

**Focus Group Results from the
National Evaluation of
Medicare & You 2000 Handbook:
Non-Beneficiary Decision Helpers**

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Executive Summary

In focus groups with friends and family members who help Medicare beneficiaries with their coverage decisions (decision helpers), we found that the friends and family members who assist Medicare beneficiaries with their coverage decisions have some informational needs that overlap with beneficiaries', while others are unique to their status. They understood the intent of the Handbook, and found it useful as a reference tool and a learning resource. Helpers expressed more confusion and frustration than did beneficiaries in similar focus groups, particularly in attempting to collect consistent information dealing with what Medicare covers and to what extent. This disparity may be because they are less familiar with the complex Medicare system. They feel the weight of responsibility to provide assistance, but often feel unprepared to help their friends and family members. HCFA should give consideration to whether the NMEP is intended to apply to non-beneficiaries who aid in decision-making as well as to beneficiaries. Informational material and the methods by which that material is disseminated may require some tailoring to the special needs of decision helpers who are not themselves beneficiaries

1.0 INTRODUCTION

This report presents the findings from three focus groups with friends and family members who help Medicare beneficiaries with their coverage decisions (decision helpers). These focus groups were held in April and May of 2000. The overall aim of this focus group activity was to illuminate the informational needs and uses of those who help beneficiaries with decision-making. The nationwide survey conducted by RTI indicated that over half of Medicare beneficiaries get help in making coverage decisions; the information needs and understandings of those decision helpers have been under-explored in previous evaluations of the National Medicare Education Program (NMEP).

The research objectives for this focus group effort built on the four goals of the NMEP:

1. Increasing beneficiary **access** to information;
2. Raising beneficiary **awareness** of the new information resources;
3. Helping beneficiaries **understand** the choices available to them; and
4. Helping beneficiaries **use** the information to make an informed choice.

The research objectives for the decision helper focus groups parallel the four NMEP goals.

The objectives were as follows:

1. Explore decision helpers' access to *Medicare & You* and other information sources.
2. Examine decision helpers' awareness of the purpose of the handbook, the meaning of the term "Original Medicare," and the services available to support decision-making.
3. Discuss decision helpers' understanding of the Medicare program, including such critical concepts as varying costs and benefits, and coverage for long-term care.
4. Learn how decision helpers used the handbook, and what aspects they found most useful.

Section 2 of this report outlines the methods that were used in designing, conducting and analyzing the focus groups, while Section 3 offers a description of the groups and participants. The focus group findings are presented in Section 4, organized along the conceptual framework of the NMEP: access, awareness, understanding and use. In Section 5 we offer a summary and conclusions. Throughout this report we compare the beneficiary helpers' responses to those expressed by beneficiaries in a parallel set of focus groups addressing many of the same topics.¹

¹ Focus Group Results from the National Evaluation of *Medicare & You* Handbook: Beneficiaries. Roussel, A.E., D. Driscoll, S. Daugherty and C.A. McCormack. Research Triangle Institute report to HCFA, February 2001.

2.0 METHODS

Focus group interviews took place over a four-week period from late-April to mid-May 2000. The interviews were designed to explore what sources of Medicare information non-beneficiary decision helpers have *access* to, how *aware* they are of the services offered to support making Medicare choices, how well they *understand* the consequences of choosing different plans, and whether they are able to *use* the information provided them. The topic guide is included in Appendix A.

We conducted one focus group in each of three locations: Boston, Memphis, and Denver. These locations were chosen to represent markets with varying levels of managed care penetration; we expected participants in the three regions to have different experiences and expectations regarding managed care. All three metropolitan regions contain at least 100,000 beneficiaries and are differentiated by Medicare managed care penetration rates. Memphis has less than a 1% Medicare HMO penetration rate, Boston has 26%, and Denver has 49% of Medicare beneficiaries as members of HMOs.²

The groups were conducted at the offices of local recruiting firms hired by RTI. The recruitment protocols for each firm are shown in Appendix B. The protocol was designed with a variety of objectives in mind. It was intended to specifically identify individuals who assist at least one Medicare beneficiary with their medical insurance decisions, as well as to identify their

² "Medicare Enrollment by State and County of Beneficiary Residence" updated July 8, 1999 (<http://www.hcfa.gov/stats/cnty98en.pdf>).

relationship with that Medicare beneficiary. By also collecting demographic data the protocol allowed us to recruit a diverse mixture of participants representing a range of ages, genders, educational levels, ethnicities, and decision-helper relationships. The protocol was also designed to screen out those individuals who are Medicare beneficiaries themselves, as well as those who assist Medicare beneficiaries who are disabled, have end-stage renal disease, have Medicaid, or are institutionalized. Finally, we instructed each recruiting firm to screen out people who participate regularly in focus groups.

The focus groups varied in size from 8 to 9 participants. All participants were sent a copy of the *Medicare & You* 2000 handbook by Federal Express two to five days prior to the session. The relatively short interval between receipt of the handbook and the date of the focus group was intended to minimize the potential for participants losing or forgetting the handbooks. This short interval, along with an enclosed letter reminding the participants to bring the handbook to the meeting, had the additional unintended consequence of giving participants the impression that the handbook was the subject of the interview. Participants in all three decision-helper focus groups demonstrated a tendency to return to the handbook even during the early portion of the interview when we discussed overall perceptions and concerns regarding the Medicare program in general.

