've never found HMOs to be worth a damn. And so that's the reason that I would not go that way.*
> —English-speaking MMC consumer

Distrust of Medi-Cal. Many consumers expressed a desire to understand why Medi-Cal wanted them to switch to an HMO. They wanted to understand the motives for pushing MMC and suspected that the motives were to cut costs and cut back on the care that is currently available to them.

> *I want to know what Medi-Cal is selling and why they want me to buy it.*
> —English-speaking FFS consumer

Lack of information about choices. Some consumers reported that they had received information about Medi-Cal choices either in the mail or through a benefits counselor. But even those who received information did not feel the information was adequate to make informed choices. Understandably, consumers said they would require specific information about prescription coverage,

out-of-pocket expenses, access to providers, language services, and an exit strategy before they would consider switching to MMC.

Consumer Feedback/Responses to Guide

Based on findings from in-depth data on consumer experiences and information needs (gathered from consumer interviews and early focus groups), HRA created draft chapters of the consumer guide. These chapters included information that responded to consumers' requests for information about FFS and MMC. Once these draft chapters were created, they were first tested in one-on-one usability tests with Medi-Cal consumers. They were then further revised and tested in focus group discussions. Below are the results of what HRA learned when testing various chapters during both usability tests and focus group testing.

Below is a list of the materials tested in both focus groups and one-on-one usability interviews, followed by a description of the main themes that emerged while testing each of the chapters. The languages that the chapters were tested in are also given.

Table 16 Chapters Tested with Consumers			
Chapter Title	Number of Times Chapter Was Tested in a Usability Test	Number of Times Chapter Was Tested in a Focus Group	Languages Chapter Was Tested In
County-Specific Insert	16	9	English Chinese Spanish ASL
Prescription Drugs	5	3	English Spanish
You Can Choose the Kind of Medi-Cal You Want	4	6	English Chinese Spanish
There Are Two Kinds of Medi-Cal	9	6	English Chinese Spanish
Costs	6	2	English Spanish
Doctors and Other Providers You Can Use	3	5	English Spanish
Language, Interpretation, and Sign Language Services	5	3	English Chinese Spanish ASL
Using Services if You Have a Disability	3	2	English Chinese
How to Enroll In, Change, or Leave a Medi-Cal Managed Care Plan		1	English

County-Specific Chart/Insert

In most consumer interviews and focus groups, participants had indicated that they wanted the guide to include information about Medi-Cal choices specific to their county. Instead of just a general comparison of Regular Medi-Cal (FFS) and Medi-Cal Managed Care, they wanted to be able to compare the details of the plans available in their county. Since Medi-Cal Managed Care Plans are different in every county, HRA designed county-specific charts for each of the three pilot counties to insert into the front of the guides. These county-specific chart/inserts list the names and numbers of the Medi-Cal Managed Care Plans in that county. They allow consumers to make a side-by-side comparison between the different Medi-Cal Managed Care Plans in their county and Regular Medi-Cal. The format and content of these charts were tested extensively in usability interviews and focus groups in all three pilot counties.

Most participants understood the chart. Overall, participants were able to understand the chart and felt it was helpful to have a comparison between the plans and the benefits. Participants in both focus groups and usability tests commented positively about the design and layout of the chart. Some liked the phone numbers and information about hospitals. They also enjoyed the convenience of having information about different Plans all on one page.

> *I like the chart because it breaks the three [choices] all down. Instead of looking for a paragraph to answer your question, you can just look at the chart, and it's easier.*
> —English-speaking Consumer

> *It says very clearly here, 'Managed Care Plan…' and which hospitals you can go to, the costs, hours, etc. This is pretty clear, the information explains everything. So these two Managed Care Plans have more hospitals than Regular [Medi-Cal]. And the costs are lower. Those are the main differences I see.*
> —Cantonese-speaking FFS Consumer

In the usability tests, participants were asked questions to ascertain whether they were able to make the connection between the chart and information in the rest of the guide. Most participants were able to look at a page number next to a topic in the chart and find corresponding information in specific chapters in the guide.

Chart shows MMC in a favorable light. Some participants felt that the chart did not provide as much information for Regular Medi-Cal as it did for the Managed Care Plans. As a result, they felt that omission of a phone number to call for Regular Medi-Cal would influence people to sign up for managed care.

> *I know there's a movement to make [as many] people enroll in the different health care plans as possible, but in omitting any information about [Regular] Medi-Cal seems to…steer [consumers] towards Plans rather than actually presenting…straight Medi-Cal [as] a reasonable alternative.*
> —English-speaking MMC Consumer

MMC quality ratings. In earlier versions of the insert, quality ratings of the different MMC plans were included in the chart. These ratings were taken from HEDIS measures and were published in the

My Medi-Cal Choice For Healthy Care handbook, created by Health Care Options. There were mixed reviews about the usefulness and credibility of these ratings. Some participants liked the ratings and said the ratings would be influential in their choice of plans.

> *I think how they rate would be the most important because you could have six doctors, you could have sixty doctors. If the six doctors don't do that well— or the sixty doctors don't do well and the six do—you're going to go with the six. So I think how they rate would probably be one of the most important to me, or to her, to a lot of people.*
> —English-speaking FFS Consumer

Other participants challenged the ratings listed in the chart, saying they would want to know more about what the ratings were based on before they would be useful.

