Project to Improve the Model Evidence of Coverage (EOC) Document, Phase I:

Summary Report of Results from Consumer Testing of the Revised Evidence of Coverage

Prepared for the Centers for Medicare & Medicaid Services (CMS)

CMS Prime Contract No. 500-95-0057, Task Order 7, TAO 50

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February 2002

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Introduction

About the Model EOC

Medicare+Choice (M+C) organizations are required by law to send certain information to their new members upon enrollment and to all members each year. They typically send this information in the form of an Evidence of Coverage (EOC). The EOC is part of the M+C organization's legal agreement with its members; it gives the details about benefits and services and how to use the plan. M+C organizations must get approval of their EOC from the Centers for Medicare & Medicaid Services (CMS) before they can mail it to their members. Each year CMS gives the M+C organizations a model EOC template that contains the type of information CMS expects in an EOC and the manner in which CMS prefers that it be presented. This template is called a "model" EOC because it is recommended but not mandatory.

To streamline the CMS approval process and make the EOC easier for beneficiaries to understand and use, CMS is improving the model EOC in a two-phase project that includes active participation of stakeholders and multiple rounds of consumer testing. Two contractors, McGee & Evers Consulting, Inc., and Barents Group of KPMG Consulting, Inc., are assisting CMS in this effort. Beginning with Phase 1 in Spring, 2001, the project has used meetings, website postings, and email communication to solicit suggestions about ways to improve the EOC from stakeholders that included the managed care industry, beneficiary organizations, and CMS staff.

Revisions to the EOC in Phase 1 of the project

CMS selected the following parts of the EOC as the focus for revisions in Phase 1 of the project:

- The cover, including the title
- Welcome Page
- Table of Contents
- Section on Appeals and Grievances
- Several paragraphs about Coordination of Benefits
- Section on Disenrollment

- An appendix about Advance Directives

Working in close collaboration with CMS staff, one of the contractors, McGee & Evers Consulting, Inc., produced revised versions of the sections listed above. These revisions drew on input from the stakeholder groups. They also used guidelines from *Writing and Designing Print Materials for Beneficiaries: A Guide for State Medicaid Agencies*, a technical assistance manual written for CMS by Jeanne McGee. (Center for Medicaid and State Operations, HCFA publication number 10145, October 1999).

The next step was to share the revisions with stakeholders for their feedback, and to test the revisions with consumers. This report summarizes results from the consumer testing of revised EOC text that was conducted in Phase 1. As described below, we interviewed beneficiaries and a few family members to find out how easy it was for them to understand and use the revised EOC. Their reactions to mockups of an EOC have helped us understand and address readers' needs and points of view. Along with feedback from stakeholders, the results from consumer testing summarized in this report helped guide the final revisions to the 2002 model EOC. This model is presently posted on the CMS website at http://www.hcfa.gov/medicare/opl130.htm.

The remaining portions of the EOC will be revised and tested during Phase 2 of the project, which concludes with the release of the 2003 model EOC in fall 2002.

Testing methodology

McGee & Evers Consulting, Inc., and Barents Group of KPMG Consulting, Inc., worked together to conduct three rounds of consumer testing of revised portions of the EOC in summer 2001. We used individual interviews to test mockups of an EOC for a fictional M+C plan that we called "Maple Health Plan."

Who participated in the testing?

We conducted the interviews at research facilities that helped with recruitment of participants, using a recruitment script that we supplied. The script verified experience with a managed care plan and sought a mix of demographic characteristics. CMS regional offices in Seattle and Denver helped us recruit several testing participants who had had experience with the appeals process, using a process designed to protect the privacy of beneficiaries and allow them to express willingness to be interviewed. We paid people for participating, and helped them with transportation, as needed.

Most of the 37 people we interviewed were current or former members of an M+C plan. A few were family members who help Medicare beneficiaries with health-related decisions; these

caretakers and advisors are also an important audience for the EOC. Our recruitment script emphasized that the interviews would involve reading and discussing some materials about Medicare benefits; nearly all of the people we interviewed had sufficient literacy skills to feel comfortable about reading the EOC mockups. In recruiting participants, we sought a good mix of demographic characteristics across the three sites:

- *Gender.* We interviewed 15 females and 22 males.
- *Age.* Three respondents were under age 65, with disabilities; 25 were between the ages of 65 and 74, and nine were 75 or older.
- *Race/ethnicity.* Of the people we interviewed, 23 were white, four were Hispanic, seven were African-American, 2 were Asian, and one was of other (non-specified) race/ethnicity.
- *Education.* Two had some high school or less, nine were high school graduates, four had a vocational or technical college education, nine had some college, and 13 were college graduates. Since our interviews required good literacy skills, the average education of our testing participants is higher than the average education of Medicare beneficiaries in general.

