

Elizabeth Hargrave

**NORC**

Jack Hoadley

**Georgetown University**

Laura Summer

**Georgetown University**

Ayesha Mahmud

**NORC**

•

**MedPAC**

601 New Jersey Avenue, NW

Suite 9000

Washington, DC 20001

(202) 220-3700

Fax: (202) 220-3759

[www.medpac.gov](http://www.medpac.gov)

•

The views expressed in this report  
are those of the authors.

No endorsement by MedPAC  
is intended or should be inferred.

# Findings from Beneficiary and Physician Focus Groups

*A study conducted by staff from NORC at the University of Chicago  
and staff from Georgetown University for the Medicare Payment  
Advisory Commission*

# Findings from Beneficiary and Physician Focus Groups

## Final Report

**NORC**  
at the UNIVERSITY OF CHICAGO

### Submitted to:

Joan Sokolovsky  
Medicare Payment Advisory Commission

### Authors:

Elizabeth Hargrave, NORC  
Jack Hoadley, Georgetown University  
Laura Summer, Georgetown University  
Ayesha Mahmud, NORC

**October 2009**

MedPAC Task Order E4046931  
NORC PN 6653.01.62

# Findings from Beneficiary and Physician Focus Groups

## Executive Summary

In July and August 2009, researchers at NORC and Georgetown University conducted a series of 18 focus groups in Baltimore, Chicago, and Seattle with a total of 99 Medicare beneficiaries and 64 physicians. The groups were designed to gather input on several topics: low-income beneficiaries' experiences with plan switches in Part D, high-spending beneficiaries' experience with the coverage gap in Part D, physicians' and beneficiaries' experience on beneficiary access to physicians, and physician views on comparative effectiveness information. Most groups also discussed concierge medicine.

### *Low-Income Beneficiaries' Experience with Part D*

**Overall, low-income beneficiaries had a difficult time explaining their enrollment status.** Not everyone could name the plan they were in; many beneficiaries cannot describe clearly whether they are in a Medicare Advantage plan or a stand-alone drug plan. Beneficiaries also have difficulty explaining what premiums they pay, tending to confuse (where applicable) the Part B premium, Part D premiums, Medicare Advantage premiums, and Medigap premiums. This general confusion made focus groups with this population on the subject of plan switching challenging.

**Many beneficiaries have had some experience relating to plan switching, but generally lacked clarity about the switches.** Beneficiaries often could not clearly articulate the reason for the switch. Most seemed to accept the new plan assignment without looking into other options, but a few took steps to change plans.

**Most beneficiaries were able to obtain their medications, but several described difficulties.** Only a few beneficiaries reported any problems getting access to medications. Most cases where they did were linked with plan switches, but some were associated with formulary changes later in the year. A number of beneficiaries said they had come to expect changes in their coverage.

**Beneficiaries turned to a variety of sources when trying to make choices or resolve problems.** Several beneficiaries said they got so much information that they did not know what to do with it; a few noted that because they have conditions that make it difficult to function on some days (chronic pain, memory loss) they have had trouble coping with confusing communication and deadlines. Participants used a variety of sources (friends, family members, pharmacists, doctors, counselors working in public or private organizations, and insurance brokers) to help make sense of the program; pharmacists were singled out as a particularly important resource.

**Low-income beneficiaries continue to be the targets of heavy marketing by Medicare Advantage plans.** As we have found in previous focus groups with low-income beneficiaries, this population seems to have more in-home visits from plan representatives than beneficiaries in higher-income groups, perhaps because they can switch plans year-round. Some beneficiaries who enrolled in Medicare Advantage were quite happy with their experience, while others had a bad experience and disenrolled in a short time frame. Several beneficiaries reported misleading promises, or less than complete information about the consequences of a change.

## ***High Spenders' Experience with the Coverage Gap***

**Many beneficiaries in our groups were hitting the gap mid-year because they were taking a few brand-name medications, along with several generic drugs, for multiple chronic conditions.** These were often common conditions such as diabetes, asthma, and heart disease that caused beneficiaries to hit the gap year after year. Only a few beneficiaries in our groups reached the catastrophic limit; these were beneficiaries taking very expensive medications for conditions such as AIDS and rheumatoid arthritis. A few beneficiaries in our groups reached the gap because of a large one-time expense, such as having to take cancer drugs for a limited time.

**Beneficiaries who had hit the gap at least once before were well aware of the gap and how it works.** Compared to focus groups we had conducted in previous years, beneficiaries seemed much more familiar with how the gap works. Nearly all focus group participants were aware of the monthly statements telling them their status and use them (or their own personal records) to know rather precisely where they stand. However, beneficiaries who were hitting the gap for the first time in 2009 seemed more confused by how the coverage gap works.

**Even those who were familiar with the gap expressed some confusion or frustration over the counting rules.** Most frequently mentioned was a frustration that both their copays and the plan's payments count toward reaching the gap.