> *I have a question, too. When you say you're rating people, like, who rated them? [It] could be just anybody's personal opinion. If it's like a group study that someone says this one does better, then maybe you should say Molina rated higher than getting appointments and treatment than IEHP, from a customer study, or something like that. 'Cause anybody could have just put that there…. I personally I would not go upon the ratings, you don't know who [is doing the] rating.*
> —English-speaking FFS Consumer

As a result of participant feedback, as well as questions about the validity of the ratings, HRA decided to omit them from the chart.

Chapter: There Are Two Kinds of Medi-Cal

Participants in the formative research were almost consistently unaware of the fact that they could choose between Regular Medi-Cal and Medi-Cal Managed Care Plans. The purpose of this chapter is to explain to Medi-Cal consumers and their caregivers/health-care proxies that there are two kinds of Medi-Cal — Regular Medi-Cal and Medi-Cal Managed Care. Other main points of this chapter include the following:

- Both kinds of Medi-Cal offer the same basic benefits.
- You do not have to pay for MMC.
- You can change back to FFS if you do not like MMC.
- Medicare is not the same as Medi-Cal.

Participants understood that there are two kinds of Medi-Cal. The following quotes show that participants understood there are two types of Medi-Cal after reading this chapter.

> *I think it comes across pretty clearly. As far as where it says Straight Medi-Cal —you could see there's a difference between that and the Medi-Cal HMOs, so I think that's pretty clear, to me at least.*
> —English-speaking FFS Consumer

> *They are talking about Medi-Cal, and it's for low-income. There are two kinds, one is Regular Medi-Cal, the other Managed Care Medi-Cal.*
> —Cantonese-speaking FFS Consumer

The same, yet different? For some participants, it was confusing when the chapter said that there are two types of Medi-Cal and that they essentially offer the same benefits. Many participants wondered what the motivation was to switch if the benefits are the same. The following quotes highlight this dilemma and the need for more details on the distinction between MMC and FFS.

> *They say it's the same, but there must be differences…I feel that this special 'Managed Care,' I feel that they MUST have something different about them. If they are the same, then there's no need to mention it. What are the differences? They say both are the same. So if they are the same, why is there a need for Managed Care Plan? Right?*
> —Cantonese-speaking FFS Consumer

> *It says, no matter what kind of Medi-Cal you choose…well, there's probably some differences between them.*
> —Cantonese-speaking FFS Consumer

There is an exit strategy. In response to participants' requests for information about the MMC exit strategy, the guide addresses this issue repeatedly.[7] After reading this chapter, usability test participants were asked, "What can you do if you enroll in a Managed Care Plan and you are not satisfied with it?" To which some participants responded the following:

> *Go back to what you originally had.*
> —English-speaking Consumer

> *You can change the kind of Medi-Cal at any time.*
> —English-speaking Consumer

Difference between Medi-Cal and Medicare. Consumers on Medicare were excluded from the study. Thus, all participants had Medi-Cal only. Many participants were very curious about Medicare because they had heard it provided better benefits. Because they wanted more information about Medicare, some were confused by early versions, thinking the guide was talking about Medicare. As a result, it was imperative for the guide to explain that Medi-Cal and Medicare are different programs and that this guide is only about Medi-Cal. After reading the chapter, most participants learned that there is a difference between Medicare and Medi-Cal even though they sound similar. Most also understood that the consumer guide was not for people on Medicare.

> *But listening to them [the names 'Medicare' and 'Medi-Cal'], it sounds like they're the same, but they're different.*
> —Spanish-speaking FFS Consumer

> *I like what it says here, 'if you have Medicare this booklet is not for you.' So that immediately tells them, OK, I don't need to bother with this, which could be very confusing if they did not.*
> —English-speaking MMC Consumer

Chapter: You Can Choose the Kind of Medi-Cal You Want
The purpose of this chapter was to help the consumer identify himself or herself as a Medi-Cal consumer who was either a person with a disability or a senior. This chapter attempts to explain to such consumers that they have different choices than people who qualify for Medi-Cal for different reasons. Another main point is to remind consumers that switching to MMC does not cost anything.

Seniors and persons with disabilities have different choices. After reading this chapter of the guide, participants understood who the guide was for and why the guide was for them.

> *Yes, this part [about who the guide is for] is quite clear, seniors and persons with disabilities. Low-income children and families will NOT use this guide.*
> —Cantonese-speaking FFS Consumer

What kind of Medi-Cal I have. After reading an early version of this chapter, some participants still had trouble identifying the information in the chapter with their own situation. These participants needed more help on how to identify the type of Medi-Cal they had.

> *It says here there are two types of Plans. I just don't know which kind I have. I really don't know. It's not clear.*
> —Mandarin-speaking FFS Consumer

> *[The woman in the story] is on Medi-Cal because she has disability, and she can choose one of the two in her county. I understand this. But the question is whether we [fit] this qualification….*
> —Mandarin-speaking FFS Consumer

Because of the difficulty some participants had identifying the type of Medi-Cal they have, HRA added information describing the different Medi-Cal cards that a consumer would have if they had FFS Medi-Cal or MMC.

Awareness of choice—questions and experiences. When participants viewed the "You Can Choose the Kind of Medi-Cal You Want" chapter, some clearly understood that they had a choice between MMC plans in their county and FFS. They also understood why they are eligible for Medi-Cal.

