FINAL

HCFA Market Research for Beneficiaries

Increasing Medicare Beneficiary Knowledge through Improved Communications:

Summary Report on the Medicare Population with Hearing Loss

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Prepared For:

Health Care Financing Administration
7500 Security Boulevard
Baltimore, MD 21244

Prepared By:

Barents Group LLC
2001 M Street, NW
Washington, D.C. 20036

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In Affiliation With:

Project HOPE - Center for Health Affairs
7500 Old Georgetown Road
Bethesda, MD 20814

WESTAT, Inc.
1650 Research Boulevard
Rockville, MD 20850
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The primary authors of the report are W. Sherman Edwards, Associate Area Director, and Mareena Wright, Senior Study Director, of Westat, Inc. The report is a synthesis of findings from three other reports prepared under this contract for HCFA’s Market Research for Beneficiaries project:

♦ *Increasing Medicare Beneficiary Knowledge Through Improved Communications: Inventory Research Findings for Vision-Impaired, Hearing-Impaired, and Low-Literate Beneficiaries*, written by Kenneth R. Cahill, Lisa Green, and Margaret Edder of Barents Group; Jennifer Dunbar of Project HOPE; and Joan E. DaVanzo, formerly of Barents Group [Final Draft, December 1997].


♦ *Increasing Medicare Beneficiary Knowledge Through Improved Communications: Medicare Current Beneficiary Survey Findings*, written by Kenneth R. Cahill, Mary A. Laschober, Lisa Green, and Margaret Edder of Barents Group; Steve Parente, Laura Hodges, and Jennifer Dunbar of Project HOPE; and Joan E. DaVanzo, formerly of Barents Group [Final Draft, August 1998].
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CHAPTER 1. SUMMARY

As part of its long-term strategic plan, the Health Care Financing Administration (HCFA) has undertaken an Agency-wide initiative to adapt its operations to improve communications with Medicare beneficiaries and with its provider partners. Helping beneficiaries to understand their choices among health care plans, providers, and treatment options and the implications of those choices on cost, quality, access and outcomes is especially important now that the Balanced Budget Act of 1997 (BBA) has expanded the health plan options available to beneficiaries. The full range of choices envisioned under BBA is not currently available in the market but an increasing number of beneficiaries will face a much more complex set of choices in the coming years. Medicare beneficiaries not only need to understand the various features of these different options to choose the design that best meets their needs, they also need basic knowledge about many aspects of the Medicare program.

Research Purpose and Methods

The Market Research for Beneficiaries project was designed to provide HCFA with answers to the two fundamental questions that underlie effective communication:

♦ What information do beneficiaries want or need from HCFA?
♦ What are the best ways to communicate that information to them?

The Market Research for Beneficiaries project collected data from three sources to answer the questions:

♦ An inventory of perceived information needs and effective communication strategies from a variety of organizations and individuals who work directly with Medicare beneficiaries,
♦ Focus groups with Medicare beneficiaries, and
♦ A national survey of the Medicare population – the Medicare Current Beneficiary Survey (MCBS).

Each of the three data sources has particular strengths. Together, they can provide HCFA with a broad, deep, and representative understanding of communication with beneficiaries. The survey of Medicare beneficiaries helps ensure that the information gathered is representative of Medicare beneficiaries, while the focus groups and inventory of organizations contribute more in-depth information than can be obtained from a large-scale survey. A description of methodologies for each of the data collection tools is contained in a separate appendix.2

1 The MCBS data used in this report apply only to Medicare beneficiaries age 65 years old or older who were not living in a short-term or long-term care facility during the first two rounds of data collection in 1997.


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As part of HCFA’s commitment to adapt its operations and communication strategies to better serve all Medicare beneficiaries, the Agency identified a diverse set of beneficiary subgroups that it believes may have special information needs regarding the Medicare program or that may require innovative communication approaches to effectively convey information to the subgroup. This report synthesizes key findings from the three data sources for one of the identified “hard to reach” beneficiary subgroups – beneficiaries with hearing loss (either with some hearing loss or profound hearing loss). The report compares the subgroup’s information needs and best communication strategies with those of the general elderly Medicare population. Additional summary reports examine the information needs and best communication strategies for African American beneficiaries, Hispanic beneficiaries, beneficiaries dually-eligible for Medicaid and Medicare, beneficiaries who live in rural areas, beneficiaries with low education or literacy levels, and beneficiaries with vision loss.

Key Findings and Implications for HCFA

Key Findings

Key findings about Medicare beneficiaries with hearing loss include the following central points:

♦ Elderly beneficiaries with some hearing loss (those with moderate or profound hearing loss) represent about 42 percent of the total elderly Medicare population.

♦ Because they comprise such a large fraction of the elderly population and are represented in all age groups and socio-demographic categories, beneficiaries with hearing loss have generally the same needs and expectations about information and information sources as the general Medicare population.

♦ Profoundly individuals with profound hearing loss, accounting for about 0.1 percent of the total elderly Medicare population, comprise the other end of the spectrum of hearing loss. Their primary form of communication is visual, such as through American Sign Language (ASL) or print materials.

♦ Unlike those who have lost hearing in later years, individuals who had profound hearing loss early in life are more likely to have developed effective personal communication channels and tools that either allow them to access information or call upon a resource to interpret or access the information for them. MCBS respondents with profound hearing loss often reported needing less additional information than other beneficiaries, and relied less on Medicare, and more on community organizations for individuals with profound hearing loss, for Medicare-related information.

♦ Important additional information needs of beneficiaries with hearing loss focus primarily on the condition itself (e.g., diagnosis and treatment for hearing loss, coverage of assistive listening devices, and cost of hearing treatments).

♦ Beneficiaries with hearing loss, like the general Medicare population, prefer to get information on Medicare-related topics directly from Medicare (i.e., HCFA). Individuals with hearing loss prefer to get information on staying healthy from their own health care providers.
Beneficiaries with some hearing loss, like the general elderly Medicare population, tend to prefer **face-to-face, in-person communication**. This communication method allows beneficiaries with hearing loss the opportunity to read lips and/or ask for clarification.