How did we conduct the testing?

Interviews typically lasted about an hour and a half. They were done by a two-person team, so that one person could take the lead on asking questions while the other took notes. We audio taped and videotaped the interviews as well, with one exception due to refusal of taping by the participant. We did our testing in three rounds in the cities of Towson, Maryland; Seattle; Washington; and Denver, Colorado. CMS staff observed some of the interviews from separate observation rooms in Towson and Denver.

We used a combination of cognitive and usability testing techniques to find out how easy it was for people to understand and apply information in the EOC, and to get ideas about ways to make improvements.

We designed our interview guide to address the following types of testing issues:

- What were people's first impressions of the EOC cover and other parts of the document?
- Was the purpose of the document clear?

- How did they react to the content and the level of detail?
- How well did they understand the information?
- Did the way the information was organized and presented make sense to them?
- Was it easy for them to locate particular types of information?
- Could they actually **use** the information?

We used a structured interview guide that was flexible enough to follow up on a respondent's interests and comments. Because our time with each respondent was limited and the EOC sections we tested differed in length and complexity, we typically used several variations of the interview guide during each round of testing. For example, in the first round of testing in Towson, we asked all respondents for feedback on the EOC cover, title, welcome page, and table of contents. Then the final part of the interview covered either 1) *Appeals and Grievances*, 2) *Disenrollment*, or 3) *Coordination of Benefits* and *Advance Directives*.

We began with a brief introduction to the project and its purpose, then showed people the mockup of an EOC for the fictional Maple Health Plan. We asked them to imagine that they were members of Maple Health Plan and had just received the booklet in the mail.

To get feedback that would be useful in guiding improvements to the EOC, we needed to make people feel comfortable enough about the interview situation to say what they really thought. We encouraged them to be critical, and tried to put them at ease by emphasizing that it was the *materials* we were testing, not them. We also wanted them to feel free to say so when they had no opinion, as well as to let us know when they were confused.

The interview guide used a combination of cognitive and usability testing techniques. We gave participants a chance to look through the mockup and observed what they did. We asked them to share their thoughts as they went through the document ("think aloud"), and included some tasks to see if they could use the information as intended ("usability testing").

We avoided asking people direct questions about comprehension, such as asking how hard or easy it was for them to understand the material. Direct questioning of this type does not yield much feedback that is useful for improving a document. Answers may be misleading as well, if people are reluctant to admit that they can't understand, or are unaware of their own mistakes in interpretation. An indirect approach is more tactful and much more informative. We took an indirect approach by asking neutrally-worded, open-ended questions that encouraged people to

share their impressions and reveal their baseline knowledge, attitudes, and interpretations. We asked respondents to explain passages using their own words, and included some navigational tasks that asked them to search for certain types of information in the EOC.

Throughout the interview, we asked open-ended follow-up questions, probing for further details and for the reasons behind what people said. If respondents raised questions from their own experience, interviewers followed up by asking them to look in the EOC for information that would have been applicable to their situations. For example, when one man told about a friend who thought he was sent home from the hospital too soon, we asked him to look at the information on hospital discharge in the Appeals and Grievances section and give his reactions.

Multiple rounds of testing

Since consumer testing helps identify problems with a document, but may not suggest ways to fix them, our approach was *iterative.* We split our interviews into three rounds so that we could make changes to our materials based on what we had learned from the interviews. We used slightly different mockups for Maple Health Plan's EOC in each round, in order to test potential solutions to problems we had identified in the previous round of testing. We also made some changes to our interview guide from one round of testing to the next, particularly if we thought that a particular line of questioning was not working very well, or we felt we had collected enough feedback on a particular section. For example, it was clear from our first round of testing in Towson that people preferred the more detailed Table of Contents to a briefer variation we also showed them, so we did not do any further testing of the short Table of Contents in the other cities. Another example is that we focused increasingly more attention on the Appeals and Grievances section in each round of testing.

The remainder of this report gives highlights of what we learned from consumer testing in Phase 1 of the project. It discusses problematic concepts, wording, and vocabulary in the EOC, as well as respondents' familiarity with the information in the EOC and their attitudes toward managed care and other topics such as the legal system.

General impressions of the EOC

Variations in ease of comprehension

How easy it was for people to read and understand most parts of the EOC depended on a number of factors. With the exception of the most technical and complicated sections (especially the Appeals and Grievances section), most of the 37 people we interviewed were able to understand the material reasonably well. Nonetheless, there great variation in their literacy skills. Several people had so much difficulty understanding the document that we had to drop some of our

questions. Several others were extremely skilled and sophisticated readers who were highly analytical in their responses.