Using the topic guide, a trained moderator guided participants through a discussion on the predetermined set of topics and encouraged them to express their opinions and experiences. A co-moderator was also present to observe and record notes on verbal and non-verbal exchanges. The sessions were videotaped. Each group lasted about 2 hours. Following each focus group, the

moderator and co-moderator debriefed prior to completing a debriefing form to document main themes and illustrative participant quotes. These debriefing forms, as well as the notes collected by the moderator and co-moderator during the interviews, were analyzed for common themes and differences among the groups.

Unlike a sample survey, focus groups cannot be generalized to a larger population. In addition, group dynamics of any one group can produce a bias, since some people may speak less because of others or a group may be swayed by the opinions of one or two strong participants. At the same time, focus groups are a rich data source through which we can obtain in-depth findings on a new segment of the population: those who aid Medicare beneficiaries in their decision-making. While we cannot generalize the focus group results, our confidence in focus group findings increases to the extent that patterns emerge regardless of group dynamics or location. The same moderator presided over all three groups, so variations by moderator should not be a concern.

3.0 DESCRIPTION OF GROUPS AND PARTICIPANTS

The groups were held in the evening, in order to allow those who work outside the home during the day to attend. While several participants had been a part of other focus groups discussions, no one had been involved in a health-related focus group discussion.

3.1 Demographics

Table 1: Demographic Characteristics of Non-Beneficiary Decision Helpers by Site

	Boston (n=8)	Memphis (n=9)	Denver (n=9)
White	50%	89%	89%
Female	50%	67%	89%
Mean Age (years)	48	52	54
Education			
High School Graduate	17%	11%	0%
Some College	42%	33%	44%
College Graduate	42%	56%	56%

Few differences existed in age or education among the non - beneficiary helpers between the three focus group sites. In contrast, racial and gender patterns varied by geographic region. The demographic distributions observed in the various focus groups may be a reflection of the limitations in the recruiting firms’ databases used to select the participants. Racial demographics among the three cities varied significantly. Less than five percent of the Denver and Boston populations are African American.³ In contrast, nearly 35% of the population in Memphis is

³ http://www.usadata.com/free_demographics.htm Scarborough, a local market research company, measures 64 markets (including the top 50) via telephone interviews conducted through CATI and mail follow-up surveys.

African American. Ethnic groups such as Hispanic communities make up a small percentage of Boston (4%) and Memphis (3%), but a much larger proportion of the Denver community (12%).² While these distributions are not stratified by age, they do provide a general indication of the racial and ethnic make-up of the cities utilized for the data collection.

Among the three sites, the Boston focus group had the highest percentage of minority participants. While the Boston focus group was not entirely representative of the city's demographic profile, it was the most racially and ethnically diverse group with nearly half of the participants being non-white. In Denver, two of the nine participants, one individual of Hispanic origin and the other African American, represented racial and ethnic groups other than Caucasian. The composition of the Memphis focus group did not reflect the significant proportion of African Americans living in the city. Only one individual of the nine participating in Memphis was African American; the rest were Caucasian.

Most of the non-beneficiary helpers were in their fifties. Slightly less than half of the individuals had completed some college, and over half of the participants had obtained at least a college degree.

The distribution of gender among the three sites varied by region. While the Boston focus group was evenly divided between males and females, Denver and Memphis participants were primarily female (see Table 1). Social trends may have a bearing on the gender of the non-beneficiary helpers, where women are more likely to be called on to fill a helping role. In Memphis, the recruiting company had difficulty recruiting three male non-beneficiary helpers

who met the screening criteria. Although the other recruiting firms did not mention having similar difficulties, assumptions regarding the gender distribution among helpers in these three sites should be made with caution.

3.2 Helper’s Relationship to Beneficiary

While the gender of the helper did not appear to influence the type of relationship between the helper and the beneficiary, Boston was the only group among the three sites that had helpers assisting friends or acquaintances rather than family members. One participant had a friend who was ill, another participant was helping a friend for unspecified reasons, and a third participant owned a shop next to “an old-age home” where customers frequently stopped in to ask questions related to Medicare. The other focus group participants in Denver and Memphis were primarily helping their parents, in particular their mothers. A small percentage of individuals in Denver and Memphis were also helping their spouses (see Table 2).

Table 2: Relationship of Medicare Beneficiary to Non-Beneficiary Helper

	Boston (n=8)	Memphis (n=9)	Denver (n=9)
Mother	25%	78%	57%
Father	12%	11%	29%
Spouse	12%	11%	14%
Friend	38%	0%	0%

3.3 Questions Helpers Assist in Answering

While helpers who assist family members tend to answer questions across a broad range of informational areas, other helpers to friends and spouses have more specific informational needs. Helpers assist their family members with questions about Medicare coverage and benefits, including prescription drugs, supplemental insurance, equipment needs, and home care. Although financial questions were mentioned as one of the Medicare questions some of the non-beneficiary helpers assist in answering, it is noteworthy that both of the Boston male helpers who were assisting friends cited that the help they provide primarily has to do with financial matters and advice. This may be due in part to a friendship being exempt from familial responsibilities such as ensuring continuous care for loved ones

3.4 Group Dynamics

Variations in individual personalities influenced the information sharing in the focus group discussions. Overall, the non-beneficiary helpers were engaged in the conversation across the three sites. Although most of the Denver participants contributed equally to the focus group discussion, one or two dominant individuals disrupted the conversational equilibrium in Memphis and Boston. While several participants in Memphis were impressed with the knowledge base of one woman in their group, her contributions to the discussion may have hindered a more genuine appraisal of the needs among other less savvy individuals. In Boston, the disruption resulted from a boisterous participant, who frequently expressed a negative perspective. Although at times it

was hard for others to express dissenting opinions because of the force of his personality, the moderator was able to ensure that other voices were heard.