In the MCBS, however, a much smaller proportion of beneficiaries with profound hearing loss listed talking with someone in person as a preferred way to acquire information about the Medicare program, compared with the general Medicare population.

**Closed captioning on videotapes, television programs, and advertisements about Medicare- and health-related information** is needed to compensate for the impact of hearing impairments on the ability of all beneficiaries with hearing loss to access information.

**Beneficiaries with some hearing loss also prefer written information** because it reduces miscommunication and misinterpretation.

Because many individuals with profound hearing loss do not read beyond the fourth grade level, however, many important documents and printed materials are not useful for this small group of beneficiaries. The primary consideration when disseminating information to these beneficiaries is to provide it in sign language through established channels within the community of individuals who have profound hearing loss.

Perhaps more important than particular sources of information for beneficiaries with some hearing loss and beneficiaries with profound hearing loss is the **way in which information is disseminated**.

**Implications for HCFA**

HCFA should consider the following when designing communications directed at beneficiaries with hearing loss:

Because such a large percentage of the Medicare population has some hearing loss, all audible communications should be designed to accommodate beneficiaries with hearing loss, such as using closed captioning for all video communications and ensuring that TTY access works smoothly by providing training to workers who answer TTY phone calls.

Moreover, the social stigma and self-esteem issues associated with hearing loss may cause beneficiaries to not readily admit they have difficulty hearing. Communication strategies involving audible communication, therefore, should not rely on beneficiaries identifying themselves as having trouble hearing to implement features that will enable beneficiaries with hearing loss to use these communication modes. HCFA should also continue to make any information that is communicated audibly available through alternative modes, such as by increasing access to computer and/or web-based information sources, and using brochures and other simple printed materials so beneficiaries do not need to depend on their hearing for the information and can refer back to them as needed.

In addition, an important first step in disseminating information is to broadly advertise that hearing loss is nothing to be ashamed of and that help is available. Testimonials are particularly effective in this regard. Because of the prevalence of hearing loss, broad
advertisements through mass media can be extremely effective, especially when they use well-known celebrities or public figures.

♦ Information on hearing loss, prevention, and treatment probably would be useful to both beneficiaries with and without hearing loss, because overall the Medicare population remains largely uninformed about hearing loss and treatment options.

♦ Beneficiaries with hearing loss prefer the same broad modes of communication as the general Medicare population (e.g., in-person communication, brochures, television, and newspapers) but need them to be adapted for their hearing difficulties.

◊ For example, individuals with hearing loss need closed captioning for television and video communications.

◊ Face-to-face communication can be facilitated through partnering with key community organizations that work with individuals who have some or profound hearing loss. This is also an effective way to share information and enhance services for this population.

◊ In-person communication through telephone hotlines can use technologies that enable both individuals with some hearing loss and those with profound hearing loss to better access this mode of communication, including telephone amplification devices, text telephones, and facsimile transmission.

♦ Because beneficiaries with some hearing loss do not share a common language, such as ASL, and can no longer reliably depend on the spoken word for information, dissemination through a variety of channels (e.g., television, newsprint, radio, brochures) and at a variety of locations (e.g., neighborhood banks, senior centers, doctor’s offices) is important. Because beneficiaries with hearing loss may isolate themselves, communication through closed-captioned television and through organizations who work with home-bound individuals or other organizations that go directly to seniors’ home to assist them are important avenues of communication for Medicare information.

♦ Beneficiaries with profound hearing loss are likely to have well-established communication networks and information channels. The community of individuals with profound hearing loss is small and close knit, making a broad approach unnecessary for this group.

**Organization of Report**

This report is organized into four additional chapters:

♦ A profile of Medicare beneficiaries with hearing loss, with their characteristics compared with those of the general elderly Medicare population;

♦ A summary of information needs, Medicare-related knowledge, and information preferences of beneficiaries with hearing loss;

♦ A discussion of information sources preferred by beneficiaries with hearing loss; and

♦ A discussion of communication modes preferred by beneficiaries with hearing loss.
CHAPTER 2. PROFILE OF MEDICARE BENEFICIARIES WITH HEARING LOSS

About two-fifths of non-institutionalized elderly Medicare beneficiaries report difficulty hearing. As many as one-half or more of these beneficiaries likely developed hearing difficulties after reaching the age of 65. Only a very small percentage of them – perhaps around one percent – have profound hearing loss, but hearing loss represents a significant barrier to communicating with a large fraction of the Medicare population.

At one end of the spectrum, individuals with mild hearing loss are able to participate in oral conversations with little difficulty, but may require repetition of phrases or words if the sound source is not directly in front of them or if there is competing background noise. The psychological dimension of hearing loss further complicates communication with these beneficiaries. The inventory research found that the social stigma associated with hearing loss and widespread denial often lead individuals to isolate themselves and withdraw socially, making outreach and general communication very difficult. Out-of-pocket costs for hearing aids, hearing care, and hearing assistive devices are also barriers to receiving the help many beneficiaries need and limits communication with this population. As many as 80 percent of Medicare beneficiaries with hearing loss may not have sought medical treatment.

Individuals with profound hearing loss comprise the other end of the spectrum of hearing loss. Their primary form of communication is visual, such as through American Sign Language (ASL) or print materials. Unlike those who have lost hearing in later years, individuals with profound hearing loss early in life are likely to have developed effective personal communication channels and tools that either allow them to access information or call upon a resource to interpret or access the information for them.

Recognizing the diverse and differing needs of Medicare beneficiaries with hearing loss is critical to HCFA’s comprehensive communication strategy to ensure that all beneficiaries are well informed of their Medicare coverage, options, and consumer rights.

Key Beneficiary Characteristics

♦ A large proportion of elderly Medicare beneficiaries have some or profound hearing loss (about 42 percent), and in most ways they resemble the general Medicare beneficiary population.