Overall, the people we interviewed differed greatly in their level of interest in the EOC and their attitudes, opinions, and experiences related to managed care. Some people made sweeping and/or negative judgments based on their previous experiences, sometimes before they began reading and other times in reaction to specific topics or sentences.

In addition to differences in their attitudes and literacy skills, people differed in their general approach to reading the document. Skimming was the typical approach, although some of the skilled and less skilled readers read slowly and carefully. Skimmers often missed important points or misinterpreted what they read. Often, they would go back and read more carefully after they had skipped around in the document. Many of the skimmers eventually noticed and corrected their mistaken impressions, either on their own or in response when we asked them specific questions about what they had read.

The document is rather intimidating to many

People reacted to both the length and some of the content of the EOC. Some remarked about the size of the document and the numerous sections. Some were hesitant and seemed intimidated by parts of the document, especially the section on appeals and grievances. However, others reacted with greater confidence and made favorable comments about content and format, saying that they found it easy to read. One person preferred the mockup for Maple Health Plan to the EOC from his own plan: *What I got from my own plan is more complicated than this. The real ones are hard for elderly people to understand.*

Doubt and skepticism were common

Interviews revealed the vulnerability of many respondents, and their comments often reflected a good deal of mistrust of the health care system and health plans, especially when appeals or grievances are involved. Several people expressed fears about being dropped from their plan if they were to file a complaint or if their health declined. Some questioned the utility of filing an appeal or grievance, and were fearful or cynical about anything to do with legal proceedings.

Others reacted very favorably to learning more about the process of appeals and grievances because it made them feel less vulnerable. For example, one respondent got nervous when she read the bullet in this section about “Feeling that you are being encouraged to leave (disenroll from) Maple Health Plan, or feeling that you are being discouraged from seeking the care you feel you need.” She felt it warned her that she might be dropped by her health plan. She was reassured when she read about the PRO later on in the section, because she felt it gave her some protection.

People lacked knowledge about many topics covered in the EOC

Most of the testing participants were unfamiliar with at least some of the information they read about in the EOC mockup. In particular, people tended to lack knowledge about appeals and grievances, and about involuntary disenrollment. Respondents occasionally remarked about what they were learning by being in the interview, and sometimes asked questions about how certain information might apply to them personally. Sometimes they were simply noting that they had been unaware of something, sometimes they were pleased to discover something new (such as learning about the process of outside review for appeals), and other times it caused them some concern to get new information (such as finding out that members can be dropped from the plan).

Purpose of the EOC and how people would use it

The EOC is not a "top of mind" information resource

Most of our testing participants did not immediately recall having received an EOC from their own health plan. Those who did remember receiving such a document usually did not recall or recognize the term "Evidence of Coverage."

People say they would set it aside, and use if later if needed

Respondents typically viewed the EOC as a reference document. They thought they should keep it on hand, but saw no need to read it right away. As one commented, *An older person's not going to take time to read all of this, but it's needed from a legal standpoint.* A few said that if they received the EOC in the mail from their health plans that they would read through it, but most indicated that they would set it aside and read it later on if a need arose. A few who remembered having received an EOC from their own plans admitted that they had never actually read or used it. Even on occasions when they had had questions or concerns, they preferred to call the plan instead.

People prefer to get information by talking with someone

Respondents said they would generally rather get help from a real person than read the EOC, although many complained about long waits on hold when they called their plan. They liked the idea of having the phone numbers prominently displayed on the cover, and some suggested adding bold face to text in various places on the inside that gives contact information.

Reactions to the title and cover

We tested content of the EOC cover by showing people mockups with different combinations of the following three things:

- Variations on wording of the title
- Whether to include the following tag line underneath the title: "This booklet gives the details about your Medicare health coverage and explains how to get the care you need. This booklet is an important legal document, so please keep it in a safe place."
- Whether to include phone numbers for the plan's Member Services at the bottom of the cover

Exhibit A shows the cover they favored, out of all the variations we showed. As we discuss below, people chose the longest title as their favorite because they felt it was the most informative. They also thought it was helpful and convenient to include both the tag line and phone numbers on the cover. When we asked if they thought the resulting cover was "too cluttered," nearly all said no. Comments included the following:

> *All the information is important and it's not too cluttered because it tells you a lot.*
>
> *This eliminates wasted time—the more information before the body of it, the better.*

Exhibit A. This cover was favored by the great majority of testing participants

Maple Health Plan

Your Medicare health benefits and services

as a member of Maple Health Plan

January - December 2002

This booklet gives the details about your Medicare health insurance and explains how to get the care you need. It's an important legal document, so please keep it in a safe place.