> *What I see, you at least you have a choice to choose, either straight Medi-Cal or a Plan. That's what I see out of this page.*
> —English-speaking MMC Consumer

It does not cost anything to change to MMC. Many participants had specific questions regarding how much it would cost to change to MMC, what the process was, and if they were required to make the change; because of those concerns, HRA added information on these issues to the "Questions and Answers" section of this chapter. After this addition, participants understood that there was no penalty for changing plans and they understood what the process entailed.

Reading both intro chapters together had the greatest impact. In some usability tests and focus groups, participants were asked to read the first few chapters of the guide. They were then asked to tell us when they understood that they could choose between FFS and MMC. Participants who read the "You Can Choose the Kind of Medi-Cal You Want" chapter in conjunction with the previous "There Are Two Kinds of Medi-Cal" chapter had the greatest understanding.

> *Not the first one [Two Kinds of MediCal], but (on the) second one [You Can Choose]…now I can see what the three choices do.*
> —English-speaking FFS Consumer

Participants also indicated that they were able to understand their choices best when they read the two introductory chapters in addition to the chart.

> *If anything was confused about the first two pages [There are 2 Kinds of Medi-Cal* and *You Can Choose the Kind of Medi-Cal You Want] [the chart/insert] pretty much answers it.*
> —English-speaking FFS Consumer

Chapter: Costs
Consumers and caregivers who were interviewed or attended focus groups expressed that out-of-pocket expenses were of major concern to them. To address this concern, information about costs and statements that MMC is not more expensive than FFS Medi-Cal are reinforced throughout the guide. In the "Costs" chapter, an attempt was made to make some specific comparisons of costs between FFS and MMC. The main points of this chapter were:

- In MMC, you do not pay anything for care or prescriptions whereas in FFS Medi-Cal you may have to pay up to $1 for prescriptions.
- To avoid getting a bill, make sure your provider takes your kind of Medi-Cal.
- The law says that if you are in MMC, your plan cannot send you a bill. In FFS, the law says that Medi-Cal providers cannot bill you for services covered by Medi-Cal.

In the usability tests, participants understood that there were differences in the costs of prescription drugs under Regular Medi-Cal and Managed Care Plans. After reading the chapter, participants understood what to do in the event they mistakenly received a bill.

In the focus groups, participants understood the content of the "Costs" chapter. They thought it provided important information that would help consumers decide which kind of Medi-Cal to choose.

> *Everything is clear.*
> —Spanish-speaking FFS Consumer

> *I think where it says your Medi-Cal providers cannot bill you for services is something that is very important for people to know.*
> –English-speaking MMC Consumer

Chapter: Prescription Drugs

The "Prescription Drugs" chapter was created because questions about prescription drug coverage were some of the most common questions and concerns participants had about their coverage. Most participants had had an experience where a drug prescribed by their doctor was not covered by Medi-Cal. As a result, one of their greatest concerns was to find out which of the plans would cover their prescription drugs and what the differences were in the number of drugs covered. In response to these and other concerns, the "Prescription Drugs" chapter emphasized the following points:

- Medi-Cal covers many prescription drugs and some over-the-counter drugs.
- There is a list of preferred drugs (the formulary). You must get drugs from this list. If you need a drug that is not on the list, you must ask for authorization from your Plan or Medi-Cal.
- You must use pharmacies that accept your kind of Medi-Cal.
- In FFS, you can get six prescription drugs per month without authorization; if you need more, you must ask for authorization. In MMC, there is no limit to how many prescriptions you can get per month without authorization.

In the usability tests, the participants understood the chapter after reading certain sections and were able to identify the chapter's main points. The participants commonly felt that the information was useful and could help them resolve issues.

How can I find out if my prescriptions are covered? Most participants indicated that they would not be able to switch to MMC without knowing more about whether or not their prescriptions would be covered. On the prescription page is an indication that you must call the health plan to find out if a prescription is covered. The individual health plan numbers are not listed on the prescription page but are located on the county-specific insert/chart; this is because the guide is for consumers statewide and MMC plans are specific to each county.

Differences between MMC and FFS Medi-Cal prescription coverage. Participants wanted specific information about any differences they might find between MMC and FFS prescription coverage. One participant recommended that we insert the information about such differences between the number of medications covered per month and the dollar amount they would cover for each type of Medi-Cal plan. The information requested by this participant was included in the guide.

> *It says 'call the number so you can find out if your medications are covered.' But I think a thing saying how many they'll cover or what dollar amount they'll cover, that's a simple one-line thing you could be added, and it would not mess up the chart too much. But it's vital for us making decisions as to change or not change.*
> —English-speaking FFS consumer

Information doesn't reflect consumer experiences with prescriptions. A challenge in creating the "Prescription Drugs" chapter was that participants felt the information did not match their real life experiences. For example, in the early versions, the materials indicated that if a consumer had difficulty getting a prescription drug covered, he could talk to the pharmacist and the medication would easily be covered. This, however, was not a scenario that seemed realistic to consumers whose experiences included filling out authorization forms and then waiting several weeks to get their medicine.

On hearing this type of feedback from consumers, HRA changed the story about this issue in the chapter to read, John asked his doctor to fill out an authorization form. It took a few weeks, but after that, John's medicine was covered again. After making this change, however, the Advisory Group suggested making further changes, as, legally, once the doctor sends in the authorization form, authorization can take only two days. So, once again this part of the chapter was changed, and it now reads, John asked his doctor to fill out an authorization form. After his doctor sends in the form, authorization takes two business days.