♦ Because hearing loss is often attributable to or aggravated by aging, Medicare beneficiaries with hearing loss tend to be older than the general Medicare population.

♦ Also, individuals with hearing loss are slightly more likely to be male, White non-Hispanic, and live in rural areas compared with the general Medicare population, although these differences are not large.

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3 The profiling data in this chapter is drawn from the MCBS, which includes only a very small sample of beneficiaries with profound hearing loss. Due to the small sample size, it is not possible to paint an accurate picture of this group in terms of its socio-demographic or health characteristics. Beneficiaries with profound hearing loss are, therefore, included with beneficiaries with some hearing loss throughout this chapter and are not profiled separately.
♦ The household living arrangements of beneficiaries with hearing loss are very similar to the general Medicare population, as are their economic circumstances including income, education, and Medicaid status.

♦ Beneficiaries with hearing loss are about as likely as beneficiaries in general to have access to VCRs, cable television, and the Internet. This suggests that communication strategies that use these sources will be equally available to those with hearing loss, although their ability to use these technologies may depend upon adaptations appropriate to their condition.

♦ Beneficiaries with hearing loss are slightly more likely to be in poorer health than other beneficiaries, in terms of poorer self-reported health status, more vision problems, and more difficulty performing activities of daily living. However, these differences are not large.

**Demographic Characteristics**

About 42 percent of the Medicare non-institutionalized population age 65 and older report difficulty hearing. Beneficiaries with hearing loss in most ways resemble the general Medicare beneficiary population. Because hearing loss is often attributable to or aggravated by aging, it is not surprising that Medicare beneficiaries with hearing loss tend to be older than the general Medicare population (Figure 2.1). In addition, individuals with hearing loss are more likely to be male, non-Hispanic White, and live in a rural area (Figures 2.2-2.4) than the general Medicare population. However, their household living arrangements are very similar to the general Medicare population (Figure 2.5).

![Figure 2.1 Age Distribution of Medicare Beneficiaries, All Beneficiaries vs. Beneficiaries with Hearing Loss, 1996](image-url)

**Source:** Figure prepared by Barents Group LLC, in collaboration with Westat, Inc.

**Data Source:** Medicare Current Beneficiary Survey
Figure 2.2 Gender of Medicare Beneficiaries, All Beneficiaries vs. Beneficiaries with Hearing Loss, 1996

Source: Figure prepared by Barents Group LLC, in collaboration with Westat, Inc.
Data Source: Medicare Current Beneficiary Survey

Figure 2.3 Race/Ethnicity Distribution of Medicare Beneficiaries, All Beneficiaries vs. Beneficiaries with Hearing Loss, 1996

Source: Figure prepared by Barents Group LLC, in collaboration with Westat, Inc.
Data Source: Medicare Current Beneficiary Survey

Figure 2.4 Metropolitan Status of Medicare Beneficiaries, All Beneficiaries vs. Beneficiaries with Hearing Loss, 1996

Source: Figure prepared by Barents Group LLC, in collaboration with Westat, Inc.
Data Source: Medicare Current Beneficiary Survey
Economic Characteristics

The economic circumstances of beneficiaries with hearing loss are also very similar to those of the general beneficiary population. These circumstances include income, education, and Medicaid status. Figures 2.6 through 2.8 display these comparisons.
Beneficiaries with hearing loss are about as likely as beneficiaries in general to have access to VCRs, cable television, and the Internet (Figure 2.9). This suggests that communication strategies that use these sources will be equally *available* to those with hearing difficulties, although their ability to *use* these technologies may depend upon adaptations appropriate to their condition (see Chapter 5).
Health Characteristics

Beneficiaries with hearing loss are slightly more likely to report being in fair or poor health, and less likely to report being in excellent or very good health, than are beneficiaries in the general Medicare population (Figure 2.10). Beneficiaries with hearing loss are also more likely to report difficulty with their vision, and are equally as likely to be blind as the general Medicare population (Figure 2.11).
A slightly higher proportion of beneficiaries with hearing loss reported difficulty performing one or two activities of daily living (ADLs) without help compared to the general Medicare population, and a moderately higher proportion reported having difficulty performing three or more ADLs (Figure 2.12).

It is not surprising that beneficiaries with hearing loss are more likely to have vision problems and difficulties with activities of daily living, given that they are slightly older on average than the general beneficiary population. Communication strategies targeting Medicare beneficiaries with hearing loss must also take into account the generally poorer health and functioning of this population.
Implications for HCFA

♦ The most important implication of the profiling for HCFA is that, because such a large proportion of the Medicare population has hearing loss, all audible communications should be designed with beneficiaries with hearing loss in mind.

♦ The similarity in demographic, economic, and health characteristics of beneficiaries with hearing loss and Medicare beneficiaries in general is reflected in the following chapters in their similarities in Medicare program and general health-related information needs. That is, the defining characteristic of the majority of the population with hearing loss is the hearing condition itself, which affects mainly the modes of communication this population prefers and is able to use.
CHAPTER 3. WHAT INFORMATION DO BENEFICIARIES WITH HEARING LOSS WANT OR NEED FROM HCFA?

Beneficiaries with some hearing loss and those with profound hearing loss ask many of the same questions and demonstrate the same gaps in understanding of the Medicare program as the general Medicare population. Furthermore, the questions that beneficiaries with hearing loss ask about Medicare are not necessarily related to the severity of hearing loss. Although all of the organizations interviewed in the inventory research made a clear distinction between the general communication strategies for reaching individuals with profound hearing loss and individuals with some hearing loss, the general information needs of both groups about health insurance and Medicare are similar.

However, beneficiaries with hearing loss need additional specific health, insurance, and cost-sharing information related to the condition itself. This chapter summarizes the key findings about the information needs and knowledge of beneficiaries with hearing loss, and highlights differences and similarities between these beneficiaries and those in the general elderly population.

Key Information Needs and Knowledge of Beneficiaries with hearing loss

♦ Overall, beneficiaries with hearing loss – both those who have some hearing loss and those who have profound hearing loss – resemble the general Medicare population in terms of Medicare-and health-related information needs not related to their condition.