**Participants reported on a wide array of coping strategies and adjustments to lower their overall costs.** These included switching from brands to generics where possible, obtaining free samples (from physicians or directly from manufacturers), shopping for lower prices (locally, by mail order, with discount cards, and from Canada), changing to less expensive medications, and reducing or stopping medications (some with and some without the knowledge or agreement of their physicians). Many beneficiaries were able to make cost-saving changes in their drug regimens without adverse consequences. However, we did hear stories of some adverse effects; some tolerated worse side effects or less control of their health conditions, while other beneficiaries chose to continue paying for an expensive drug through the gap.

**Participants also reported tricks they use to improve their cash flow, but these were less common than strategies for reducing overall costs.** These included buying inexpensive medications without using their insurance card, timing which prescriptions to fill first as they approach the gap, and limiting fills at the end of the year knowing they will have better coverage in January. In addition, many reported saving all year so that they would have the money to cover their prescriptions during the gap.

**Few high-spending beneficiaries had any coverage in the gap, even for generics.** There was little discussion of changing drug plans to improve their cost situation, but at least a few were taking this step. Many beneficiaries were either unaware of the availability of coverage for generics in the gap, or didn't see it as helpful.

**With these coping strategies, many beneficiaries could afford to continue taking their drugs in the gap, but some could not.** One participant in particular reported (at the time of the session) being only a few days away from being unable to fill a prescription for diabetes medications that were critical to his health. He had tried numerous strategies already and was at a loss to know what to do next.

**Despite their problems with the gap, most were glad to have the Medicare drug benefit – and Medicare.** Particularly for those who had not had drug coverage prior to enrolling in the program, Part D was seen as a big help, despite the gap.

### *Physicians' Views on Comparative Effectiveness*

**Physicians point to a variety of sources they currently consult for information on new procedures or drugs.** These include professional meetings and journals, Internet and other electronic sources such as PDA programs and subscription websites, professional organizations, formal and informal consultation with colleagues, and representatives of pharmaceutical and device manufacturers.

**Many physicians spoke about the need to filter any information they receive from these sources, based on their perception of the bias of the source.** Different physicians have different perceptions of bias. For example, government is regarded by some as a trustworthy source, but others see the government as having its own sources of bias (e.g., the need to save money). Although drug representatives are generally seen as a helpful and timely source of information, many physicians view the information provided with some skepticism because of the potential bias in favor of the products they represent. Professional organizations and sources such as UpToDate.com were generally a trusted source of information, and physicians perceive them as having little bias (though one or two physicians pointed out that even these groups can be influenced by sponsorships or other outside input). Sources of support for various types of research was a topic of conversation among physicians with some noting that sponsorship could make the results suspect; some discussed the possibility of having industry contribute to a research fund administered by the government.

**Physicians currently have little access to head-to-head comparison information for drugs, devices, or procedures, but there was disagreement on whether more is needed.** Even when two drugs or devices are aimed at treating the same problem, new studies are often done with different parameters so comparisons to other studies are difficult. Some physicians were satisfied with the level of comparison or guidance available in the clinical guidelines they see from professional organizations or other sources. Many thought more comparative information would be helpful, but were concerned about whether it was the best use of research dollars or that comparative research might be conducted by organizations with a financial stake in showing that a particular product was superior.

**Physicians expect they will have to do the same sort of filtering for comparative effectiveness research that they do for other clinical information.** There was a good deal of discussion and disagreement about the best source for comparative effectiveness research, following the same arguments as those about bias in general. Some see the government as a good source, but others fear the research will be biased in favor of cheaper alternatives. Different government sponsors may be seen as more or less trustworthy. For example, some physicians mentioned the NIH or FDA as unbiased research sources, while others would see CMS as a biased source because of its payment responsibility.

**There was considerable concern that comparative effectiveness research would lead to restrictive guidelines by government or health plans and that those guidelines would be biased toward cheaper treatments.** Physicians feared that they would be unable to use the “losing” drugs or procedures; most said they wanted to continue to have multiple options available for treatment of their patients. Some went a step further to suggest that the inevitability of some drugs or devices being losers would slow the

development of new treatments. A few also were concerned about the interaction of liability and CE research; they want to know if they will have protection from liability claims if they used guidelines based on good research.

**If there are new comparative effectiveness research results, physicians want results in a form that is concise and easy to read.** While some seem to take the time to do considerable research through journals and conferences, others feel they lack the time and are looking for shortcuts. Email alerts that call attention to new findings (particularly alerts from their professional societies) were mentioned by several. Some liked the idea of using such comparative effectiveness information when telling patients about treatment options, but others were skeptical that it would be a good approach for all patients.

### *Beneficiaries' Experiences with Access to Physicians*

**We heard few concerns about access to physicians in any of the three locations selected for this study.** Although access issues do not appear to be widespread in any of our focus group locations, we heard access issues raised a little more often in Chicago and Seattle than in Baltimore. However, these city-based observations are based on smaller numbers than other findings. Most beneficiaries felt they could get appointments in a reasonable amount of time as appropriate to the medical situation. For the most part, access issues do not appear to have changed for these beneficiaries over the past several years.

**Most beneficiaries have no trouble finding doctors, but there were a few more reports of issues with access to specialists than for primary care.** These usually involved one particular specialty (rheumatology, dermatology) or service (physical therapy), but most beneficiaries were not having problems, even finding a specialist.