Maple Health Plan Member Services

For help or information, please call any time Monday-Friday, 8 am to 6 pm.

Calls to these numbers are free:

1-800-244-8775

TTY/TDD: 1-800-223-8880 (This number is for people who have difficulties with hearing or speech. You need special telephone equipment to use it.)

Title preference

The first title we showed, "**Evidence of Coverage as a Member of Maple Health Plan**" was strongly rejected compared to the other two. Few people were familiar with the term, "Evidence of Coverage." To some, the word "evidence" suggested courtroom proceedings or being in a defensive position of needing to prove something. Here are a few of the comments they made about this title:

> *Too formal.*
>
> *I wouldn't know what it's about. I'm not familiar with the words, "Evidence of Coverage."*
>
> *"Evidence" could mean a lot of things.*

Another title we showed was acceptable to most, but not preferred: "**Your Medicare Coverage as a Member of Maple Health Plan.**" Respondents liked this one better than the "Evidence of Coverage title, but not as much as the third option, "Medicare Health Benefits and Services." As they commented:

> *This is not as complete as the title that says "Medicare Health Benefits and Services."*
>
> *Too vague.*

Although conventional wisdom suggests that shorter is often better, this was not the case for title preferences. The great majority of testing participants favored the following title, which was the longest of the three we tested: "**Your Medicare health benefits and services as a member of Maple Health Plan.** Most people thought this title explained more, was more specific, and more straightforward. Even though some were unclear (or mistaken) about the difference between "benefits" and "services," they felt that compared to the other titles, this one gave them a better sense of what they would find inside the booklet. Here are comments about this title from two of the respondents:

> *You need to get to the lowest common denominator, so this is probably much clearer to most people than using a word like "evidence."*
>
> *That really says it! I like this one much better.*

Reactions to having the tag line on the cover

Overall, participants reacted very positively to including the tag line underneath the title, as shown in Exhibit A, because it told them the purpose and importance of the document.

Reactions to having the telephone numbers on the cover

People liked the convenience of having the number on the cover, and several commented favorably about the large print and including the calling hours. Several mentioned that they never knew what a TTY-TDD number was until they read the explanation on the cover. (This explanation was included to help deter people from calling the TTY-TDD number when there was a long wait on the regular toll-free number). Putting the Member Services phone numbers on the cover makes it possible to replace full information about phone numbers with a simple reference to the cover in numerous places within the text of the EOC. A couple of people wanted the number to appear whenever it was mentioned, but most favored the convenience of easy reference in large print on the cover. (Besides being shown on the cover, the Member Services number also appears in Section 1, a new reference section that was added to the EOC in Phase 1 of this project).

Reactions to the welcome page

Overall, respondents reacted favorably to the welcome page. They thought the content and tone were appropriate, and seemed to have few problems understanding it. We made minor edits to the welcome page for each new round of testing, based on reactions and suggestions from participants. Ultimately, we made it significantly shorter by condensing and cutting some of the information. We edited and rearranged some of the bullets to emphasize topics of greater interest to respondents, such as payment.

Reactions to the Table of Contents

Getting people's reactions to the Table of Contents gave us many insights into their comprehension and ease of navigation through the document. We wanted to know their general impressions, whether any terms or topics seemed unclear or confusing, and whether the information was organized in a way that made sense to them.

Reactions to two versions of the Table of Contents

We tested the Table of Contents in the first round of interviews in Towson by showing people two versions. In the "long version," sections and detailed subsections were separate line-items with page numbers. The "short version" described major sections in paragraph form and gave page numbers for the main sections only. Respondents overwhelmingly preferred the long version because it was much easier to locate information of specific interest. They also found it easier to use when we gave them navigational tasks, such as showing where they would look to

find a particular topic. Several people thought the EOC should have an index; one mentioned the helpfulness of the index in *Medicare and You*.

Since participants strongly favored the more detailed Table of Contents, we showed only this version in the next two rounds of testing done in Seattle and Denver. In these subsequent rounds, we continued to seek feedback from respondents about the Table of Contents, including whether they preferred "section" or "chapter" as the label for the main divisions in the document. They preferred "sections," because calling them "chapters" made it sound like a novel or a long book.

Reactions to the sequence of topics

Reactions to the Table of Contents in the mockups we tested revealed a problem with the sequence of topics. To draw beneficiaries' attention to the Appeals and Grievances section, we had moved this section forward in the document. Testing showed that this new placement didn't make sense to people: they wanted to read about their coverage before reading about what to do if there's a problem. In suggesting a different placement for the section, several people expressed their ambivalence about the topic. As one person commented, *Put Appeals and Grievances at the end because hopefully there won't be any.*

Reactions to terms and topics shown in the Table of Contents

When respondents browsed through the EOC mockup on their own, it was information about day-to-day use of the plan that attracted their interest. They wanted to see what the document said about things such as payment, prescription drugs, changing PCPs, and getting care while traveling. Some people mentioned the provider directory as the plan document they have used the most; and several searched for provider listings in the EOC mockup.