♦ However, beneficiaries with profound hearing loss often expressed less need for additional information compared with other beneficiaries. Unlike those who have lost hearing in later years, individuals who experienced profound hearing loss early in life are likely to have developed effective personal communication channels and tools that either allow them to access information or call upon a resource to interpret or access the information for them.

♦ Additional information needs of beneficiaries with hearing loss – especially for those with recent hearing loss - focus on the condition itself. These needs differ according to the extent of an individual’s hearing loss, the coping strategy used, and the extent to which the individual is in denial of their loss of functioning.

◊ Beneficiaries with hearing loss who are not in denial about their condition want basic information about hearing loss in general, as well as detailed information about diagnosis of hearing loss, prevention and treatment options, and resources for obtaining more information on these topics.

◊ A major concern for beneficiaries with some hearing loss is being able to afford hearing aids, screenings, and associated tests, most of which are not covered by Medicare. Organizations such as Hear Now, however, can offer some financial help and planning.

◊ Both beneficiaries with profound hearing loss and those with some hearing loss need information about alternative communication tools, “key” hearing health care providers (e.g., otolaryngologists and audiologists), and assistive listening devices (e.g., telephone amplifiers and alerting systems).
Many beneficiaries with hearing loss are confused whether managed care plans offer assistive hearing devices, and why some managed care plans cover hearing aids while Medicare does not.

Especially for those who have lost their hearing over time and are not accustomed to having difficulty hearing, beneficiaries and their families want advice on coping strategies.

Information Needs

Medicare-related information needs. The inventory and focus group research found that beneficiaries with hearing loss – both those who have some hearing loss and those who have profound hearing loss – need essentially the same information about the Medicare program and related topics as the general Medicare population. In fact, focus group participants with hearing loss had relatively few basic questions about the relations between the Medicare program, the insurance companies who pay Medicare claims, and supplemental insurers compared with beneficiaries in general. Participants with hearing loss, however, were recruited through a hearing loss consumer organization, so the lack of basic questions may reflect how active involvement with consumer groups can contribute to knowledge of the Medicare program.

The market research found that for both beneficiaries with hearing loss and beneficiaries in general there is general confusion over the services Medicare does and does not cover, the concept of a physician “accepting assignment,” and general administrative questions over claims payment and who to contact for appeals or claims status. Beneficiaries struggle with basic Medicare concepts such as “out-of-pocket expenses,” and often do not understand the distinction between the Social Security Administration and HCFA, or between the carrier and their personal insurance companies. Both beneficiaries with hearing loss and beneficiaries in general said they would like to receive regular information about Medicare program changes.

Managed care is an increasingly confusing and frustrating topic for beneficiaries with hearing problems, especially in terms of its relationship to Medicare. Because Medicare does not provide coverage for hearing aids or assistive listening devices, beneficiaries with hearing loss tend not

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The number of beneficiaries with profound hearing loss in the MCBS sample is very small, so for most MCBS analyses, these beneficiaries were combined with those who said they had some or a lot of trouble hearing. Similarly, although focus groups included both individuals with some hearing loss and individuals with severe hearing loss, focus group analysis was not conducted separately for each group.

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to think of HCFA as a resource for Medicare or managed care information, and do not
understand why some managed care plans offer hearing aids while Medicare does not.

The MCBS analysis confirms the findings from the inventory and focus group research: beneficiaries with hearing loss (beneficiaries with some hearing loss and beneficiaries with profound hearing loss combined) were no different from the general Medicare population in terms of what they considered to be the most important topics for more information (Table 3.1) or in their self-reported knowledge about the Medicare program (Table 3.2). Similar to Medicare beneficiaries in general, around 35 percent of MCBS respondents with hearing loss reported that they had no information needs. Among those who said that they did have information needs, 37 percent mentioned Medicare itself, 24 percent mentioned information on staying healthy, and 14 percent wanted more information about out-of-pocket payments for services (Table 3.1). However, beneficiaries with profound hearing loss more often than other beneficiary groups said they did not need information on any of the Medicare-related topics surveyed in the MCBS.

<table>
<thead>
<tr>
<th>Medicare Topic</th>
<th>All Beneficiaries Citing Topic as Most Important to Have More Information On*</th>
<th>Beneficiaries with Hearing Loss Citing Topic as Most Important to Have More Information On*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medicare program</td>
<td>37.8%</td>
<td>37.3%</td>
</tr>
<tr>
<td>Staying healthy</td>
<td>25.8%</td>
<td>24.4%</td>
</tr>
<tr>
<td>Payment for Medicare services</td>
<td>14.3%</td>
<td>14.4%</td>
</tr>
<tr>
<td>Medicare HMOs</td>
<td>9.4%</td>
<td>10.4%</td>
</tr>
<tr>
<td>Supplemental insurance</td>
<td>6.2%</td>
<td>7.1%</td>
</tr>
<tr>
<td>Choosing or finding a doctor</td>
<td>6.7%</td>
<td>6.6%</td>
</tr>
</tbody>
</table>

Source: Table prepared by Barents Group LLC, in collaboration with Westat, Inc.
Data Source: Medicare Current Beneficiary Survey

*Percentages are based on the number of beneficiaries who said they needed information about at least one of the topics in the table.