Chapter: Doctors and Other Providers You Can Use
In response to consumers' concerns about how choosing MMC could affect their access to providers, HRA created a chapter addressing these issues. The main points of this chapter were:

- A provider is a doctor or someone else who offers medical care. Your main doctor is your primary care provider (PCP).
- In FFS, you may have a PCP, but you do not have to have one; if you want a PCP, you have to find him or her on your own. In MMC, you must have a PCP and your Plan can help you find one. Similarly, if you are in MMC, your Plan can help you find specialists.
- In FFS, you must use providers who accept FFS. In MMC, you must use providers in your Plan, which is called the network.

Information about access to specialists particularly helpful. In usability tests and focus groups, participants found that the information about specialists was particularly helpful. Many participants also thought that the chapter indicated it would be easier to access specialists in MMC Plans.

> *Ah, here's finally something good about the Managed Care Plans. The Plan will help you find a specialist. You're not entirely on your own. So if I had trouble finding a specialist, I might wish I was in the Managed Care Plan.*
> —English-speaking FFS Consumer

> *Yeah the whole page just says basically that if you choose the Medi-Cal with Managed Care Plan you have it simpler.*
> —English-speaking MMC Consumer

Information in the guide does not reflect consumer experiences. Some participants thought the provider chapter did not match their experiences of being referred to a provider on FFS. Some participants on FFS had been referred to specialists by their primary care provider. Others on FFS required a referral to a specialist.

> *There's some false information in here, though. Regular Medi-Cal, on the right side, says, 'You must find a specialist who takes regular Medi-Cal.' And then Medi-Cal Managed Care, it says, 'Your primary care doctor will refer you,' and that's false, because under Regular Medi-Cal, my doctor referred me. They found me and referred me. They did both things.*
> —English-speaking FFS Consumer

I tried to go to UC San Francisco to get a mammogram. But I had to be referred. I still had Regular Medi-Cal. This is acting like Regular Medi-Cal, you don't have to need a referral. But you really do. So they're kind of deceiving you a little bit.
<div align="right">—English-speaking FFS Consumer</div>

The information about how to see a specialist outside your Plan was helpful.

This is something I did not know, over here in the question and answers. If you want to — you have to see a specialist in your Plan first, and then you can go to a specialist outside of your plan if they approve it, it says. I did not know about that.
<div align="right">–English-speaking FFS Consumer</div>

Chapter: Language, Interpretation, and Sign Language Services
When the "Language, Interpretation, and Sign Language Services" chapter was tested with English speakers, it was not something they could relate to and thus, gave very little feedback. However, when Mandarin- and Spanish-speakers were tested with the chapter, they found the information useful. They understood, based on the chapter, that translation and interpreting services were available to them no matter what kind of Medi-Cal they have. Participants also understood that they could request someone other than their child to serve as an interpreter.

Participants' perception of managed care's language services. Based on the draft chapter, some participants thought MMC Plans offer better access to interpreters.

It seems a little dubious … the way they wrote it…with Managed Care Medi-Cal, it is easier… it's easier to find translation service….
<div align="right">—Mandarin-speaking FFS Consumer</div>

It seems the Managed Care kind works better for people like us. It seems that it is easier to find translation service (with managed care).
<div align="right">—Mandarin-speaking FFS Consumer</div>

Like look at the Chinese girl who found a doctor who speaks her language, that's really good.
<div align="right">—Spanish-speaking FFS Consumer</div>

Comments about the draft language chapter by Deaf participants. The "Language, Interpretation, and Sign Language Services" chapter was tested extensively in the focus group with Deaf consumers, who gave a great deal of feedback on how to improve the chapter. Many suggested revisions to the title, text, and photos to make it more specific to the Deaf community. Some thought ASL should be in the title of the chapter; others suggested moving the ASL symbol to the top so it would be more noticeable.

I like this [sign language symbol], because sometimes when you go in you know you, it has the interpreter symbol so it's easy to access that and to know, maybe they could have a symbol in the doctor's office so I know where to meet the interpreter when I go in.
<div align="right">—Deaf FFS Consumer</div>

I'd prefer to see ASL right in the title because it's not as clear to me the um, the way that you just mentioned. Um, because they might mean foreign language interpreters, so I'd like to see ASL interpreter there.

—Deaf FFS Consumer

You know, [the sign language symbol] is all the way down here. You know, they could have it all the way at the top. So people could recognize it.

—Deaf FFS Consumer

Other suggestions for content. One other suggestion from the participants in the Deaf focus group was that there should be at least one photo in the "Language, Interpretation, and Sign Language Services" chapter that included a Deaf patient, a sign language interpreter, and a provider. HRA is currently conducting a photo shoot and plans to include this image in the guide.

They should have three interpreters in this picture. One, uh, a deaf interpreter, the doctor, the interpreter, the doctor, and the patient.

—Deaf FFS Consumer

Suggestions for other formats / complementary interventions. Deaf consumers had many recommendations for other formats that would be helpful for consumers with hearing impairment. They suggested TTY numbers, websites, and video-streaming technology.

So it should have a [website] where you can click on for deaf people where it has issues related to deaf people…. It should have a 'Deaf,' and then all the issues related to Deaf people would listed under there.