4.0 FINDINGS

This section presents the findings from the beneficiary helper focus groups, arranged along the NMEP conceptual framework of access, awareness, understanding and use.

4.1 Access

In exploring issues relating to access, we discussed how Medicare decision helpers felt about all the informational sources they currently used, and then focused specifically on how these participants perceived the handbook.

We found that while decision helpers rely on the same sources of Medicare information as beneficiaries themselves, they feel less informed or prepared. As with beneficiaries, decision helpers had access to a wide variety of information sources including friends and family, HMOs, senior groups, hospitals, nursing homes, the AARP, and county, state, and federal governments. They were more likely than beneficiaries to turn to the internet for information about the Medicare program.

Despite the scope and diversity of information sources available to them, many decision helpers who participated in our focus groups were concerned and frustrated by their perceived lack of information. One Memphis man observed that trying to find out about Medicare was like *“looking off into a canyon, where do I start to get my arms around this subject? ... I didn’t know whom to contact.”* A Boston man remarked that when trying to get information from *“the people*

who run the Medicare program...you almost gotta threaten them. They don't care, and they don't care that they don't care. It's bureaucracy at its greatest."

Decision helpers were particularly frustrated in attempting to collect consistent information dealing with what Medicare covers and to what extent. A Memphis woman found that *"even some of these providers don't know, they blame the changing of the rules...it's what is heard frequently."* Other participants agreed, and one man described how *"sometimes the doctor tells you [a piece of equipment is] covered under Medicare, but the person with equipment says 'oh no, he has to receive a prescription so it will be covered'."* A Denver woman described a similar problem collecting consistent information: *"it's extremely confusing, I don't know how long Medicare would cover a stay in a nursing home. You're at the mercy of the staff at the hospital, and it changes - one day they say 'if he is not like this by Friday he has to leave' and then on Friday they put him in a nursing home."*

Approximately half of the participants we asked said that they had seen the *Medicare & You* handbook previously. Most of those who had seen it reported that the beneficiary they helped had saved a copy for them, as one Denver woman told us, her mother said *"I can't read this, you read it."* Most liked it as a single source of information: a Memphis woman summed up the most common response with *"it's a start."* There were, however, a number of dissenting opinions. When asked what they thought of the handbook generally, several Boston participants responded:

- *"It doesn't make sense."*
- *"It's confusing."*

- *“I thought it was a joke.”*

One reason for the frustration among the Boston group was an apparent inconsistency in the plan comparisons that was pointed out by an especially strong personality in the group. This Boston decision helper pointed out that *“if I have Medicare and want to go to Blue Cross/Blue Shield, how much is it going to cost me? The information in here is wrong....it’s bogus.”* This opinion was voiced early in the interview, was consistently repeated by the participant, and appeared to bias many subsequent comments by the other participants in the Boston group.

When asked how they felt about the way information was presented in the handbook, some participants complained about the complexity of that information. A Denver woman said *“I think you need to sit and read it several times,”* and another agreed, *“I thought it was confusing, like wait a minute let me read this again.”* When probed to determine if the information or the program was the source of confusion, the first woman responded *“It’s 50/50. It’s a humongous program. I wouldn’t wish it on my worst enemy to be director and coordinate this program. It’s difficult to maintain mind set to get from point A to point B, you get lost with all the mights, maybes, howevers, and commas.”* Other participants also pointed out limitations in the information presented, *“See, this ‘might’ be covered, with a double asterisk, where do you find the ‘mights’?”* Some specific suggestions for making the material more easily understandable included placing a *“definition of important terms at back of book,”* as well as using an outline format, *“something that you can tick off, the paragraph form is hard to pick out cogent points. Every sentence was important to understand.”*

Despite problems with the manner in which information was presented, most decision helpers were able to navigate the handbook to find the information they needed. The Question and Answer section of the handbook was consistently praised, as one Memphis woman said “*I could pick out the questions I wanted to specifically answer, I could choose what I need to know.*” Other participants liked the internet address, as one Denver woman noted “*it’s nice to have something in print, to have it in writing.*” Finally, the tables contained in the regional insert were identified as helpful because, as a Denver woman pointed out, “*visuals are easier to understand quickly.*”

Ultimately, decision helpers seemed more likely to be frustrated by issues of access than were the beneficiaries themselves. One possible reason for this is the difficult role of information broker between the beneficiary and Medicare. As a Boston man described it “*the gentleman I take care of, he has good days and bad days. He may not remember the name of the person he talked to, or he’ll give me a name and there’s nobody there by that name.*” The difficulties inherent in identifying information sources and the communicating with the beneficiaries they assist create an especially stressful and frustrating situation for these participants. As a consequence, the relatively simple and clear information available in some sections of the handbook was more useful for these decision helpers than was the more complex background text.