Three-fourths of MCBS respondents in both groups indicated that they feel they know everything they need to about staying healthy in general, while about two-thirds said they had all the information they need about how to locate a doctor who accepts Medicare payments (Table 3.2). Slightly less than one-half of each group, however, reported that they know everything they feel they need to know about the Medicare program, payment for services, and Medigap insurance.
### Table 3.2
Self-Reported Knowledge of Medicare Topics
All Beneficiaries vs. Beneficiaries with Hearing Loss, 1997

<table>
<thead>
<tr>
<th>Medicare Topic</th>
<th>All Beneficiaries Reporting “Everything I need to know about topic”</th>
<th>Beneficiaries with Hearing Loss Reporting “Everything I need to know about topic”</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medicare program</td>
<td>46%</td>
<td>45%</td>
</tr>
<tr>
<td>Payment for Medicare services</td>
<td>48%</td>
<td>47%</td>
</tr>
<tr>
<td>Supplemental Insurance</td>
<td>46%</td>
<td>45%</td>
</tr>
<tr>
<td>Medicare HMOs</td>
<td>30%</td>
<td>28%</td>
</tr>
<tr>
<td>Choosing or finding a doctor</td>
<td>65%</td>
<td>63%</td>
</tr>
<tr>
<td>Staying healthy</td>
<td>77%</td>
<td>75%</td>
</tr>
</tbody>
</table>

Source: Table prepared by Barents Group LLC, in collaboration with Westat, Inc.
Data Source: Medicare Current Beneficiary Survey

Not only do beneficiaries with hearing loss resemble the general Medicare population in their need for information about most Medicare topics during the past year, they were as likely to be successful in finding answers to their questions (Table 3.3). While a very small percentage (3 to 8 percent) reported needing information about specific Medicare topics in the past year, most reported being able to find answers to their questions (70 to 86 percent). Less than one in five of both groups were unable to find the information they needed.

### Table 3.3
Medicare Beneficiary Need for Information in the Past Year
All Beneficiaries vs. Beneficiaries with Hearing Loss, 1997

<table>
<thead>
<tr>
<th>Information Topic</th>
<th>Needed information</th>
<th>Found information and answers</th>
<th>Found information, no answers</th>
<th>Did not find information</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>All beneficiaries</td>
<td>Hearing Loss</td>
<td>All beneficiaries</td>
<td>Hearing Loss</td>
</tr>
<tr>
<td>New benefits/changes in Medicare</td>
<td>4%</td>
<td>5%</td>
<td>75%</td>
<td>74%</td>
</tr>
<tr>
<td>Find doctors who accept Medicare assignment</td>
<td>2</td>
<td>3</td>
<td>80</td>
<td>76</td>
</tr>
<tr>
<td>Medicare covered services</td>
<td>5</td>
<td>6</td>
<td>74</td>
<td>74</td>
</tr>
<tr>
<td>Medigap policies</td>
<td>7</td>
<td>8</td>
<td>72</td>
<td>76</td>
</tr>
<tr>
<td>Amount owed for services</td>
<td>3</td>
<td>3</td>
<td>70</td>
<td>73</td>
</tr>
<tr>
<td>Availability and benefits of HMOs</td>
<td>6</td>
<td>6</td>
<td>85</td>
<td>86</td>
</tr>
</tbody>
</table>

Source: Table prepared by Barents Group LLC, in collaboration with Westat, Inc.
Data Source: Medicare Current Beneficiary Survey
As with other beneficiary subgroups, according to the focus group research, beneficiaries with hearing loss varied considerably in their information-seeking preferences. Some participants with hearing loss said they are proactive information seekers who prefer a high level of involvement with Medicare and Medicare processes. These beneficiaries indicated that they want detailed information about their Medicare claims so they can track the care they receive from Medicare and identify errors. Other beneficiaries with hearing loss said they are primarily reactive information seekers who prefer specific information. These beneficiaries tend to seek information when they need it to answer specific questions. They want to go directly to a source that is trained or has the experience to answer their questions. They do not want to have to filter through a lot of extraneous or immediately unnecessary information to get the specific information they are looking for. A third set of beneficiaries with hearing loss said that they do not need additional information about Medicare because the system works smoothly for them.

MCBS analysis indicated that beneficiaries with some hearing loss were more likely than the general Medicare population to be characterized as active information seekers in terms of the number of sources they contact to obtain Medicare-related information. However, this may not be true of all beneficiaries with hearing loss, especially those who are more isolated and withdrawn because of the condition.

**Health-related information needs.** Moving beyond information about Medicare in general and managed care, the focus group and inventory research found that beneficiaries with some hearing loss often lack important information about their condition. Beneficiaries with profound hearing loss are considerably more likely to have established channels for receiving information and often can depend on sign language, for example, as a reliable form of communication. Individuals who have lost their hearing in later life, however, no longer have a dependable method of communication and are likely to be uninformed about both their hearing loss and the utility of seeking medical and mental health help. The latter group comprises beneficiaries most in need of hearing-related information.

- Because of the stigma associated with hearing loss and the cost of assistive listening devices, large information gaps exist within the population with some hearing loss. Perhaps three-fourths of beneficiaries needing hearing aids do not have them, and many wait as long as 10 years to seek treatment for hearing loss.

- Important needs for those with more recent hearing loss include additional information on:
  
  ◊ Diagnosis and treatment,
  ◊ Alternative communication tools,
  ◊ Hearing health care providers,
  ◊ Assistive listening technology, and
  ◊ Coping strategies.

  “I think the biggest help, what would help me, like I’m trying to decide do I want the digital hearing aides. I think that’s where the government – some agency should evaluate. There are so many different kinds of hearing aids. I’m not competent to judge.”

  -- *Focus Group Participant with Hearing Loss*
Cost is also a major concern for many beneficiaries with hearing loss. An additional important information need is the extent of coverage under Medicare and other health insurance options.

In addition, the market research found that medical providers not specializing in hearing-related disciplines often do not detect hearing problems and are unable to offer beneficiaries information about treatment or assistive listening options. Fewer than one-fourth of physicians refer their elderly patients for otologic screening.

“I would like to have some information why does not Medicare pay for some people’s hearing aids. They pay for those roll-around chairs and they pay for the chairs that lift you up off the floor to make you stand up but there are a lot of people that really, especially in nursing homes, they can’t afford hearing aids. And why can’t they pay some on those?”

-- Focus Group Participant with Hearing Loss

Implications for HCFA

Because beneficiaries with hearing loss have the same Medicare-related information needs as Medicare beneficiaries in general, information strategies to provide basic information about Medicare and other health insurance options to the general Medicare population will be appropriate for those with hearing loss as well.