—Deaf FFS Consumer

Key Informant Interviews

Another formative research component was the use of key informant (KI) interviews to solicit information from a broad range of professionals, providers, policymakers, and advocates who serve seniors and persons with disabilities on Medi-Cal. The main goals of the key informant interviews were to:
1) Get professional opinions about the barriers SPD face in making informed choices about Medi-Cal;
2) Ascertain professionals' understanding of Medi-Cal choices and major misconceptions about MMC;
3) Discern professional opinions about the unmet informational needs of SPD; and,
4) Understand professional opinions about the best formats for and means of disseminating information.

Methods and Recruitment
Purposive sampling techniques, informed by the literature review; input from the project Advisory Group members; and DHCS were used to develop a list of the kinds of organizations and services and the specific disability/senior groups whose perspectives should be included in the interviews. Project

staff identified a long list of potential key informants in each of the three pilot counties. Potential key informants were assigned to one or more organizational, service, or cultural ethnic categories in their county, and the list was prioritized within each category and county.

Potential key informants were invited, by phone or email, to participate in the interview. When they agreed to participate, an appointment was set up and they were emailed or mailed a copy of the interview and consent script.

The key informant interview was semi-structured. Some of the data collected was quantified, and those frequencies are reported below. Other open-ended responses were thematically analyzed and not quantified.

Sample

Telephone interviews were conducted with 51 key informants in the three pilot counties as well as individuals who could speak to statewide issues:

- 12 statewide and in nonpilot counties
- 17 in Alameda County
- 13 in Riverside County
- 9 in Sacramento County

There were three main types of key informants:

- 24 service providers
- 7 policy makers
- 20 representatives of Medi-Cal Managed Care Plans

Service provider key informants. Twenty-four service provider key informants from 24 different service-providing organizations were interviewed, both individually and in groups. Types of organizations included:

- 7 Federally Qualified Health Centers (FQHCs), including one Latino-specific clinic, one Native American-specific clinic, and one Asian-specific clinic
- 2 county hospitals
- 1 county social services agencies
- 1 community clinic
- 1 Independent Living Center (ILC)
- 1 blind services/advocacy organization
- 1 Multipurpose Senior Services Program (MSSP) in a city department of aging, health, and human services
- 1 DME contractor accepting Medi-Cal
- 1 Regional Center
- 2 independent primary care providers accepting Medi-Cal
- 1 Rehabilitation Center
- 1 Homeless Senior Case Management program
- 1 community organization serving persons with disabilities and their families
- 1 independent pharmacy (large chain) accepting Medi-Cal FFS and MMC
- 1 supported living program for persons with developmental disabilities
- 1 Program of All-Inclusive Care for the Elderly (PACE) plan

Target populations served. Of these service-providing organizations:
- 3 serve seniors
- 6 serve persons with disabilities, including seniors with disabilities
- 2 serve persons with developmental disabilities
- 15 serve all Medi-Cal consumers, including seniors and persons with disabilities

Ethnic groups served. Of these service-providing organizations:
- 9 reported serving African-American consumers
- 8 reported serving Latino consumers
- 8 reported serving white consumers
- 8 reported serving Asian/Pacific Islander consumers
- 3 reported serving Chinese consumers
- 5 reported serving American Indian consumers

Types of provider roles. Provider key informants held a variety of roles within their organizations:
- 7 physicians, including 2 physicians-in-charge and 2 department chiefs
- 1 physician's assistant/clinic manager
- 1 Medi-Cal billing specialist
- 1 social worker
- 2 member services managers
- 1 Deaf services counselor
- 1 DME specialist/vendor
- 1 pharmacist
- 1 coordinator of a county developmental disabilities council
- 1 case manager for homeless seniors
- 3 executive directors/CEOs
- 4 program directors or managers

Policy key informants. Seven key informants from seven different policy/advocacy organizations were interviewed, both individually and in groups:
- 1 MMC enrollment contractor
- 1 county public health department
- 1 clinical pharmacist
- 1 long-term care integration program
- 1 consultant for a disability organization
- 1 disability consultant for Medi-Cal
- 1 public hospital association

Types of policy roles. Policy key informants held a variety of roles within their organizations:
- 1 enrollment service representative
- 1 Director of Policy
- 1 clinical pharmacist
- 1 county health officer/Chief of Medical Services
- 1 consultant with expertise on disability access
- 1 consultant with expertise in occupational therapy
- 1 consultant with expertise on the Long Term Care Integration Project in California

Medi-Cal Managed Care Plan key informants. Twenty key informants from 12 different Medi-Cal Managed Care Plans were interviewed, both individually and in groups. These included key informants from Two-Plan, Geographic Managed Care, and County-Organized Health System counties.

Types of Medi-Cal Managed Care Plan roles.
MMC Plan key informants held a variety of roles within their organizations:
- 1 member services director
- 3 program directors
- 1 outreach specialist
- 1 chief marketing officer
- 2 disability program managers
- 1 special needs consultant/former director of health education and cultural and linguistic services
- 1 Medi-Cal product manager
- 1 case manager
- 1 regional director
- 1 Medi-Cal contract compliance specialist
- 3 directors of pharmacy services
- 2 medical directors, including one specializing in durable medical equipment (DME) services
- 1 director of health services
- 1 regional center community liaison

Findings from Key Informant Interviews

Information Sources for SPD
Key informants were asked to report on the types of information that consumers use to make Medi-Cal choices. The most commonly cited sources of information for consumers about Medi-Cal choices were:
- Information from providers (3)
- Information from Health Care Options (2)
- Information from HICAP (2)
- Information from Medi-Cal or DHCS (1)
- Information from one or more of the MMC plans (1)
- Information from some other source (6)
- MMC plan website (1)

Barriers to Making Informed Choices About MMC
Key informants were asked to report on the barriers to consumer decision-making and enrolling in MMC.