**There were a few more reports of access issues with the low-income participants than with the higher-income beneficiaries.** In particular, dual eligibles sometimes said they had trouble finding providers who would accept Medicaid. A few beneficiaries felt they had been treated differently as the type of insurance they carry changed (from private to Medicare or Medicaid).

### *Physicians' Views on Medicare Access*

**Most physicians were accepting new Medicare patients, but a few were not.** All physicians were required to have at least 10 percent Medicare patients in their practice to be invited to one of our focus groups, but a few reported that they had stopped taking new Medicare patients. A few others have given serious consideration to stopping.

**Physicians perceive a problem with access to certain specialists.** We heard an assortment of examples of specialists for which physicians thought Medicare access was a consistent problem (urology, psychiatry, rheumatology, dermatology).

**The acceptance of other types of insurance varied among physicians in our groups, with Medicaid being the least accepted.** Some physicians who did not take traditional Medicare would accept Medicare Advantage; conversely, there were some physicians who would accept fee-for-service Medicare patients but not certain MA plans. Some physicians also refuse to accept certain private insurers. Medicaid was by far the least accepted source of insurance among the physicians.

**Physicians named predictability, the pleasure of treating older patients, and the absence of preapproval requirements as the things they like most about Medicare.** Physicians see Medicare as a reliable payer, and appreciate the lack of preapproval requirements. When we asked physicians what they liked most about Medicare, some also said they liked the safety net that Medicare provides for the elderly and the universal nature of the program. A few said they found pleasure in treating older patients, because of their interesting life histories or the interesting problems they present.

**Physicians said they disliked Medicare's level of payment, and they were concerned about some of Medicare's coding and billing policies.** Physicians reported consistently that private insurance payment rates were higher than Medicare –30 percent higher to double Medicare's rates. Those who had stopped seeing Medicare patients generally argued that they were not compensated adequately for the time they spend with Medicare patients. In addition to wishing Medicare paid more, physicians are concerned about challenges to their billing practices such as threats for audits and reviews for fraud. Several mentioned that no other insurer can threaten to send them to jail. Others mentioned issues with Medicare's coverage, including poor coverage for preventive services, the drug benefit coverage gap, and other specific coverage issues.

### *Concierge Care*

**Some participants were aware of concierge care, but it did not seem widespread.** Two beneficiaries had signed up with concierge physicians and were generally happy with their experience. A few had physicians who were considering converting their practices and had concerns with this development.

**Concierge care was modestly familiar to most physicians in our groups.** But only a few saw this as a positive development (one cited a friend who was doing well with it). A number of others raised concerns about issues such as the cost of the care and the potential for patients to demand too much time of their doctors.

# Findings from Beneficiary and Physician Focus Groups

This report describes the themes that emerged from a series of 18 focus groups held in July and August 2009, in Baltimore, Chicago, and Seattle. It begins with a section on methodology, which describes the group participants, our procedures, and some of the strengths and limitations of focus groups that should be kept in mind when considering these results. We then present six sections on the topics covered by the focus groups: low-income beneficiaries' experiences with plan switches in Part D, high-spending beneficiaries' experience with the coverage gap in Part D, beneficiary access to physicians (from the beneficiary perspective and the physician perspective), physician views on comparative effectiveness information, and concierge medicine.

## Methodology

We conducted a total of 18 focus groups in July and August of 2009 at focus group facilities in Baltimore, Chicago, and Seattle. In each location, we held two of each of the following types of groups:

- **Low-income beneficiaries.** For these groups, we sought beneficiaries who were enrolled in the Part D low-income subsidy. Discussion topics included plan selection and experiences with being switched among plans, as well as questions about access to physicians.
- **Beneficiaries with high drug spending.** These groups included beneficiaries who had reached the Part D coverage gap in 2008 or 2009, or who expected to reach it in 2009. Discussion topics included strategies for avoiding the gap or lessening its impact, as well as questions about access to physicians.
- **Physicians.** In each location, we spoke with both primary care physicians and specialists. In two locations, the two types of physicians were in separate groups, while in the third both groups included a mix of types. Discussion topics included physicians' use of and desire for comparative effectiveness information, as well as questions about acceptance of Medicare and access by beneficiaries.

The discussions were facilitated by researchers from NORC and Georgetown University, with two moderators leading each group. Each focus group lasted for approximately 90 minutes. Each discussion was recorded and transcribed; quotes included in this report are taken verbatim from those transcriptions. All procedures and protocols for the focus groups were approved by the Institutional Review Boards (IRBs) at both NORC and Georgetown, and participants were promised that their names and other identifying information would be protected.

### *Participants in the Focus Groups*

Participants were recruited by professional recruiters at the focus group facility in each location, using a screening questionnaire developed by project staff at NORC and Georgetown University. Potential participants were identified based on the group criteria cited above, while also seeking a mix of participants on other factors. For beneficiaries, these factors included sex, race, age, education, and enrollment in Medicare Advantage plans. For physicians, these factors included number of years in practice and practice setting. All participants received an honorarium for participating.



A total of 54 beneficiaries with high drug spending, 45 low-income beneficiaries, and 64 physicians participated in the 18 focus groups. The distribution of participants according to several criteria is shown in Exhibits 1 and 2.