For a variety of reasons, beneficiaries with hearing loss need information on hearing loss, prevention, and treatment options.

Cost is a major barrier to obtaining help for hearing loss. Therefore, information on coverage of diagnosis, treatment, and assistive devices under original Medicare and other Medicare plan choices is particularly important to beneficiaries with hearing loss. HCFA might also consider providing information about other groups or programs that can help beneficiaries pay for hearing-related costs that are not covered by the Medicare program.

Because such a large proportion of the Medicare population has hearing loss, and because friends and family of beneficiaries with hearing loss may be more aware of the condition than the affected beneficiaries themselves, information on hearing loss, prevention, and treatment options should be widely disseminated. HCFA should also broadcast the message that hearing loss is often a natural part of the aging process and is nothing to be ashamed of.

Many physicians appear not to detect hearing problems, make appropriate referrals, or inform beneficiaries of treatment options. Physicians and health plans – in particular, primary care physicians who have first and continuing contact with their patients – should also be targets for information about hearing loss and information about Medicare coverage of hearing-related health.

Beneficiaries with hearing loss are somewhat more likely than the general Medicare population to be active information seekers. HCFA can, therefore, expect that a greater proportion of beneficiaries who make contact with HCFA will have some hearing loss. HCFA needs to ensure that information sources (such as toll-free Medicare hotlines) can accommodate the information and health needs of these beneficiaries.
CHAPTER 4. WHAT INFORMATION SOURCES DO BENEFICIARIES WITH HEARING LOSS PREFER?

Communication strategies and tools targeting beneficiaries with hearing loss who have some functional use of residual hearing require some different activities than strategies for reaching those with profound hearing loss. Health care delivery and information dissemination is particularly difficult for the elderly with some hearing loss. The denial and social isolation that characterizes the adult-onset hearing loss population impedes traditional methods of delivering information. Information sources and information dissemination strategies that are best for beneficiaries with some hearing loss and beneficiaries with profound hearing loss are discussed in this chapter.

Key Findings on Preferred Information Sources for Beneficiaries with Hearing Loss

Beneficiaries with Some Hearing Loss

Beneficiaries with some hearing loss – who comprise a very large proportion of the elderly Medicare population – differ little from the general Medicare population in the sources they rely on to obtain information about the Medicare program and related topics. Focus group, inventory, and MCBS data indicate that beneficiaries with some hearing loss prefer the following information sources:

♦ Similar to beneficiaries in general, beneficiaries with some hearing loss prefer to contact Medicare sources (i.e., local Medicare or Social Security offices, Medicare counseling programs, Medicare publications, and toll-free Medicare hotlines) for Medicare information (including program concepts, co-payments and out-of-pocket expenses, and HMO benefits).

♦ HCFA is an important source of information (although beneficiaries with some hearing loss, like the general Medicare population, are generally unaware of the name of the Federal agency that runs Medicare), as are medical providers and senior citizen organizations such as AARP.

♦ Beneficiaries with hearing loss are similar to the general Medicare population in their reliance on friends and family as resources for selecting primary care providers, and on primary care providers for choosing specialists. Like beneficiaries in the general Medicare population, beneficiaries with hearing loss had mixed reactions to receiving government information about providers.

♦ Similar to the general Medicare population, beneficiaries with hearing loss reported that TV and video (provided that they are closed-captioned), and doctors or other service providers are good sources of information for general health-related information. As might be expected, for hearing loss information, they rely most heavily on hearing health care specialists and hearing-related consumer organizations.

♦ Beneficiaries with some hearing loss also rely on family and friends for information, but similar to beneficiaries in general, report that sometimes these sources are not very knowledgeable about Medicare.
Perhaps more important than particular sources of information for those with some hearing loss is the way in which information is disseminated. For example, among beneficiaries with some hearing loss, preferences for sources tend to be based on whether the source provides or uses assistive listening devices.

**Beneficiaries with Profound Hearing Loss**

- Beneficiaries with profound hearing loss are likely to have well-established communication networks and information channels, relying on these sources for information. The community of individuals with profound hearing loss is small and close knit, making a broad approach to disseminating information unnecessary.
- In the MCBS analysis, beneficiaries with profound hearing loss were often less likely to list any of the source options as preferred sources for receiving Medicare-related information compared with the general Medicare population, instead responding that they did not need information on the topic in question.

**Information Sources**

As evidenced in Table 4.1 below, preferred information sources for beneficiaries with hearing loss in the MCBS (beneficiaries with some hearing loss and beneficiaries with profound hearing loss combined)\(^5\) were virtually identical to those of the general Medicare population across the six selected topic areas.

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\(^5\) Since the sample of beneficiaries in the MCBS with some hearing loss overwhelms the number who have profound hearing loss, most answers that are combined can be assumed to reflect the responses of beneficiaries with hearing loss and may not reflect those with profound hearing loss.
**Table 4.1 Preferred Information Sources for Medicare Beneficiaries with Hearing Loss**

*Source: Table prepared by Barents Group LLC, in collaboration with Westat, Inc.*

Data Source: Medicare Current Beneficiary Survey

*Percentages are based on respondents who chose at least one source. Respondents who said they did not need information on the topic are excluded from the figures in the table.

**Beneficiaries with hearing loss include both those with some hearing loss and those with profound hearing loss.**

Similar to the MCBS results, focus group participants with hearing loss rated sources in terms of the amount of information provided at about the same level as did the general Medicare population. For both groups, the three highest-rated sources of information were:

- **AARP/other consumer groups,**
- **Medicare sources/ Medicare carriers/1-800 numbers,** and
- **Supplemental insurance companies.**

Moderator: How about information about supplemental insurance plans. Would you like to be able to get that kind of information by computer? Participant: I would think that you would call the AARP and have them send you a brochure which would give you all the information possible, which they will do very readily.

--- Focus Group Participant with Hearing Loss
the highest rankings to doctors and other medical providers, HCFA, and AARP/other consumer groups, while beneficiaries in general gave highest ratings to supplemental insurance companies, Medicare contractors, and AARP/other consumer groups. These results are displayed in Table 4.2 below.