1) Consumers lack information or knowledge about MMC.
- 41 KIs said that consumers cannot make informed choices because they lack information or knowledge about MMC.

- 27 of the KIs knew that there was currently information available about Medi-Cal choices for SPD.
- 3 KIs believed that SPD currently receive adequate information to make a choice.
- 33 KIs said that the current information available is inadequate, incorrect, or biased.
- 3 KIs said that consumers don't know what kind of Medi-Cal they currently have.

2) The enrollment process is too lengthy or confusing.
- Consumers face language barriers when seeking out information on Medi-Cal choices or trying to complete paperwork.
- Consumers are fatigued with frequent Medi-Cal changes.

3) There is a lack of direct outreach to consumers by Medi-Cal, MMC Plans, and community and advocacy organizations.
- Information does not reach marginalized groups.
- Some consumers are isolated and lack access to resources and social support.

4) Consumers have negative perceptions of MMC.
- Consumers already have many misconceptions about MMC.
- Consumers are not aware of the advantages of enrolling in MMC.

They know they have a choice but they already have misinformation. They've already been told that MMC is horrible. 'Stay with FFS for as long as you can.' That is definitely the message. I was working at the county when they had the BIC cards and when people had to give up these cards…there were practically riots on the streets. Nobody wanted to give up their freedom to have their Disneyland tickets to see any doctor they wanted. They have not been hearing about the studies that people do better on MMC. They only hear anecdotal stories about managed care.
—Anonymous key informant

5) Providers are not explaining Medi-Cal choices to SPD.
- Providers are uninformed about Medi-Cal choices for SPD.

I don't really understand how it's decided – whether a patient can say FFS or opt for an HMO or if it's cheaper or if there's an income cutoff, I really don't know.
—Medical Director of an FQHC

Providers need to be educated. Social workers, too. It would be a good idea to have a separate guidebook for providers giving them information about the differences and other provider-related information, like what is covered, reimbursement rates, etc. Most providers are underinformed.
— Private provider who accepts Medi-Cal

- Providers have little time to explain choices to consumers.
- Providers may be biased against MMC because of lower reimbursement rates.

The main difference between FFS and MMC for us is the reimbursement rate. We have a negotiated capitated rate for our MMC consumers since we are a Federally Qualified Health Center, and it is lower than the reimbursement rate for FFS consumers. The disadvantages of MMC is that we get a capitated rate and often times the visit will cost more than the capitated rate, especially if the patient visits four times a month with a chronic illness versus patients who are healthy and never come in (and we still get a monthly capitated rate for them). We absorb a loss when we have patients in MMC plans who use lots of services.
                                        —Member Services Manager at FQHC

Although we see everyone, ...we get more with FFS usually and do better financially if patients have FFS. We get FQHC reimbursement, so we get more than $15, as in MMC. With FFS, we bill for services at the Medi-Cal rate.
                                        —Medical Officer at County Health Department

Key Informant Suggestions for Consumer Guide Content
General suggestions from key informants for additions to the guide:
- Question and answer sections
- Stories and scenarios about factors important to consumers
- Side-by-side comparisons of Medi-Cal options
- Resources that help consumers learn how to get more information and assistance
- Step-by-step instructions that empower consumers to find out whether FFS or MMC better meets their specific needs

Content suggestions from key informants (their numbers in parentheses) for the guide:
- General information about MMC benefits and costs (18)
- Information about access to providers (18)
- How to get support and help with Medi-Cal choices (6)
- Information about prescription drug coverage (8)
- Information about DME coverage (4)
- Side-by-side comparisons of the advantages and disadvantages of FFS and MMC (2)
- Information about transportation (3)
- Information about the appeals process (2)

Many key informants also suggested that the consumer guide should include tips about how to navigate the Medi-Cal system:

- How to find out more about Medi-Cal benefits and choices (7)
- How to find providers (7)
- How to enroll in or disenroll from MMC (3)
- How to access prescription, language interpretation, and DME services (4)

Writing the Guide

The Process

Staff at HRA began this project by writing a draft guide. This was used for internal discussions and discussions with the Advisory Group to determine what information should be included in the guide. After creating multiple drafts of the guide, HRA began usability testing of specific sections of the guide. Based on the results of usability testing, changes to those sections would be made, and they would then be brought to focus groups for testing. Based on those results, additional changes would be made, and sometimes additional usability testing was conducted. The next step was for DHCS to review the guide, and after their feedback was incorporated, the Advisory Group reviewed it. Their changes were then incorporated, additional usability testing was conducted on the entire guide (rather than on specific sections), and again, more changes were incorporated. Finally, DHCS received the guide for final sign-off; at the time of writing this report, DHCS is in the midst of their review process.