4.2 Awareness

The focus groups explored four aspects of decision helpers' awareness on the NMEP and Medicare choices:

- The perceived purpose and trustworthiness of the *Medicare & You* handbook
- The meaning of the term "Original Medicare"
- Services available to get help with Medicare choices
- The rights of Medicare beneficiaries

In all three communities, initial discussions of the purpose of the handbook revolved around the idea that the intent was to provide basic information on the Medicare program. As they expanded on that basic informational purpose, the three groups diverged. In Memphis, participants wondered how the handbook was distributed. "*Where is it available?*" asked one participant. "*I found it at my mom's house. We're the ones who need it.*" In Denver, participants seemed to believe that the purpose of the handbook was to present basic information, but that there was other information that was hidden in the handbook. One pointed out that for some coverage issues, beneficiaries "*have to meet certain conditions – [there are] asterisks – have to go digging*" for more detailed information. This was echoed by another participant, who described the process as "*go to page 28, then to page 38, and you still don't find what you need.*" While the Denver decision helpers discussed the information that was lacking or hidden, the Boston participants expressed opinions that the handbook contained too much information. "*This is going to overwhelm someone,*" said one, while another group member said "*no-one's going to read this encyclopedia.*"

The Boston participants found the handbook less trustworthy than participants in other communities. They mentioned the quality indicators in particular. When one said, “*Doctors who communicate well – who the hell cares?*”, another aired suspicions: “*Who took the survey?*” Similarly, a participant zeroed in on the mammography rate: “*percent of women who receive mammograms – why isn’t it the percent who didn’t because they can’t afford it? I don’t want them to blow their horn – I want the other side of it.*” One participant asked point-blank: “*Is this a marketing tool?*” When probed as to what the handbook might be marketing, he replied “*the HMOs.*”

All three groups addressed the meaning of the term “Original Medicare.” In Denver, the group seemed to think it was just Medicare Part A, and that it was still available. In Memphis, it was described as “*the core plan – I thought it was like Coke Classic.*” Participants seemed aware that the original Medicare plan was still available and that choices were available as well – one described it as “*this one policy and then they expanded on it greatly.*” The Boston group expressed rather more confusion, describing original Medicare as “*What it used to be before they made the changes.*” Participants were not able to articulate what changes they were referring to, but it was clear that the term Original Medicare led them to think that there had been changes in the Medicare program, and that the options that are currently available do not include Original Medicare.

In general participants were aware of the various services available to assist with coverage decisions, and they generally found the handbook useful in listing more resources. Perhaps because these focus group participants are involved in aiding friends or family members with

decisions about Medicare coverage and related issues, they were aware of and had drawn upon a variety of information sources. Participants reported varying results of their inquiries. *“Most of them are very courteous,”* said one participant, while another remarked on how long it took to obtain the information they sought: *“It took a full day – by the time they had transferred me from this person to this person... Do they have any concept on how much time it takes?”*

Awareness of the rights of Medicare beneficiaries was relatively low. In both the Boston and Memphis groups, there were long silences and heavy sighs when the moderator asked what they had learned about the rights of people with Medicare. *“That was confusing,”* said one Boston participant. *“It told me one thing and then the next page would throw me off. I had to go back to the previous page.”* In general it seemed that the main thing that participants gleaned was that Medicare beneficiaries do have rights, though they did not completely understand the presentation of those rights. The handbook did serve to heighten awareness of the issue; as one Memphis participant said, *“They wrote all of that in there. It must be really important.”*

4.3 Understanding

The focus groups explored decision helpers’ understanding of Medicare options in two ways. First, we discussed how prepared participants felt to help with coverage decisions, along with the aspects of the Medicare program that participants found most difficult to understand. Then we probed regarding their understanding of three key concepts:

- How costs differ between different Medicare options
- How benefits differ between different Medicare options

- Coverage for long-term care

Participants in all three groups did not feel particularly well prepared to help their friends or family members decide which Medicare plan is best for them. In Boston, participants' discomfort seemed to stem from the fact that, as one said, *"It's a personal decision."* There are limits to how much assistance a friend or family member can provide. Instead, said another participant, *"You try to sympathize."* Responses in Memphis reflected uncertainty about what decisions need to be made. *"What else is available?"* asked a participant. *"I didn't even know what the decision was."* Another noted that *"at the time they [beneficiaries] probably didn't even know the decision was made."* Some of this uncertainty was reflected in Denver as well: *"When you say plan, what part are you talking about?"* In general participants did not feel prepared to help with decision-making because they were not familiar with the decisions to be made.

In Denver, participants felt that their understanding made them unprepared to help their friends or family members with issues related to the rights of beneficiaries. They pointed out that *"Nothing is spelled out – information is so vague."* In Memphis, participants' responses suggested that the complexity of the Medicare program made overall understanding difficult. *"For me, just getting started is a major undertaking,"* said one. *"Where do you start? What about the basics of where it is? It's overwhelming."* This was echoed by another participant who said, *"I don't even know what questions to ask, where to go."* A participant who seemed more familiar with the basics of Medicare found the changes in the Medicare program the most difficult thing to understand and keep up with: *"We're not told in a timely manner about what is changing."*

In Boston, participants raised issues with understanding the basic structure of the Medicare program and the pricing structure. *“I don’t understand why they have Part A and Part B – that’s a lot of nonsense to me. And now they have this new thing where they’re taking insurance money out of their disability – why are they doing that?”* Another participant expressed confusion about what the varying rates mean: *“You look at all these HMOs. Harvard Pilgrim, you pay \$3 a pop, others you don’t pay anything, one guy pays \$25 – does that mean it’s better?”*

In all three groups, understanding of how costs differ between the different types of Medicare options was limited. They expressed confusion about the costs of Part A, Part B, and, especially, supplemental insurance. A Memphis participant had a parent *“on AARP. Is that Plan B or is that a supplement?”* The Boston group’s discussion of costs was colored by a participant who vociferously expressed the opinion that the costs for Medicare managed care plans listed in the handbook were incorrect. *“How can we learn anything if they don’t have the costs down there?”* A participant in Memphis had difficulty with the local area tables for another reason: *“Nothing seemed to cover Memphis so I didn’t know what I was looking at... Tennessee service area – I didn’t know if that meant the only thing available for this area.”* Costs and premiums were a concern in all three groups, but the handbook was of limited utility in building decision helpers’ understanding of the issue.