<table>
<thead>
<tr>
<th>Table 4.2. Medicare Beneficiaries’ Most Trusted Sources of Information</th>
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</thead>
<tbody>
<tr>
<td><strong>Beneficiaries with Hearing Loss</strong></td>
</tr>
<tr>
<td>Doctors and other health care providers</td>
</tr>
<tr>
<td>HCFA</td>
</tr>
<tr>
<td>AARP and other consumer groups</td>
</tr>
</tbody>
</table>

*Source: Table prepared by Barents Group LLC, in collaboration with Westat, Inc.*
*Data Source: Medicare Current Beneficiary Survey*

**Information Dissemination Strategies**

Perhaps more important than particular sources of information for beneficiaries with some hearing loss and beneficiaries with profound hearing loss is the way in which information is disseminated. Following are key suggestions for improving communications with this group of hard-to-reach beneficiaries.

**Beneficiaries with Some Hearing Loss**

♦ A major barrier for many beneficiaries with some hearing loss is their underdeveloped “support” network. Beneficiaries are required to navigate a confusing network of information, often through an automated telephone menu or a series of calls to unrelated organizations. This frustrates them and deters proactive information seeking. Taking the “guesswork” out of accessing information and having one’s questions answered directly is extremely important for these beneficiaries.

♦ Because many individuals with some hearing loss are in denial about their condition, an important first step in disseminating information is overcoming this barrier through broadly advertising that hearing loss is nothing to be ashamed of. It is important, however, that HCFA first conduct formative research on which to base the development of key messages to this audience that will help them overcome their perception about hearing loss. Key messages should be tested with members of the target audience to ensure that they will be the most appropriate for reaching these beneficiaries. Messages should also encompass the type of behavior that HCFA would like them to take, such as finding help for dealing with their hearing loss through appropriate health-related professionals and health-related consumer groups.

♦ Because beneficiaries with some hearing loss do not share a common language, such as ASL, and can no longer reliably depend on the spoken word for information, dissemination through a variety of channels (e.g., television, newsprint, radio, brochures) and at a variety of locations (e.g., neighborhood banks, senior centers, doctor’s offices) is important.

♦ Identify and cross educate all “key players” in an individual’s life who has hearing loss (including family members, different types of doctors, health service delivery groups, social
service groups, government agencies) to help raise awareness of the need for developing a supportive network.

**Beneficiaries with Profound Hearing Loss**

♦ Beneficiaries with profound hearing loss are likely to have well-established communication networks and information channels. The community of individuals with profound hearing loss is small and close knit, making a broad approach unnecessary.

♦ Given the strength of the community and culture of individuals with profound hearing loss, working through known and respected leaders within this community will increase the credibility and reception of the presented information.

♦ Because most community groups serve a broad constituency, it is difficult to develop specialized services and outreach without help and/or guidance from them. Partnering with social and direct service groups who work with individuals with profound hearing loss is an effective way to share information and enhance services.

**Implications for HCFA**

♦ As with the general Medicare population, HCFA can build on the general positive feelings that beneficiaries with hearing loss have about the Medicare program by enhancing its “brand name.”

♦ Beneficiaries with hearing loss need and want information about hearing loss and related services, especially when facing new hearing loss. In this area, teaming with hearing-related consumer organizations, especially those who are most effective at reaching isolated people in their homes, can be an effective way for HCFA to provide comprehensive and accurate information on helping them identify their options for treatment and hearing assistive devices.

♦ HCFA should ensure that Medicare contractors and supplemental insurance companies provide accurate and complete information on coverage for hearing-related care and equipment.

♦ Because of the apparent high regard beneficiaries with hearing loss have for their medical providers, part of an effective communication strategy to help such beneficiaries should be to increase primary care physicians’ awareness of hearing issues and what to do when they discover them. HCFA can also provide general Medicare-related information to providers to pass onto their patients.

♦ TV programs and videos with closed captioning may be an important alternative to oral communication for some information needs.

♦ Partnering with social and direct service groups who work with the community of individuals who have profound hearing loss is an effective way to share information and enhance services. Many organizations are able to provide equal access to services and information for these beneficiaries by providing interpreter services or by delivering information first-hand through sign language. HCFA needs to continue to make sure that the organizations working with these beneficiaries have high-quality, up-to-date information on the Medicare program and health benefits.
Given the strength of the community and culture of individuals with profound hearing loss, working through known and respected leaders within the community will increase the credibility and reception of the presented information.
CHAPTER 5. WHAT COMMUNICATION MODES DO BENEFICIARIES WITH HEARING LOSS PREFER?

Key Findings on Preferred Communication Modes for Beneficiaries with Hearing Loss

Beneficiaries with hearing loss have much the same preferences as the general Medicare population for communication modes, notably in-person conversations and printed materials (especially brochures), although for somewhat different reasons. The similarity in preferences for communication modes, however, depends on the extent of hearing loss, with beneficiaries who have profound hearing loss often differing from the general Medicare population. Beneficiaries with hearing loss prefer:

♦ **Face-to-face conversations** (for beneficiaries with some hearing loss, in similar proportions to the general beneficiary population) because they facilitate lip reading:

  “I find that if you’re face-to-face you automatically begin to watch their lips and get an idea of what they’re saying by their lips.”

◊ In the MCBS, a much smaller proportion of beneficiaries with profound hearing loss, however, listed talking with someone in person as a preferred way to acquire information about the Medicare program compared with the general Medicare population.

♦ **Television and videotapes** (in similar proportions to the general beneficiary population in the MCBS, but focus group participants with hearing loss said they were more likely to rely on television and videotapes) because they allow closed-captioning:

  “I wish they would caption almost everything.”

♦ **Written information** (for beneficiaries with some hearing loss, again in similar proportions to the general beneficiary population) because it reduces miscommunication and misinterpretation:

  “You have to get it in writing in order to be sure.”