**Exhibit 1. Beneficiaries Participating in Focus Groups**

<b>Characteristic</b>	<b>Beneficiaries with High Drug Spending</b>	<b>Low-Income Beneficiaries</b>
<b>TOTAL</b>	<b>54</b>	<b>45</b>
<b>Income</b>		
Under \$15,000 (\$20,000 if married)	1	29
\$15,000 to \$29,000 (\$20,000 to \$34,000 if married)	23	10
\$30,000 or more (\$35,000 if married)	29	1
Unspecified	1	5
<b>Education</b>		
Some high school or high school graduate	10	10
Some college	16	17
College graduate	18	12
Post-graduate	9	6
Unspecified	1	0
<b>Age</b>		
Under 65	7	20
65-70	22	13
71-74	16	7
75-80	6	3
80+	3	2
<b>Medicare Advantage</b>		
Yes	18	19
No	36	26
<b>Plan Sponsor</b>		
Blue Cross-Blue Shield	8	2
Bravo	0	6
Caremark Silverscript	0	5
Community Care CCRx	2	2
First Health	0	3
Group Health Cooperative	0	2
Health Spring	0	2
Humana	9	2
United Healthcare / AARP / Secure Horizons	19	2
Wellcare	0	3
Other*	5	6
Unspecified	11	0

\* The other category includes plans with just a single participant.

## Exhibit 2. Physicians Participating in Focus Groups

Characteristic	Number
<b>Specialty</b>	
Primary Care Physician	32
Specialist*	32
<b>Years of Practice</b>	
Up to 10 years	11
11 to 20 years	18
21 or more years	28
Unspecified	7
<b>Practice Setting**</b>	
Solo Practice	23
Small Group Practice (fewer than 25 physicians)	18***
Large Group Practice (25 or more physicians)	16
Hospital or Academic Medical Center	3
Integrated Health Plan	1
Clinic	3

\* Among the specialists, 18 different specialties were represented. Specialties represented by two or three physicians include cardiology, ear-nose-throat specialists, endocrinology, neurology, obstetrics/gynecology, psychiatry, rheumatology, and urology.

\*\* Among physicians specifying solo or group practice settings, 7 also indicated that the practice was based at or affiliated with a hospital.

\*\*\* Includes 4 physicians that responded “solo or small practice,” but did not distinguish which type.

### ***Strengths and Limitations of Using the Focus Group Approach***

The focus group methodology is inherently different from quantitative methods such as surveys and the analysis of claims data. While we made an effort to recruit beneficiaries and physicians with a wide range of characteristics, they do not represent a random sample of the respective populations. In addition, the number of respondents was relatively small, as noted above. As a result, care should be taken not to over-generalize the results of these groups. For example, in places, this report notes specific numbers of beneficiaries or physicians who made a certain type of comment. The total number of focus group participants with this perspective may be greater since not everyone responded to a given subject. Furthermore, because these groups are small and not a random sample of the population, it cannot be assumed that the share of beneficiaries or physicians in the general population holding the same opinion is the same as the share in the focus group.

With these caveats, focus groups can provide rich insight into beneficiary and physician experiences with and opinions of Medicare and other matters. Participants tell personal stories that cannot be accessed easily through more quantitative methods. In addition, they often raise unexpected topics that might never come up using more controlled methods. Facilitators have the opportunity to probe the personal stories or unexpected topics to get additional information on the point being made. Thus, the results of these groups can be an important supplement to claims analysis, more structured surveys, or other quantitative methods.

In developing the themes that emerged from the focus groups, we have sought to highlight opinions or experiences that seemed to be fairly widespread across multiple groups. We have also pointed out minority opinions or experiences that, while not widespread, might be important to take into account. For example, we report on the experience of a single beneficiary who had serious problems after switching insurance plans. Our intention is not to imply that such problems are widespread, but to bring to light potential problems that policy makers might want to be aware of.

## **1. Low-Income Beneficiaries' Experience with Part D**

All beneficiaries can choose whether to change drug plans from year to year, but beneficiaries who receive the Part D Low-Income Subsidy and are enrolled in a drug plan that will not qualify for fully subsidized premiums the next year may be randomly reassigned to a new plan or may be expected to change plans themselves in order to avoid paying premiums. Between 2008 and 2009, 1.6 million LIS beneficiaries were reassigned to a new plan by CMS. Another 620,000 were notified about the premium increase for their current plan, but were not reassigned.<sup>1</sup> Nevertheless, an estimated 2 million LIS beneficiaries paid a monthly premium in 2009 because they remained in a non-benchmark plan.<sup>2</sup>

We sought beneficiaries for the focus groups who were receiving the Low-Income Subsidy and who had either been reassigned to a new plan between 2008 and 2009 or had remained in their plan, but were paying premiums in 2009 because the plan no longer qualified for subsidy status. Recruitment for these focus groups was challenging, however. Beneficiaries were confused about their Medicare coverage. Not everyone could name the participating drug plan in which they were enrolled. When they could, they often did not seem to know whether it was the plan sponsor's PDP or MA plan or which version of the plan it was. Many beneficiaries cannot describe clearly whether they are in a Medicare Advantage plan or a standalone drug plan. In Illinois and Maryland, state programs that provide assistance with prescription drugs pose an additional complication. Several noted that they have multiple insurance cards and they just show them all each time they require services or prescriptions.