Turning to how benefits differ between the different Medicare options, participants again expressed limited understanding. In Denver and in Boston, participants noted that the handbook helped them to understand variations in what is covered, but not in the costs to the beneficiaries. *“What they pay for is in there, but not how much.”* In Denver, participants suggested that a visual

display of original Medicare compared with other options would be useful, with columns demonstrating “*what you would pay*” and “*what’s left to pick up – if supplement or no supplement.*” Memphis participants noted that part of what makes this issue difficult to understand is the complexity of the program: “*Different benefits for different plans. It’s not that the book is complicated, but the program is complicated.*” Overall, participants understood that benefits differed, but desired more information about the details of the differences, especially out-of-pocket costs.

When the discussion turned to long-term care coverage, participants frequently turned to the handbook, flipping through it to confirm their impression that Medicare does not provide coverage for long-term care. They did not appear to have difficulty understanding this point, though several noted that long-term care is a complex issue quite apart from Medicare coverage. (One participant suggested: “*Get a law book.*”) Denver participants discussed long-term care insurance companies as an additional source of information, but cautioned that “*insurance companies have different perspectives, different ways of presenting it – it can be confusing.*” A Memphis participant expressed reluctance to deal with the issue. “*I know it’s coming. I probably haven’t wanted to get information in that. I had better know something about it. I’m going to be caught up short.*” The Boston group was the only one where some participants acknowledged that they hadn’t paid a great deal of attention to the long-term care issue. Reasons for that differed: “*I glanced over it because I can’t look that far ahead,*” said one, while another believed that “*nursing homes have to take them.*” One family member offered a cogent explanation of why she did not follow long-term care issues: “*It’s difficult for me with my mom to look at long-term care. She has ten children and we don’t see her as a candidate for a nursing home. So I didn’t*

look at it because it's not my mom.” Overall, participants understood the basic message that Medicare doesn't cover long-term care, and varied in their interest in learning more about long-term care coverage options.

4.4 Use

Non-beneficiary helpers were asked how *Medicare & You* might be useful to them in helping their family member make decisions about Medicare. In the process of identifying how the handbook might be of use to them, the capacity of the handbook in meeting the informational needs of this particular population was assessed. Suggestions for making the handbook more useful were requested so that areas that need further attention would be highlighted.

Participants discussed the usefulness of handbook in two ways. First, the handbook was described as a reference guide that contained telephone numbers and descriptive referrals to Medicare informational resources. Because non-beneficiary helpers are frequently called on by the beneficiary to gather Medicare information or aid in the health care decision making process, resources listed in the *Medicare & You* provided an additional option for information seekers who want to follow-up on more personalized or specific information requests.

Second, *Medicare & You* was perceived to be useful as a learning tool. It served as a “*starting point*” that helped the non-beneficiaries establish the “*basics to be prepared to ask questions.*” This background information is essential to introduce a Medicare vocabulary within

which non-beneficiary helpers can effectively and efficiently investigate answers to their questions.

Although these two uses are not mutually exclusive, participants approached the handbook with varying utilization strategies. The word “reference” implies using the handbook for a pre-conceived purpose in which one would refer to the text to find the answer to specific questions. A “learning tool,” however, may be read more thoroughly to gather a broader base of knowledge from which to work.

The Boston discussion group provides evidence that some participants were not combining these two utilization strategies but rather approaching the handbook in the way that best suited their individual needs. While one Boston participant highlighted the State Health Insurance Advisory Program resource (listed in the handbook on pg. 24) as useful for him, several other participants admitted they were not aware of the resource listing in the handbook at all. *“Everybody has a different story,”* one participant said, *“some of these things don’t mean anything to me until she [his wife] needs it.”*

Integration of the two utilization strategies was more prominent in the Memphis group. *“It triggered a lot of thoughts.”* Another participant said *“it helps me approach my mom to ask questions, things she wouldn’t think to ask.”* Possibly this difference is a result of the Memphis non-beneficiary helpers not being as aware of the Medicare program or other informational resources as their counterparts in other regions.

Each site provided a unique perspective on how the booklet could be more useful. Memphis participants recognized the limitations of a general reference guide or informational learning tool. Nonetheless, they were the most pleased with the handbook among the three sites. *“As a primer, this is just excellent, it is not geared toward or intended to be all inclusive but rather to trigger thoughts.”*

In contrast, both Denver and Boston participants addressed the need for a *“simpler”* or more *“condensed”* version of the handbook. Denver participants, in particular, were concerned with the presentation of the text not being *“user-friendly”*. While technical terms and rates were referred to in the text, their definitions were found in other sections of the handbook requiring significant navigational skills from the reader. *“If they are going to use technical terms, they should have them [listed] right away rather than later in the back of the book.”*

Recommendations such as flowcharts, category tabs, and highlighted cheat sheets were offered to improve the ease with which individuals could access, and thus, synthesize the information. While still working with the concise handbook idea, several participants wanted the option of a more in-depth informational tool. One participant suggested the handbook could ameliorate the frustration of gathering the information from other resources by having *“pamphlets in the appropriate sections so you don’t have to dig for more information. You can just go get what you want.”*

Finally, participants discussed the issue of accessibility. *“What is there for people who are ‘pre’[beneficiary]?”* Although non-beneficiaries serve as informational aids to their beneficiary, little information targets the needs of the helping population. *“It is a subject we know so little about until you are in the middle of it.”* Placing the handbook in frequently visited areas

such as the “*doctor’s office*” where you can “*sit and read whatever is there*” would provide some preparatory reading for individuals who need to access Medicare information either for themselves or for the beneficiaries they are helping.