Dissemination Plan

During all aspects of the formative research, HRA queried focus group and consumer interview participants as well as key informants on how to best disseminate the guide. Below are the main findings:

1) **Mail the guide directly to new beneficiaries and those with both Regular Medi-Cal and MMC.**

   I think through the mail is really good. Because I don't go out that much…and I don't look on a computer or anything.
   —English-speaking MMC Consumer

   Send them out like they send out everything else, in the mail.
   —English-speaking FFS Consumer

   Medi-Cal Managed Care Plans send a welcome packet and this guidebook should be part of the packet.
   —Member Services Manager at FQHC

2) **Distribute the guide through providers.**
   Some participants, both consumers and key informants, recommended distributing the guide at doctor's offices and clinics.

The place where we see the doctors ...what we call the waiting room. I have seen many pamphlets there, such as the one about ...seeing a doctor.... Once I read (the pamphlet), I understood how to go see a doctor at the Asian Health Services.
—Mandarin-speaking FFS Consumer

Well, I think it's obvious that ...you would want to circulate (them at) the health clinics.
—English-speaking FFS Consumer

I think you could probably send it out to clinics. Like at our clinic, we have a Medi-Cal worker who(se) job it is just to enroll people and help them with the application process in Medi-Cal.... That would be a very useful tool for us to have.
—Medical Director of an FQHC

3) Distribute through community service and advocacy organizations.

Maybe the senior assisted living type, some of those places maybe...They have it in other languages, you know, they have...a lot of different cultural, different places, too.
—English-speaking FFS Consumer

Even some local churches might be willing to put pamphlets out. You'd cover a lot of people in the community.
—English-speaking MMC Consumer

Churches, community centers, recreation centers, adult day programs...
—Clinic Manager at FQHC

4) Distribute through SSI or County Medi-Cal offices and all DHCS contractors.

Maybe at the Social Security office, because that's where a lot of people seek information.
—English-speaking FFS beneficiary

Mental health case managers, every state contractor of DHCS (such as Maximus), DHS offices, clinics, hospitals....
—MMC Plan Director of State Programs

5) Additional suggestions for dissemination points included the following:
- Assisted technology programs
- Durable Medical Equipment (DME) stores
- Health fairs
- HICAP, Legal Aid, Health Care Options, and other benefits counseling agencies
- Pharmacies, grocery stores
- Regional Centers

On presenting these findings to the Advisory Group, several additional modes of dissemination were suggested:
- Paratransit offices
- Social work departments in hospitals
- Specialty care centers
- Pharmacies, which have the highest volume of Medi-Cal encounters
- Low-income housing or senior housing
- Regional Centers, but note that mail does not always get to the right place
- Mental health and other case management programs
- Via letters or education pieces, explaining to social workers, etc., the purpose.
- Department of Rehabilitation
- Posters for clinics or hospitals that say, "For information, please call."
- Throw-away newspapers
- Reinforcing, saturating, and providing information from multiple sources

Because beneficiaries requested quite strongly for the guide to be mailed to them, the U.S. Postal Service will be HRA's primary method of dissemination. According to numbers provided to HRA from DHCS, there are close to 70,000 Medi-Cal beneficiaries in the target population for the pilot project; this was the rationale for deciding that HRA would print 60,000 – 70,000 copies of the guide, and means that virtually all of them will be mailed directly to beneficiaries.

The guides will be mailed in envelopes created based on feedback from formative research and will be sent out in lateApril 2008. Any remaining guides will be distributed to:
- Health Care Options
- Regional Centers
- Federally Qualified Health Centers (FQHCs)
- Advocacy groups
- HICAP
- Legal Aid

In addition to distributing the remaining guides to the above-mentioned types of organizations, HRA may conduct trainings at those organizations to demonstrate how the guide can best be used, point out specific sections, and give background information on how it was created.

Future Steps

Translation

On completion of the guide in English, HRA will translate it into Spanish and Chinese. The Spanish and Chinese versions will be included in the dissemination to the pilot counties.

Alternative Formats

HRA plans to make the guide available in text-only, Braille, large print, audiotape, and CD-ROM, as needed.

Advisory Group Meetings

HRA will hold five more Advisory Group meetings throughout the duration of this project.

Evaluation of Guide in Pilot Counties

In year two of the project, HRA will conduct a comprehensive evaluation of the guide in the three pilot counties. This evaluation will include:
- A pre- and post-intervention telephone survey
- 20-40 consumer interviews with members of the target population
- 25 key informant interviews with providers, advocates, and policymakers
- 9 evaluative focus groups with members of the target population

Telephone Survey
The purpose of the Medi-Cal Access Project telephone survey is to conduct an outcomes evaluation of the consumer guide in the three pilot counties. A pre- and post-intervention telephone survey will be conducted with SPD Medi-Cal beneficiaries in the three pilot counties. The purpose of the telephone survey is to:
1) Assess the level of understanding of Medi-Cal choices in a random sample of Medi-Cal beneficiaries in the target population;
2) Assess the impact of the guide on those beneficiaries' core knowledge about their Medi-Cal choices; and
3) Assess whether receipt of the guide makes an impact on beneficiary behavior or potential behavior, especially in terms of making an informed choice to choose a Medi-Cal Managed Care Plan.