Beneficiaries who reported that they were paying premiums often had difficulty explaining what premiums they pay, tending to confuse (where applicable) the Part B premium, Part D premium, Medicare Advantage premium, and Medigap premium. Because some of these premiums are paid as deductions from monthly Social Security checks, it becomes even harder for people to sort out what they are paying. Beneficiaries are also unclear about the type of assistance that is available and the type they receive. They had difficulty distinguishing among the Part D low-income subsidy, the Medicare Savings Programs, and stimulus payments they received from Social Security. In the focus groups, beneficiaries were able to tell us if their drug coverage or subsidies had changed in the past year or over the years, but often could not explain exactly when, how, or why changes had occurred.

A variety of circumstances and experiences were represented among the 45 beneficiaries we spoke with in the focus groups. The number of plans in which they were enrolled over a four-year period ranged from one to four. At least some had received letters explaining that their coverage was about to change. A few sought assistance when they received the letters. Premium payers were represented in

---

<sup>1</sup> CMS, "Year 2008 Re-Assignment Data – Premium Increase" and "Year 2008 Re-Assignment Data – Terminating Plans." November 2008; accessible at <http://www.cms.hhs.gov/limitedincomeandresources/>.

<sup>2</sup> Elizabeth Hargrave, Jack Hoadley, Juliette Cubanski and Tricia Neuman. "Medicare Prescription Drug Plans in 2009 and Key Changes Since 2006: Summary of Findings." Kaiser Family Foundation publication 7917. June 2009.

the groups as were beneficiaries who participated in the Medicare Savings Programs and therefore did not pay Part B or D premiums. Some of the low-income beneficiaries were dually eligible for Medicare and Medicaid, while others did not have Medicaid coverage.

The primary intent of the focus groups with low-income beneficiaries was to learn about their experiences with plan switching. While focus group participants were eager to discuss the topic, it was not always easy to discern the exact circumstances related to their experiences. Nonetheless, in the course of the discussions they provided useful information on the topic. Focus group participants were also asked to talk about their experiences related to obtaining health services, including access to both prescription drugs and physician services. The discussants also brought up related topics such as their experience with marketing activities by prescription drug and Medicare Advantage plans.

***Many beneficiaries have had some experience related to plan switching, but generally lacked clarity about the switches.***

A few low-income beneficiaries could describe being told by letter that they had to switch plans. In most cases this appears to have been because of changes in plans' benchmark status, but many of these beneficiaries could not clearly articulate the reason for the switch. One woman remarked, "I don't believe I actively changed it [the plan], but it seems that some of them just sort of get shifted around and I suppose it's kind of like mortgages or something."

When beneficiaries knew that they had been switched from one plan to another, most went along with the switch; it appears that they accepted the new plan assignment without looking into other options. One woman who accepted the change said that she was sad to have to leave her old plan. She described her experience,

Last year I had [plan]...and I had them for a couple of years and they were fantastic. If I had problems I could call them and the ladies down there were wonderful. I was sorry to leave them, but Medicare didn't give me a chance... when I had [plan], if I had a drug that couldn't be paid for - that they didn't cover - I would call them and they would call the drugstore or my doctor and tell them that they have to do certain things and then...I would get it. And I don't have that so much with this one. I don't even know who to call, really. I'm sure I have the number somewhere, but it was so easy before to do it.

A couple of beneficiaries specifically said that they were aware that they had the opportunity to switch, but chose not to. A few beneficiaries did take steps to change plans, but spoke about difficulties determining which plan is best for them. One reported that he changed plans four times and each time he had done the research himself. He said,

I would get a letter saying that my coverage was changed. And then I'd have to go...and do a whole series of research again...and figure out what the next best one was...most of the information being unavailable or inaccurate. And even the stuff from the Medicare Web site, you'd go...down the next level to the individual companies and it doesn't agree. And...you spend more time trying to keep track of what's going on to try and stay ahead of it.

Other beneficiaries said they had more positive experiences, including help enrolling in new more appropriate plans. One reported that she called the number on the letter she received,

I called...when I received the letter...because they said if you don't choose by a certain day...they would pick it for you...she heard me, all my needs, what I really wanted and she was able to guide me through that...and I was thankful because people are not willing to be patient and help you all the time.

Few low-income beneficiaries reported that they paid premiums for Part D coverage, though, as noted above, most were confused about their obligations for premiums and co-payments related to different parts of Medicare. Part D program data show that about 2 million low-income beneficiaries in 2009 are enrolled in drug plans with premiums that are not below the benchmark and therefore are paying premiums. Some may have chosen to pay the premiums in order to avoid switching plans, particularly if the premiums are modest. Others may be unaware that they are paying premiums especially if the premiums are deducted from their Social Security payments. When low-income beneficiaries in these focus groups were asked if they would be willing to pay premiums in order to keep their current prescription drug coverage, a few in each group indicated that they would because they were satisfied with their current situation and willing to pay a small amount of money to avoid potential problems associated with the change. A smaller number noted, however, that they had no disposable income and could not afford to pay any more.