People's reactions to the Table of Contents revealed some problems with terminology and a few misunderstandings about content, especially among those with less education and less experience with managed care. For example, many respondents said they did not know the meaning of the word "formulary," which appears in the Table of Contents as a subsection ("What is a formulary?") with its own page number in the section on prescription drugs. One respondent remarked that she was satisfied with the current title of this subsection even though she didn't know the term, because if she wanted to know the answer to the question it poses, she could simply turn to the page where the answer appears.

Another example concerns Section 1, the new reference section in the mockups that gives a brief description and contact information for a number of organizations that are mentioned in different contexts in various places within the EOC. These organizations include the plan's Member Services, CMS, SHIPs, PROs, Medicaid, the Social Security Administration, and the Railroad Retirement Board. Section 1 was added to the model EOC to serve as a convenient directory of

resources for beneficiaries who may wish to contact one or more of these organizations. It also explains a bit about each organization and what it does. Results from testing confirmed the need to provide such explanations. For example, very few respondents were familiar with SHIPs or PROs, and many were pleased to hear of their existence and interested in learning more about them. In contrast, several people were puzzled about why the EOC should include information about the Social Security Administration, and several recommended that the entry for the Railroad Retirement Board be dropped because they saw no personal relevance.

Several people had problems with the Table of Contents entries for emergency care and urgent care because they found it hard to understand the difference between "urgent" and "emergency." As one man put it, an *"'urgent need for care' is really on the borderline of an emergency …. An emergency does not have to be life-threatening."*

When people were unclear about the meaning of a topic or a terms, they occasionally made guesses, or tried to figure it out based on previous experiences that might be related in some way. For example, here is one person's reaction to an entry in the Table of Contents about Religious Nonmedical Health Care Institutions: *I'm trying to think how religion gets into there. If you're in a good facility, religion shouldn't matter…It's important that the plan doesn't discriminate against religion.*

Reactions to the section on appeals and grievances

This long and complex section poses special challenges for readers

As we have mentioned, CMS identified the EOC section on appeals and grievances as a priority for improvement in Phase 1. It is long --about 16 pages-- and the most complex section of the EOC. This section describes important safeguards for M+C members who experience problems, but it is exceedingly challenging for them to understand and use the information in this section, for a combination of reasons:

Wariness and concern about the topic

As we have already noted, the topic itself triggers some concern. Many participants tended to be wary or cynical about the health plan and outside review organizations. While they liked what they read about their rights in this section on appeals and grievances, some lacked confidence that the health plans would really follow through or that the process could work to their advantage. Several respondents expressed concern that their PCP might not help them with their appeal because of concern about retribution from the plan. They wanted to know who was making decisions at their health plan, and questioned whether financial considerations would take precedence over their health care needs.

Respondents also showed a general distaste for legal proceedings. They expressed personal reluctance to take legal action; and some said they felt their efforts would be futile or even detrimental in the end because they feared possible retaliation.

Very limited knowledge and experience

Respondents were largely unfamiliar with the information in this section. Only a few had personal experiences to draw on, and even they had quite limited knowledge in most areas, as well as some misconceptions. A few who were familiar with the idea of appealing and filing grievances remarked that they had learned some new and important things by reading the section.

Most respondents who had been through the appeals process had called their health plans with their complaints and were not familiar with the process described in the EOC. One respondent who had a successful appeal experience said he simply made phone calls to his plan and "*never went through all this*." Other respondents stated that their first instinct would be to call their plans if they had complaints, rather than to consult the EOC. Some respondents thought that since this section is so difficult, it should emphasize where to call to get help from a "real person" if you have a problem.

Cognitive complexity

The subject matter of appeals and grievances is extremely complex. The section has three main parts that deal with the rules and process that apply to different situations (appeals, review of hospital discharge, grievances). There are many technical terms, many different types of deadlines for action, and a number of outside organizations such as PROs and the courts that play different roles depending on the nature and stage of the problem. For appeals in particular, there are several variations in the legal process depending on the nature of the appeal. When processes are this complex, there are limits on the extent to which the language that describes them can be simplified. To comprehend the appeals and grievances processes, M+C members must be able to do all of the following:

- Understand many new terms, concepts, and time frames, and be able to keep them all in mind well enough to follow the discussion where they are used
- Envision unfamiliar circumstances and complex processes that are described in a brief and general way

- Sift through all of the details, making judgments about what is personally relevant and what is not

Examples of text revision for appeals and grievances

Exhibits B and C give examples taken from this section on appeals and grievances. The text labeled “before” is from the model 2001 EOC. The “after” text illustrates the type of text we tested with beneficiaries and family members during Phase 1 of the EOC Improvement Project. These examples illustrate the complexity of terminology and processes included in the section on appeals and grievances.