The population surveyed will include Medi-Cal beneficiaries who are seniors (over 65 years old) or persons with disabilities. Only people over age 18 will be interviewed. Potential participants will be randomly selected from a list provided by the California Department of Health Care Services (DHCS), which will include all Medi-Cal beneficiaries who are included in approximately ten different SPD aid codes in Alameda, Riverside, and Sacramento counties. If a potential participant does not make his or her own health care choices due to cognitive impairment or other disability, a caregiver or proxy who is their primary health-care decision maker may be interviewed. To be included in this study, participants must be fluent in English, Spanish, Cantonese, or Mandarin. Medi-Cal beneficiaries are excluded from this study if they are also Medicare beneficiaries.

Potential participants will receive a letter notifying them that they will receive a phone call about participating in the study. The telephone survey will include a baseline telephone survey with a random sample of SPD Medi-Cal beneficiaries or health care proxies. Half of those surveyed will

then get mailed a copy of the guide (intervention group) while the other half will not get the guide (comparison group). All participants will then receive the first follow-up telephone survey. After the first follow-up call, the comparison group will then get mailed a copy of the guide and will get a second follow-up telephone survey. All survey participants will receive a stipend to compensate them for their participation time.

The number of baseline interviews needed is estimated to be 840 (280 English readers, 280 Spanish readers, and 280 Chinese readers.) To reach these numbers, it is anticipated that 1,200– 2,000 Medi-Cal beneficiaries will be screened; many people who are initially called may not be eligible based on our exclusion criteria, may not be reachable by phone, or may not be willing to participate. HRA expects to conduct 672 Time 2 (T2) interviews and 330 Time 3 (T3) interviews, given that some participants will drop out after the first or second interview.

The interviews will contain several different sections of questions. Core knowledge questions will assess participants' knowledge about MMC plans, the differences between Regular Medi-Cal and MMC plans, and the choices available to SPD. Questions about behavior change will assess participants' interest in changing from Regular Medi-Cal to MMC and any action taken. HRA will be able to determine if there was a change in core knowledge and behavior after receipt of the guide.

The interview after the participant has received the guide will include additional questions related to the use and helpfulness of the guide. The initial baseline interview will include questions on basic demographics, (e.g., age, education, race, marital status, and type of disability), which will allow us to see if the effectiveness of the guide varied by any of these factors. The survey instruments are currently being developed and revised, and HRA plans to pilot the instruments prior to beginning the telephone survey.

It is anticipated that the entire survey process will take approximately 18 weeks. Dissemination of the guide to the three pilot counties can begin by week 13, as the second interviews will be completed by then. Assuming a print date for the guide of late January 2008, HRA anticipates completion of the data collection by mid-June 2008. Data analysis will begin after this and is expected to take an additional three to four months.

HRA is in the process of submitting an application to the UC Berkeley Committee for the Protection of Human Subjects (CPHS). Survey participants will be consented over the phone for screening and interviewing, per CPHS requirements. HRA will contract with a survey research company to do the actual telephone survey using Computer-Assisted Telephone Interview (CATI) technology.

Consumer Interviews
Twenty to 40 interviews with SPD Medi-Cal consumers will be conducted before the telephone survey. The purpose of these is to conduct an in-depth qualitative evaluation of the guide. Consumers will be interviewed using the same domains as the baseline telephone survey instrument, but instead of a closed-ended, structured interview such as they will have during the telephone survey, in these interviews, consumers will be allowed to respond to the questions in an open-ended format. After the first interview, consumers will then be sent the guide and will be interviewed a second time using the same domains as the follow-up telephone survey instrument. These interviews will provide rich and detailed data about how SPD consumers use and how well they understand the guide. Because the

interviews will include both pre- and post-intervention interviews, gains in core knowledge can be documented. Conducting these interviews before the telephone survey will allow us to use this data to refine the telephone survey and assure reliability of the instrument.

Key Informant Interviews
Twenty-five key informants who are providers, policymakers, and advocates for the SPD Medi-Cal population will be interviewed to evaluate the usefulness and relevance of the guide. KIs who participated in the formative research were all asked whether they would be interested in seeing the guide and participating in a second interview. Those who consented will be mailed the guide and then called for a telephone interview. KIs will be asked to react to the format and content of the guide. They will also be asked to report on their use of the guide and whether reading the guide resulted in any knowledge gains on their part. Finally, they will be asked to advise on sites and techniques for statewide dissemination of the guide.

Focus Groups
Nine focus groups with consumers and caregivers from the target population will be conducted both during and after the telephone survey. These focus groups will be used to supplement the data collected in the telephone survey. If the survey fails to enroll a certain proportion of SPD consumers (for example, Chinese-reading seniors), HRA will conduct focus groups with that population to supplement the data from the telephone survey. Focus group participants will be mailed copies of the guide so they can discuss it when the group meets. Some focus groups may also be used to test complementary interventions.

Statewide Rollout

On completion of the dissemination of the guide in the three pilot counties, HRA will conduct evaluative research on the usefulness of the guide and the methods of dissemination. Based on feedback, HRA will modify the guide and create a statewide dissemination plan. DHCS will then be responsible for disseminating the guide in all California counties with Medi-Cal Managed Care Plans as well as translating it into threshold languages.

Complementary Interventions

The following complementary interventions were suggested during the formative research:
- Phone line/help line
- Website
- DVDs
- Trainings

HRA will explore these options further, along with additional analysis of information gathered on this subject during the formative research, and in upcoming years will develop selected complementary interventions.