***Most beneficiaries were able to obtain their medications, but several described difficulties.***#

Regardless of how or why a plan switch occurred, most beneficiaries were able to obtain their medications after switching plans. However, we did hear about some problems regarding access to medications. Some seemed to be associated with plan switches and others with plan formularies or utilization management procedures. In the end, most such cases were resolved satisfactorily but a number of beneficiaries spoke of having considerable difficulties prior to the resolution. A few cases remained unresolved.

Beneficiaries' experiences were mixed with the majority of those needing transition or temporary supplies of medicine reporting that they received what they needed, but a few describing situations that made them anxious about having timely access to their medications. One beneficiary noted that when she had so much trouble getting her medication she considered going to the emergency room. She was aware of the symptoms she could describe, given her medical history, to ensure that she could be admitted to the hospital and get her medicine there.

Some problems involved the need to stay on a particular drug that may have been off formulary or require prior authorization or step therapy. One beneficiary said he had been getting a particular drug for years, but after he changed plans he was surprised one day at the pharmacy to learn that he could not get the prescription filled without having paperwork completed. He received a temporary supply of medicine and his doctors completed the paperwork, but he expressed concerns about others who might not be able to reach get such a quick response from their doctors. A couple of beneficiaries said that they experienced delays in obtaining medications because their doctors did not return paperwork quickly enough.

There was also some discussion in the focus groups about experiences obtaining brand name drugs when generics were not working. As one woman described her situation,

What the doctor did, he upped the dosage [of the generic]. And I'm still waiting for it to get approved. That's the only thing I don't like about this. They have to approve it first while I'm sitting here with an ulcer. And I'm waiting and I have no medicine.

The use of generic drugs was common among low-income beneficiaries and most expressed satisfaction with them. Only three beneficiaries, among those who commented on this topic, reported having had problems with or were suspicious of generic drugs.

***Beneficiaries turned to a variety of sources when trying to make choices or resolve problems.***

A common theme in the focus groups was that beneficiaries got so much information that they didn't know what to do with it. Several also noted that when they attempted to resolve problems, they were referred from drug plans to Medicare and vice versa. A few noted that because they have conditions such as chronic pain or memory loss that make it difficult to function on some days they have had trouble coping with confusing communication and deadlines. Participants used a variety of sources to help make sense of the program. These include friends, family members, pharmacists, doctors, counselors working in public or private organizations, and insurance brokers.

Several reported positive experiences obtaining assistance. For example, one man who lives in a senior citizens building saw a pamphlet provided by the Department of Aging and called the number for help with Medicare and Medicaid. He reported,

This nice lady called me back several weeks later and said if...you're paying a premium it's because they raised the premium and the [government] is not paying anymore...[She] got me into something...and there's no premium.

Another focus group participant told a similar story about receiving assistance from a counselor from the Medicare program. Generally, the 1-800-Medicare phone line got fewer favorable than unfavorable reviews, however. One participant noted that it is difficult to get questions answered because "They read from a script." Another said that the Medicare counselors are helpful, "if you can get on the line. Last time I called they either put me hold, they just hang up, or maybe I have to call again and just wait and wait." The Medicare website was considered helpful by most of those able to use it. Some beneficiaries said they go to the library when they need to use computers and are able to go. One beneficiary noted that when he saw a counselor she was able to help because she has a computer, while he does not.

A couple of participants spoke about how much their caseworkers at community agencies had helped them, expressing confidence in and gratitude for the work that the caseworkers do on their behalf. The beneficiaries were aware of problems related to their prescription drug coverage that had been resolved, but were not familiar with the details of the resolution.

Public resources such as State Health Insurance Assistance Programs (SHIPs), State Offices on Aging, or local Area Agencies on Aging were not familiar to the majority of focus group participants, although usually two or three members of each group were aware. Fewer had used the resources. Many focus group participants were interested to know that these resources were available.

Pharmacists were singled out as a particularly important help resource. Beneficiaries mentioned that pharmacists provided explanations or helped them when they were confused after plan switches. We

also heard that pharmacists would call doctors when necessary. In one case the pharmacist gave the beneficiary a small number of pills despite the fact that there were problems with her coverage and she could not afford to pay for the medicine.

***Low-income beneficiaries continue to be the targets of heavy marketing by Medicare Advantage plans.***

As we have found in previous focus groups with low-income beneficiaries,<sup>3</sup> this population seems to have more in-home visits from plan representatives than beneficiaries in higher-income groups, perhaps because they can switch plans year-round. At least ten beneficiaries described visits; most appeared to have been the result of a beneficiary agreeing to a visit during a phone solicitation.

Beneficiaries said that on occasion sales representatives led beneficiaries to think they were “from Medicare” but they were representing particular plans. As one woman described it, “...they say they’re from Medicare...and he opened up his suitcase or satchel...and there weren’t any plans or anything in it except for his company.”