Exhibit B. Example from section on appeals and grievances

BEFORE revisions were made in Phase 1:

As a member of Maple Health Plan, you have the right to appeal any decision about our failure to approve, furnish, arrange for, or continue, what you believe are covered services or to pay for services that you believe we are required to pay (including non-Original Medicare covered benefits) under Maple Health Plan.

AFTER revisions were made in Phase 1 (used in consumer testing):

This part of Section 10 explains what you can do if you have problems getting the medical care you believe that we should provide. We use the word “provide” in a general way to include such things as authorizing care, paying for it, arranging for someone to provide it, or continuing to provide a medical treatment you have been getting.

Exhibit C. Example from section on appeals and grievances

BEFORE revisions were made in Phase 1:

From page 47 (for standard appeals):

If CHDR decides in your favor and reverses our decision the following must occur:

Request for service:

If CHDR decides in your favor, we must authorize the service under dispute within 72 hours from the date we receive CHDR's notice reversing our decision, or provide the service under dispute as expeditiously as your health condition requires, but no later than 14 calendar days from the date of CHDR's notice.

Request for Payment:

If CHDR decides in your favor, we must pay for the service no later than 30 calendar days from the date we receive CHDR's notice reversing our decision.

From page 52 (for expedited reviews):

If CHDR decides in your favor and reverses our decision the following must occur:

If CHDR decides in your favor, we must authorize or provide the service under dispute as expeditiously as your health condition requires, but no later than 72 hours from the date we receive CHDR's notice reversing our decision.

See next page for the revised text ("AFTER")

Exhibit C, continued. Example from section on appeals and grievances

AFTER revisions were made in Phase 1 (used in consumer testing):

If the independent review organization decides completely in your favor:

The independent review organization will tell you in writing about its decision and the reasons for it. What happens next depends on the type of appeal:

1. *For an appeal about payment for care,* we must pay within 30 calendar days after receiving the decision.
2. *For a standard appeal about medical care,* we must *authorize* the care you have asked for within 72 hours after receiving notice of the decision from the independent review organization, or *provide* the care as quickly as your health requires, but no later than 14 calendar days after receiving the decision.
3. *For a fast appeal about medical care,* we must authorize or provide you with the care you have asked for within 72 hours of receiving the decision.

General reactions to information about appeals and grievances

Overall, we found that testing participants were interested in this section and felt it was important to know about their rights. At the same time, many found this section confusing, frustrating, or problematic in other ways, especially those who had less education and less personal experience related to this topic.

Here are some of the comments people made about their first impressions of the section:

> *It's a little repetitious but it needs to be.*
>
> *This is protection for things that could go amiss.*
>
> *I stay away from legal issues, and would just sign up for a new plan if I had any problems.*

There are a lot of steps to go through, and the average person knows they won't go that far. If you don't have money, you can't sue. I would bail out in Step 3… the health plans will protect themselves no matter what.

I'm a poor one to ask about Appeals and Grievances – I don't need the stress factor. I don't even play golf—don't need the stress.

They should cut out Step 6 because it sounds scary. [In Step 6 of an appeal, the case goes to Federal Court]

Unfamiliar and difficult words and concepts

Given the purpose of the EOC and the content it must cover, there is tension between maintaining the integrity of the document in a legal sense and making the language as simple as possible. As described below, testing revealed problems with many of the terms and concepts included in this section.

"Appeal" and "grievance" were difficult vocabulary for most people and it was hard for them to understand the difference between an appeal and a grievance.

- Some thought these terms were synonymous; others thought the difference was a matter of degree, one being "more serious" than the other. Some thought a grievance is a step that comes before or after the appeals process.

- While the first part of the section covers appeals and the third part covers grievances, the part that describes appeals mentions the possibility of filing a grievance related to something that goes wrong during the appeals process. This seemed to make it even harder for people to grasp the difference between an appeal and a grievance. It was also hard for people to understand the different time periods in both processes. One respondent thought that the option to file a grievance over the timing of the "fast" review would lead to a cyclical problem that would keep beneficiaries stuck at Step 1 of the appeals process.