While the handbook was cited as being useful as both a reference guide and a starting point for establishing the basics on Medicare information, handbook utilization strategies varied by participant needs. A more user- friendly format and a more accessible location for perusing was recommended. Perhaps with modifications to the format of the handbook and increased visibility or accessibility of the *Medicare & You* handbook to helpers, more individuals would integrate utilization strategies and thus use the handbook not only as a reference guide but also as a background informational resource on Medicare.

5.0 SUMMARY AND CONCLUSIONS

This report presented the findings from three focus groups with friends and family members who help Medicare beneficiaries with their coverage decisions (decision helpers). We conducted focus groups in three locations (Boston, Memphis, and Denver) in order to gauge regional differences in experiences and expectations regarding managed care. Findings are summarized in Table 3.

The overall aim of this focus group activity was to illuminate the informational needs and uses of those who help beneficiaries with decision-making. We found that while helpers who assist family members tend to answer questions across a broad range of informational areas, those who help friends and spouses have more specific informational needs. Helpers are assisting their family members in answering questions about Medicare coverage and benefits, including prescription drugs, supplemental insurance, equipment needs, and home care. The friends of beneficiaries who participated in these focus groups suggested that the help they provide is primarily financial advice. This may be due in part to a friendship being exempt from familial responsibilities such as ensuring continuous care for loved ones. We summarize our findings according to their relationship to the four goals of the NMEP: access, awareness, understanding, and use.

5.1 Access

We found that while decision helpers may rely on the same sources of Medicare information as beneficiaries themselves, they feel less informed or prepared. As with beneficiaries, decision helpers

Table 3: Summary of Findings

Research Area	Main Findings	Illustrative Quote
Access to Information	Helpers had access to several sources of Medicare information. These include sources used by beneficiaries: health care providers, seminars, HCFA, AARP, and HMO materials, as well as the internet.	“Published books, like a senior directory, put out by different organizations.”
Original Medicare	While most participants understood the term’s meaning, some felt this meant the present plan had been changed in some way.	“Just Part A.” “What it used to be before they made the changes.”
Understanding of the Medicare Program	Frustrations with understanding which medical conditions are covered by Medicare and to what extent.	“Even some of these providers don’t know, they blame the changing of the rules...it’s what is heard frequently.”
Understanding of Long-term Care Coverage	Most understand that Medicare does not provide long-term care.	“There is no long-term care provided.”
Use of the Handbook	While the Boston participants were the least impressed, most were appreciative of the handbook as a general source of information, and were able to navigate the handbook to address specific topics during the interviews.	“It’s a start.” “I could pick out the questions I wanted to specifically answer.”

beneficiaries, decision helpers had access to a wide variety of information sources including friends and family, HMOs, senior groups, hospitals, nursing homes, the AARP, and county, state, and federal governments. They were more likely than beneficiaries to turn to the internet for information about the Medicare program.

Decision helpers were particularly frustrated in attempting to collect consistent information dealing with what Medicare covers and to what extent. When asked how they felt about the way information was presented in the handbook, participants generally complained about the complexity of that information. Despite problems with the manner in which information was presented, however, most decision helpers were able to navigate the handbook to find the information they needed, as were the beneficiaries themselves.

Ultimately, decision helpers seemed more likely to be frustrated by issues of access than were the beneficiaries themselves. One possible reason for this is the difficult role of information broker between the beneficiary and Medicare. The difficulties inherent in identifying information sources and the communicating with the beneficiaries they assist create an especially stressful and frustrating situation for these participants. As a consequence, the relatively simple and clear information available in some sections of the handbook was more useful for these decision helpers than was the more complex background text.

5.2 Awareness

In all three communities, initial discussions of the purpose of the handbook revolved around the idea that the intent was to provide basic information on the Medicare program. In

Denver, participants seemed to believe that the purpose of the handbook was to present basic information, but that there was other information that was hidden in the handbook.

All three groups discussed the meaning of the term “Original Medicare.” Participants in Denver and in Memphis seemed aware that the original Medicare plan was still available and that choices were available as well – one described it as “*this one policy and then they expanded on it greatly.*” The Boston group expressed rather more confusion, describing original Medicare as “*What it used to be before they made the changes.*” Participants were not able to articulate what changes they were referring to, but it was clear that the term Original Medicare led them to think that there had been changes in the Medicare program, and that the options that are currently available do not include Original Medicare. Some beneficiaries were likewise confused by the term Original Medicare.

In general decision-helpers, like beneficiaries, were aware of the various services available to assist with coverage decisions, and they generally found the resources listed in the handbook to be useful. Perhaps because these focus group participants are involved in aiding friends or family members with decisions about Medicare coverage and related issues, they were aware of and had drawn upon a variety of information sources.