Some beneficiaries who enrolled in Medicare Advantage plans were quite happy with their experience. They noted, for example, that they were particularly happy with the dental benefits. One woman reported that she and her husband enrolled in a Medicare Advantage plan to save money and they were very pleased with their coverage. Other beneficiaries were not satisfied after they changed to a Medicare Advantage plan; they disenrolled in a short time frame. Several beneficiaries reported misleading promises, or less than complete information about the consequences of a change in coverage. For example, one beneficiary reported,

Somebody made the switch for me - came to our building and talked to us in the senior building housing and came and served snacks and stuff and enticed us to come in and they gave the advantages to that. And we were hooked - we were sold on it. That’s what happened, but I thought I made a bad choice.

Most of those who said they signed up for MA plans switched back to traditional Medicare or their old plan when they realized their doctors would not accept the MA plan. One beneficiary said,

This young man had come to my home...and he tells me...as you get older you probably might have to go into an institutional home or some kind of a home plan...and [Plan A] would cover your expenses. And his presentation was so convincing...So I signed up for the [Plan A]...When I went to see my heart specialist they did not accept [Plan A]...so that’s why I hurried up and went back to [Plan B].

---

<sup>3</sup> Elizabeth Hargrave, Bhumika Piya, Jack Hoadley, Laura Summer, and Jennifer Thompson, " Experiences Obtaining Drugs under Part D: Focus Groups with Beneficiaries, Physicians, and Pharmacists." Contractor report for MedPAC, March 2008.

In another instance we heard,

He came out there with his clipboard and...asked me some questions and marked them off and then asked me to sign it. And I really couldn't see anything on it that said that I was disenrolling from [Plan 1] and enrolling in their plan. All he said was it was something that won't cost you nothing and it would probably reinstate your premium payments that you now pay for. I said "Okay, fine", you know? But, unbeknownst to me...I disenrolled from [Plan 1] and reenrolled with that - with [Plan 2].

Almost all of the beneficiaries we spoke with were able to make the switch to their previous plans without difficulty, but they were unhappy about having been misled. One beneficiary reported difficulties with the switch, however,

They came to visit me [and said] "This will cost you nothing. This is just - ask you a few questions, perhaps - expanding your benefits and all." And before I knew it, I was signed up with [Plan C] and was unable to go to any of my doctors because they did not accept [Plan C]...And when I called to get back to [Plan D], it was just a big fat mess...[I] missed a scheduled colonoscopy which was prescreened for cancer and had some cancer that I had to take care of...couldn't do that, because of this whole snafu...I went back and forth for months trying to get it straightened out and still was not able to.

In the course of the discussion we also heard from a couple of participants about services they received that they felt were unnecessary – home health care in one instance and extra replacement parts or supplies for breathing machines that had not been requested in another instance.

## 2. High Spenders' Experience with the Coverage Gap

The Medicare Part D benefit design includes a coverage gap, or "doughnut hole," in which beneficiaries are required to pay 100 percent of drug costs until they reach catastrophic coverage. In 2009, nearly all Part D plans have a coverage gap, which starts when a beneficiary has \$2,700 in total drug spending, and ends when the beneficiary has spent \$4,350 out of pocket. About a quarter of stand-alone drug plans (PDPs) and about half of Medicare Advantage drug plans (MA-PDs) offer some coverage for the gap, but most of these plans offer coverage only for generics.<sup>4</sup> Approximately 14 percent of Part D enrollees have spending high enough to reach the coverage gap.<sup>5</sup>

For the focus groups described in this section, we sought out beneficiaries who had reached the coverage gap in 2008 or 2009, or those who thought they were going to reach the gap in 2009. Four-fifths of the participants in the focus groups had reached the coverage gap in 2008, and nearly half had already reached the gap by the time of the focus group, in July or August of 2009 (Exhibit 3).

#

---

<sup>4</sup> Jack Hoadley, Jennifer Thompson, Elizabeth Hargrave, Juliette Cubanski, and Tricia Neuman. "Medicare Part D 2009 Data Spotlight: The Coverage Gap." Kaiser Family Foundation publication 7834. November 2008.

<sup>5</sup> Jack Hoadley, Elizabeth Hargrave, Juliette Cubanski, and Tricia Neuman. The Medicare Part D Coverage Gap: Costs and Consequences in 2007. Kaiser Family Foundation publication 7811. August 2008.



**Exhibit 3. Gap Status of High-Spending Respondents as of Focus Group Date (July or August 2009)**

	<b>Already Reached Gap in 2009</b>	<b>Likely to Reach Gap in 2009</b>	<b>Unlikely to Reach Gap in 2009</b>	<b>Total</b>
Did Not Reach Gap in 2008	4	4	1	9
Reached Gap in 2008	22	14	9	45
<b>Total</b>	<b>26</b>	<b>18</b>	<b>10</b>	<b>54</b>

#

We asked beneficiaries to describe their experience with the coverage gap, particularly the strategies they use to lower their costs while they are in the gap. We also asked about strategies they use, if any, to avoid or postpone reaching the gap. Because we were interested in these coping strategies, potential participants were excluded from the group if they had a change in health that caused them to no longer have high drug expenses. Conversely, we did include one participant who had reached the gap in 2007, lowered her costs enough to miss the gap by \$75 in 2008, and thought she might miss it again in 2009.