- It was not clear to respondents what the result of a grievance was. As one respondent commented: *Grievances – what happens with a grievance?* In part, this was an artifact of testing, since when we prepared the Maple Health Plan mockups we did not invent and describe the plan's grievance procedure. We simply made reference to "Maple Health Plan's grievance procedure," rather than describing the procedure as an actual EOC would do.

- The definition of the word "appeal" included the word "legal," which intimidated some respondents because it made them think of lawyers and lawsuits. As one person noted: *It sounds like you're getting ready to sue someone*. Conversely, without similar wording in the definition of "grievance," several respondents concluded that there is nothing "legal" about filing a grievance. This seeming lack of formality made them view the grievance process as less intimidating than the appeals process, but they tended to doubt that complaining would be productive in either case.

- A few people had trouble understanding the difference between one of the starting points for an appeals process ("If we do not approve or provide services quickly enough,") and one of the possible grounds for filing a grievance that was mentioned much later in the section ("Time spent waiting").

The concepts of "fast appeal" and "standard appeal" were difficult for many people to understand. One person who was quite confused about this section in general thought these terms referred to types of medical appointments. Confusion about the concepts was exacerbated by difficulty with navigation through this complex description of the appeals process: the first mention of the "fast" initial decision or appeal appears a number of pages into the section in the longer description of Step 1, by which time many respondents were already confused or frustrated. One suggestion to help clarify the concept of a fast appeal was to use the phrase, "how you can make it [the initial decision] happen faster."

The term, "Peer Review Organization," and its acronym, PRO, were unfamiliar to most respondents. It was hard for many to understand how a PRO might function. One woman who didn't recognize the term searched her memory for associations and remarked: *"Peer pressure" is what "peer review" sounds like.*

The concept of an "independent outside review organization," also caused problems for a lot of people. Many failed to grasp the meaning of "independent" in this context. They were also unable to picture the organization and wanted to know more about who was involved, how they were chosen, and the like. Some worried that this organization would be expensive and might have a hidden agenda to help Maple Health Plan, since they as beneficiaries had no knowledge of outside organizations that they could go to with complaints. Here are some of the comments people made about this term:

> *Who chooses the "independent outside review organization"? I'd leave it to Maple Health Plan, and maybe they'd pick someone they know.*
>
> *Be more explicit – explain what this means*

> *This term has negative connotations, like there's something to hide. Who's in it? Doctors? Lawyers? Is it part of the plan?*
>
> *I would want CMS to review my case – not some unknown independent organization. [She thought CMS contracted with an outside organization because it couldn't handle all the cases itself]*
>
> *Who are they? What are their qualifications?*

Besides having problems with much of the specialized terminology that appears in this section, testing showed that many respondents reacted to other words and concepts:

- Simple words associated with law and government (such as "legal," "written," "court," "judge") triggered guarded or negative reactions in some people. There were misunderstandings of other words as well. For example, in discussing time periods and deadlines in this section of the EOC, one respondent gave the following definition of "calendar day": *It means work day – Monday through Friday.*

- Respondents who read the section carefully sometimes pointed out problems with word choices. For example, reacting to the information about hospital discharge, one respondent noted that the word "*review*" did not indicate to her the possibility of a *change* in the discharge date.

- Occasionally, people questioned whether the content made sense or objected to the way it was presented. For example, one person wondered why there should be an option for requesting a fast appeal in writing: *If you need a "fast" appeal, what are you doing writing?* Another reacted negatively to the statement that receiving *no response* is the same as a rejection of a request, because it gives the patient no respect: *They're just going to ignore you*? It might help to explain under what circumstances this could happen.

Understanding the six steps of the appeals process

It was clear from our first round of testing that people tended to get lost (and intimidated) trying to follow the six-step appeals process, especially since the steps differ depending on the situation (fast v. standard; care v. payment for care received). Our first try at fixing this problem was to add an overview that summarized the six steps. This summary was followed by a more detailed discussion of each step. However, further testing revealed that people had trouble connecting the step-by-step overview to the detailed discussion of each step that followed. Ultimately, we put the details about the appeals process in an appendix. This shortened the section considerably,

which may help people differentiate among the three main parts of the section (appeals, review of hospital discharge, grievances).

Respondents had some difficulty understanding who was the decision maker at each step of the six-step appeals process. Sometimes when the text said "we" they were unsure about who was "we." In Steps 3-6, the decision maker is described as being either an employee of government or paid by government. One woman thought that Steps 3-6 would never apply to her because she wasn't a government employee. Another woman thought that the term, "decision-maker," meant herself.

The description of the last two steps is much briefer and does not follow the same structure as the explanations of the first four steps ("If we decide against you in (previous) step, then you can …"). This change bothered a few respondents because they were anticipating the same pattern that had been established in explaining the earlier steps.