As with beneficiaries, awareness among decision-helpers of the rights of Medicare beneficiaries was relatively low. In general it seemed that the main thing that participants gleaned was that Medicare beneficiaries do have rights, though they did not completely understand the presentation of those rights.

5.3 Understanding

Participants in all three groups did not feel particularly well prepared to help their friends or family members decide which Medicare plan is best for them. In Boston, participants' discomfort seemed to stem from the fact that, as one said, "*It's a personal decision.*" There are limits to how much assistance a friend or family member can provide. Instead, said another participant, "*You try to sympathize.*"

In Denver, participants felt that their understanding left them unprepared to help their friends or family members with issues related to the rights of beneficiaries. They pointed out that "*Nothing is spelled out – information is so vague.*" In Memphis, participants' responses suggested that the complexity of the Medicare program made overall understanding difficult. A participant who seemed more familiar with the basics of Medicare found the changes in the Medicare program the most difficult thing to understand and keep up with: "*We're not told in a timely manner about what is changing.*"

In all three groups, understanding of how costs differ between the different types of Medicare options was limited. They expressed confusion about the costs of Part A, Part B, and, especially, supplemental insurance. When the discussion turned to long-term care coverage, participants frequently turned to the handbook, flipping through it to confirm their impression that Medicare does not provide coverage for long-term care. They did not appear to have difficulty

understanding this point, though several noted that long-term care is a complex issue quite apart from Medicare coverage.

5.4 Use

Non-beneficiary helpers were asked how the *Medicare & You* handbook might be useful to them in helping their family member make decisions about Medicare. They discussed two aspects of usefulness. First, the handbook was described as a reference guide that contained telephone numbers and descriptive referrals to Medicare informational resources. Because non-beneficiary helpers are frequently called on by the beneficiary to gather Medicare information or aid in the health care decision making process, resources listed in *Medicare & You* provided an additional option for information seekers who want to follow-up on more personalized or specific information requests.

Second, *Medicare & You* was perceived to be useful as a learning tool. It served as a “starting point” that helped the non-beneficiaries establish the “basics to be prepared to ask questions.” This background information is essential to introduce a Medicare vocabulary within which non-beneficiary helpers can effectively and efficiently investigate answers to their questions.

While the handbook was cited as being useful as both a reference guide and a starting point for establishing the basics on Medicare information, handbook utilization strategies varied by participant needs. A more user-friendly format and a more accessible location for perusing were recommended. Table 4 presents a summary of participants’ suggestions regarding the

Table 4: Decision Helpers' Suggestions for the Handbook

Theme	Participant Comments
Different information	"I want to be able to make more comparisons. It doesn't tell me how much to pay for prescriptions, or do you pay up front, and which pharmacy, and original or generic... Outline the costs and benefits for each option."
Less detail	"It could be done simpler. There are things in here we don't need to know." "You get lost with all the mights, maybes, however, and commas."
More information	"How do they coordinate with the VA?"
More detail:	[in a discussion of what is covered, on page 8] "Limited' 'Very limited' – what does that mean?" "This might be covered, with a double asterisk – where do you find the 'might'?" The asterisk "certain conditions' are covered but the booklet don't tell you what they are. Maybe a booklet like this is not intended for that, but it could refer to other places to go that is not covered here."
More precision	"It needs to be more precise, more accurate."
Format	"Explain in simple terminology, and in big bold letters." "Spiral loose-leaf – people could be sent pages – pull the old page out and then you don't have to replace the whole book." "Need 1,2,3 – something you can tick off. The paragraph form is hard to pick out cogent points. Every sentence was important to understand." "They should say: 'put this in your records –for future reference – in case you need it – keep this it's important'." "Bigger letters" "Visuals are easier to understand." "More user-friendly language" "Not so much text" "Flowcharts" "additional color"
Distribution	Put it in the doctor's office – you can sit and read whatever is there. Where is it available? I found it at my mom's house. We're the ones who need it.
Positive attributes	"I liked the internet address. It's nice to have something in print, to have it in writing." "Questions and answers were interesting because general types of things were talked about there, like what Part B and Part A covers." "How to dial, on page 41 – that was good." "I appreciate the stuff on page 9, the sources."

handbook. Perhaps with modifications to the format of the handbook and increased visibility or accessibility of the *Medicare and You* handbook to helpers, more individuals would integrate utilization strategies and thus use the handbook not only as a reference guide but also as a background informational resource on Medicare. Ultimately, the handbook was widely perceived as a useful tool for beginning the information search, but was did not completely fulfill the informational needs and uses of those who help beneficiaries with decision-making.

5.5 Policy Implications

This exploratory analysis indicates that the friends and family members who assist Medicare beneficiaries with their coverage decisions have some informational needs that overlap with beneficiaries', while others are unique to their status. Helpers expressed more confusion and frustration than did beneficiaries in similar focus groups; this may be because they are less familiar with the complex Medicare system. They feel the weight of responsibility to provide assistance, but often feel unprepared to help their friends and family members.

HCFA should give explicit consideration to whether the NMEP is intended to apply to non-beneficiaries who aid in decision-making as well as to beneficiaries. Informational material may require some tailoring to the special needs of decision helpers who are not themselves beneficiaries, focusing on the general issues and areas of concern to this population. Dissemination of this information to decision helpers is another avenue worth exploring; those who help beneficiaries with the Medicare decisions need access to the same information that beneficiaries receive in order to provide assistance to their friends or family members.