◊ Several organizations interviewed for the market research that work with individuals with profound hearing loss said that many of these individuals do not read beyond the fourth grade level and that many documents and printed materials are therefore not as useful for this group of beneficiaries. The primary consideration when disseminating information to these beneficiaries is to provide it in sign language through established channels within the community of individuals who have profound hearing loss.

♦ **Computers and Internet technology** (in the same proportions as the general Medicare population in the MCBS, but a relatively high proportion of focus group participants with hearing loss expressed interest in learning how to obtain information from computers) perhaps because this is an interactive forum in which they are able to participate more fully:

  “I’ve taken a couple of short courses on the computer and I just don’t feel like I’m that proficient yet, but if I could use a computer, I think there’s a lot on the Internet that would be very helpful.”
Communication Modes

Preferences for modes of communication for beneficiaries with hearing loss differ depending on the extent of hearing loss.

♦ According to the inventory research, the telephone is a relatively useless communication vehicle for seniors with hearing loss, particularly since many of them do not take advantage of assistive technologies. However, among focus group participants with hearing loss, most reported that they do use the telephone, albeit with varying degrees of success. Some rely on friends or family to get information over the telephone; others have amplification devices or aids such as text telephones; a few can use the telephone without any devices or with the help of their hearing aids. Participants reported problems ranging from voice quality and volume, to operator insensitivity, to poor interface between their assistive devices and telecommunication technology.

♦ Beneficiaries with some or profound hearing loss prefer interactive communication methods, notably teletypewriters (TTY). Those that have TTY equipment like being able to use it, although sometimes they encounter problems with interfacing with hearing individuals.

♦ Beneficiaries with profound hearing loss are about one-half as likely as other beneficiaries to prefer talking to someone in person as a way to get information.

♦ Individuals with some hearing loss, on the other hand, may benefit from:
  ◇ Aural rehabilitation, including training on how to make use of the hearing ability they have remaining;
  ◇ Training in speech reading;
  ◇ Hearing aid orientation; and
  ◇ Counseling to overcome denial of and embarrassment about their impairment.

"Many of the people who answer [the TTY]… are not responsive very well to a TTY user."

-- Focus Group Participant with Hearing Loss
Communication tools and technologies available to assist individuals who have some or profound hearing loss include:

<table>
<thead>
<tr>
<th>Communication Tools for Beneficiaries with Some or Profound Hearing Loss</th>
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<tbody>
<tr>
<td>♦ Computerized Speech Recognition Systems, which are computer software packages that convert spoken words into text;</td>
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<tr>
<td>♦ Hard-wired devices that provide a direct link to a sound source;</td>
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<tr>
<td>♦ E-Mail and FAX;</td>
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<td>♦ Open/closed captioning;</td>
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<tr>
<td>♦ Sign boxes, in which a translator signs the spoken portions of a video or presentation either in a full screen format or in a box at the bottom of the screen;</td>
</tr>
<tr>
<td>♦ Telephone amplification devices;</td>
</tr>
<tr>
<td>♦ Assistive listening devices, which include a variety of technologies such as audio loop systems, AM/FM amplification, or infrared amplification systems that interact with hearing aids or special receivers to amplify and clarify sound;</td>
</tr>
<tr>
<td>♦ Text telephones;</td>
</tr>
<tr>
<td>♦ Telephone relay services for using TTY services interactively with hearing persons;</td>
</tr>
<tr>
<td>♦ Aural rehabilitation including auditory training, speechreading, and hearing aid orientation; and</td>
</tr>
<tr>
<td>♦ Counseling</td>
</tr>
</tbody>
</table>

Implications for HCFA

For better communication with beneficiaries who have some hearing loss and beneficiaries who have profound hearing loss, HCFA should consider:

♦ Using closed captioning for all video communications;

♦ Increasing access to computer and/or web-based information sources;

♦ Ensuring that TTY access works smoothly, by providing training to workers who answer TTY phone calls, and making the Medicare TTY number more visible; and

♦ Dedicating a few operators to beneficiaries with hearing loss on its toll-free telephone lines who would be trained to modify their speech and to be particularly sensitive the needs of beneficiaries with hearing loss.

Communication strategies and tools targeting beneficiaries with some hearing loss, who have some functional use of residual hearing, require somewhat different activities than strategies for reaching beneficiaries with profound hearing loss:

♦ Although HCFA provides a TTY line, most individuals with some hearing loss do not own or do not have easy access to a text telephone. Individuals with hearing loss (as well as the general beneficiary population) have a difficult time navigating an automated telephone
menu, either because they have trouble hearing the recording or because they are confused by the numerous options listed. Respondents noted that one solution for most of the current generation of beneficiaries is to provide a live operator who is a trained customer service representative to aid the caller with his or her questions and concerns. In addition, increased awareness of hearing difficulties by staff on relay services and at TTY locations will be helpful for those individuals with hearing loss.

♦ Beneficiaries with some hearing loss do not share a common language such as ASL and can no longer reliably depend on the spoken word for information. Dissemination through a variety of channels (e.g., television, newsprint, radio, brochures) and at a variety of locations (e.g., neighborhood banks, senior centers, doctor’s offices) is important.

♦ HCFA should partner with organizations that can provide one-on-one Medicare information to beneficiaries, such as senior centers, churches, State Health Insurance and Assistance Programs (SHIPs), and hearing-related national and community-based organizations such as Self-Help for Hard-of-Hearing People, the Better Hearing Institute, Communication Services for the Deaf and Hard of Hearing, Hard of Hearing Advocates, and the League for the Hard of Hearing. These organizations in particular might be an effective way for HCFA to reach out to beneficiaries with hearing loss who have isolated themselves. HCFA needs to study which organizations have the capacity and desire to conduct such potentially expensive outreach activities.

♦ Use brochures and other simple printed materials so beneficiaries do not need to depend on their hearing for the information and can refer back to the information as needed.

The primary consideration when disseminating information to beneficiaries with profound hearing loss is to provide it in sign language through established channels within the community of individuals who have profound hearing loss.