Reactions to the paragraphs about coordination of benefits

The first version of the paragraphs about coordination of benefits was significantly longer than the final version that appears in the 2002 model EOC. The first version was longer because it included a number of examples of other sources of benefits and more details about the process of coordinating benefits. Testing showed that this extra information served mainly to confuse people rather than to enlighten them. Based on results from testing, we condensed the section to focus on the key points, emphasizing the need for members who have other sources of health coverage to notify their plan.

Reactions to the section on disenrollment

The word "disenrollment" is unfamiliar and intimidating to many people. As one person remarked:

> *"Disenrollment" – that's a hundred-dollar word, at least – too many syllables. "Dis" isn't very attractive or positive; it doesn't put power in the hands of the person. [She noted other negative "dis" words: disenfranchise, discriminate]*

To address these issues of vocabulary and tone, we changed the title of this section from "Disenrollment from *{name of M+C plan}*" to "Disenrollment: Leaving *{name of M+C plan}* and your choices for continuing Medicare after you leave." The expanded new title incorporates an explanation of the meaning of the word *disenrollment,* and indicates what kind of information is in the section.

Overall, respondents thought the information in this section was important, and those who read the information carefully seemed to understand this section reasonably well. The process and rules related to disenrollment seemed rather complicated to a number of them.

Several respondents commented on this section based on their own experiences. For example, one woman urged that the booklet make it very clear that you have to keep paying your premiums until you are no longer enrolled. She thought her membership would end immediately if she simply stopped paying her premium, and discovered that failure to pay is not the same as disenrolling.

Reactions to the new rules about when members can disenroll

Testing results for this section were of particular interest, since the section included the new rules about disenrollment. These new rules that limit when and how often people can make changes were confusing to some people. The phase-in of the new rules, together with a number of exceptions to the rules, made this section harder for people to understand. Several questioned the reasons for imposing new restrictions of this sort.

Here are some comments people made:

> *(I'd like to know why you can't change plans during certain periods) – if people tell me* ***why****, I'm more likely to understand.*
>
> *They're trying to make it hard to change, and they're succeeding.*
>
> *All that November stuff is pretty hazy to me.*
>
> *I'd have to really study this. There are too many dates. It's very confusing.*
>
> *It's good to point out how to get your options lined up before you disenroll.*

Some people remarked favorably about the repetition in this section because it helped them understand what the plan and the member can and cannot do during the disenrollment process. Respondents wanted more information about re-enrollment as well as disenrollment. One person asked: *If you leave the plan, can you come back?*

"Original Medicare" was a confusing term for some respondents, and some thought that it referred to something different than Medicare. Once the term was explained, many respondents thought that using the word "Medicare" by itself would be better than saying "Original Medicare."

Concerns about involuntary disenrollment

The concept of involuntary disenrollment was new to many of our testing participants. In the first round of testing, we discovered that the overview we gave at the beginning of the section triggered some concerns among respondents about being dropped from their plan They were reacting to the following sentence that appeared near concerned The first mockup we tested included this sentence included in the overview:

- "In addition, as we explain later in this section, Maple Health Plan is allowed to end your membership under certain special conditions."

This sentence caused a few people to worry that their plan might drop them if they got really sick or made a complaint. As one person put it, *It's scary that the plan can make members leave– I can't imagine any "special conditions" for that.* After a quick review of the section, another person asked with alarm, *"Can they disenroll me on the basis of my health status? It sounds like they can.*

While the discussion later in this section made it clear that this was not the case, these results from testing show the importance of anticipating possible concerns and providing immediate reassurance. For the next round of testing, we changed the sentence near the beginning to provide this reassurance at the first mention of the topic:

- "In addition, as we explain later in this section, Maple Health Plan is allowed to end your membership under certain special conditions (these conditions do *not* include asking you to leave because of your health)."

Reactions to the appendix on advance directives

Overall, people responded favorably to the topic of advance directives and its inclusion in the EOC. They were more familiar with the terms "living will" and "power of attorney," and preferred these terms to the more generic and less familiar term, "advance directives." A few people wanted the EOC to include a sample of a living will. They thought this would be especially helpful to people with lower incomes levels and less access to an attorney, since they could take the document to their doctors to discuss.

Using results from testing to improve the EOC

Reinforced and fine-tuned by testing results and comments from stakeholders, the revisions to the EOC in Phase 1 emphasized:

- Making it easier for people to skim and pick up the key points in each section, since the EOC is used as a reference document
- Addressing people's concerns directly (for example, emphasizing that they can't be dropped if they complain or get really sick)
- Using language that is as simple as possible without compromising its legal integrity
- Making the overall tone friendly and helpful