Appendix A: Medicare and You Non-Beneficiary Focus Group Topic Guide 5-9-2000

Introduction

Welcome. Thank you for coming to this group discussion. Your participation is very important to us and to the agency that manages Medicare.

I'm [first name] and I will be facilitating our group today. [First name] will be helping me and will be taking notes during the discussion.

We're from the Research Triangle Institute, a non-profit organization that does health-related research. The agency that manages the Medicare program asked us to conduct these groups.

Project objective:

The Medicare program is trying to learn more about what information people who make decisions about Medicare coverage want, and what's the best way to give it to them.

Group objective:

As part of this effort, we are conducting these discussion groups with people like you who help Medicare beneficiaries make decisions about their healthcare plans, to learn what you think about the materials that Medicare has developed.

Confidentiality statement:

Your participation today is voluntary and confidential. You can refuse to answer any question, and at any point you are free to stop participating. We will write a report summarizing what we hear in all the groups we do, and it will be impossible to identify any single person's comments. I would like to have an open conversation today, so that everyone is comfortable saying whatever they feel.

[If participants have not already done so, have them complete and turn in the informed consent form. Remind them that one copy is for them to keep, with phone numbers in case they have any questions or comments afterwards.]

Procedure:

- We'll be having an open conversation, so feel free to respond to me, or to others in the group, without waiting to be called on.
- We want to hear what everyone has to say, so only one person should talk at a time.
- We'll be talking for about 2 hours. There are several topics we want to cover, so I may move us along sometimes.
- I'll be using this topic guide to help make sure we cover everything we need to.
- [Explain where the bathrooms are]; feel free to excuse yourself if you need to.
- Since we won't have a break, feel free to get up and help yourself to refreshments while we talk.
- If any of my questions are unclear or confusing, let me know and I'll try to explain better.
- There are no right or wrong answers. We really want to hear from everyone. You are the experts.
- We are here to learn from you,; I'm afraid we won't be able to answer your questions about Medicare.
- Please give your frank and honest opinions. We're here to understand your perspective.
- We will be video-taping the discussion, to make it a little easier on the note-taker and to make sure we understand your views in our analysis later.

Ice-breaker

We'll be on a first-name basis today. I'd like to start by going around the room – will each of you tell us your first name and your relationship to the Medicare beneficiary or beneficiaries whose Medicare decisions you help out with?

Introductory Questions

- I1. What kinds of Medicare questions do you help answer?
[make sure focus is on coverage and not health care choices.]
- I2. Where do you usually get information about Medicare that you need to help out with these coverage questions?
- I3. What informational needs do these sources not provide?

Transition Questions

- T1. Generally, based on information you've collected from these sources, how prepared do you feel to help people make decisions ...
...about the Medicare plan that is best for them?
...about the long-term health care services that Medicare covers and doesn't cover?
...about the rights of Medicare beneficiaries?
- T2. What aspects of the Medicare program do you find the most difficult to understand?

Key Questions

[Hold up the Medicare and You handbook.]
We sent a copy of this to you recently...

- K1. Had you seen this before?
Did you bring a copy with you? [Pass out copies to those who don't have one.]

Access:

- K2. Generally, what did you think of the handbook?
...How the information was presented?
...How useful was the information it contains?
...What sections did you pay particular attention to?
[probe for why: because they were interesting? Difficult? Relevant? Etc.]
...What questions do you have about Medicare that were not answered in the book?

Awareness:

- K3. What would you say is the main purpose of the *Medicare & You* handbook?
[Probe as warranted. If possible probe for perceived trustworthiness of the material.]
- K4. What do you think "Original Medicare" refers to? [Can skip this one if in a time bind.]
...Do you know if this is still available?

Understanding:

K5. I'm going to list some topics that the handbook addressed, and I'd like you to tell me what you feel you've learned, if anything, from the handbook about that subject:
[Probe to understand why they did and/or didn't learn from the handbook on each topic: complexity of material, lack of interest., lack of perceived relevance, etc.]

- How costs differ between the different types of health insurance options?

- How benefits differ between the different types of health insurance options?

- Coverage for long-term care?

- What services people with Medicare can use to get help understanding and comparing health insurance options?

- The rights of people with Medicare?

Use:

K6. Generally, how do you feel this handbook might be useful for you in helping your family member to make decisions about Medicare?

[Probe as warranted for how they would use, why they might not use, etc.]

K7. How could this handbook be made more useful to you?

Ending Questions

[The assistant moderator gives a short oral summary of the discussion.]

E1. Is this an adequate summary?

[After the participants have answered the question, the moderator then repeats the purpose of the study, perhaps taken right off the advance letters.]

E2. Have we missed anything that you think we should know to achieve this objective?

E3. Is there anything we did not discuss that seems relevant or important that you would like us to know?

Thanks again for all your comments on the materials. You have really helped us in thinking more about ways to meet the information needs of people who assist in Medicare decision making.

Appendix B: Recruitment Protocols for Decision Helpers
(3/22/00)

Target population: Individuals who help beneficiaries make decisions about their Medicare coverage.

- Screen out “professional participants”
- Screen out those whose benes are disabled, ESRD, have Medicaid or are institutionalized
- Screen out those who are themselves Medicare beneficiaries
- Aim for a mix of differing Medicare plans (HMOs and FFS)
- Aim for a mix of different types of relationships to the beneficiaries
- Aim for a mix of decision “helpers” and “makers”
- Aim for a mix of helper ages
- Aim for a mix of helper genders
- Aim for a mix of helper ethnicities
- Aim for mix of helper education levels