***Many beneficiaries in our groups were hitting the gap mid-year because they were taking a few brand-name medications, along with several generic drugs, for multiple chronic conditions.***

Common chronic conditions such as diabetes, asthma, and heart disease caused many beneficiaries in our focus groups to hit the gap year after year. A few beneficiaries in our groups reached the gap because of a large one-time expense, such as having to take cancer drugs for a limited time. A few others were able to lower their expenses enough that they thought they would miss the gap in 2009, after having hit it in a prior year.

Of the 54 beneficiaries in our groups, eight had reached catastrophic coverage in 2008 or 2009; two others thought they might reach it for the first time this year. These were generally beneficiaries taking very expensive medications for conditions such as cancer, a kidney transplant, or multiple sclerosis. Most other participants fell well short of catastrophic coverage and did not consider it a factor in their decisions about medication use.

***Beneficiaries who had hit the gap at least once before were well aware of the gap and how it works.***

Compared to focus groups we had conducted in previous years, these beneficiaries seemed much more familiar with how the gap works. Nearly all focus group participants were aware of the monthly statements telling them their status. Many scrutinize the statements quite carefully, and many knew to the dollar how much they had left in their initial benefit period.

Nonetheless, a few beneficiaries reported that they had difficulties monitoring their progress toward the initial coverage limit. For example, some thought it was difficult to find out the full cost of a drug (as opposed to the cost sharing) ahead of time, and did not want to wait until receiving the statement from the plan to find out. One frustrated beneficiary told us:

The doctors don't know what medications cost and the pharmacies assume you don't care.... I was prescribed something last year that I was told was \$9 a pop, and it turned out it was \$800 a pop and my benefit was gone in three months... I have to be very careful now. I double-check the cost of every medication.

A few other beneficiaries said they had difficulties following the math the plans used to calculate their status. These beneficiaries said the statements they got from their plans did not compare clearly to their own records of what their drugs had cost. One told us, "it's a very clear statement; I just don't understand what they're basing it on." One had received a refund in 2009 saying the plan had overcharged her in 2008. She told us, "I stopped reading the statements...because I cannot recreate the math. I must have spent 15 hours trying to do it once, more than 15 hours. On the phone. You know what? I can't figure this out. I just have to hope that I'm being charged correctly."

Beneficiaries who were hitting the gap for the first time seemed somewhat more confused by how the coverage gap works. For example, a beneficiary in one of our groups expected to hit the gap for the first time later in the year because of an expensive cancer medication she was taking. "I don't know how it's going to work," she told us, "and I don't know what I do when I hit that point." Another was caught off guard because she didn't realize the initial coverage limit was calculated on the total cost of her drugs. And still others noted they had not been paying attention to their summary reports before hitting the gap for the first time.

***Even those who were familiar with the gap expressed some confusion or frustration over the counting rules.***

Most frequently mentioned was a frustration that both their copays and the plan's payments count toward reaching the gap. Several beneficiaries told us things like, "What bothers me more than anything is that the insurance company counts what I pay for my copay against my doughnut hole. I don't think that's fair." These beneficiaries believe only what the plan has paid should count toward a benefit limit.

One beneficiary said he wished Medicare would combine drug costs across a couple: "My wife is also on Medicare, and she won't reach the doughnut, so I wonder if there's any consideration ever given to combining the two so the family saves some money." Another said she thought it was unfair that beneficiaries have to pay a premium while they are in the gap. One participant who thought the gap was "ridiculous" said he would rather pay more all year than to have "three different systems." In other words, he would prefer to smooth out the costs of the initial coverage period, the gap, and the catastrophic benefit. When asked several others agreed they might prefer this approach, which would tend to benefit those exceeding the gap over those with lower spending.

***Participants reported on a wide array of coping strategies and adjustments to lower their overall costs.***

Every participant in these focus groups had changed behavior in some way because of the coverage gap. The most common strategies included obtaining free supplies, shopping for lower prices, changing medications, and reducing or stopping medications.

**Free supplies.** Many beneficiaries mentioned receiving free samples from their physicians, with the exception of one who said he was embarrassed to ask for them. One beneficiary said that he now receives samples of drugs that otherwise would cost \$200 or \$300 per prescription and that might make the difference between hitting the gap in August 2008 and possibly not hitting it at all in 2009. Others described receiving just small samples as "a drop in the bucket" that "eases the pain a little."

A few beneficiaries said that their physicians seemed to have fewer samples available than they used to. One had been told that demand for the samples had increased; another thought the doctor's office was receiving fewer samples from the manufacturer. In addition, several noted that for some drugs, their physicians never receive samples. Participants noted that this is true particularly for generics, but some also reported that their physicians did not receive samples of the on-patent drugs they were taking.

In a few focus groups with physicians, the coverage gap came up. These physicians confirmed that samples play a major role in how they help beneficiaries in the gap. None mentioned that samples were becoming less common, although we did not specifically ask about whether that was a trend.

A few beneficiaries said they had tried to apply for manufacturer-sponsored programs or other programs to help with their drug costs. All who mentioned these programs had been turned down, either because of their income or because of their Medicare coverage. Some of them expressed frustration with program rules that often have the effect of preventing their use of these programs. One beneficiary received help from a foundation to cover her extremely high costs until she reached the catastrophic limit.

**Shopping for lower prices.** Many beneficiaries shop for lower prices by comparing local pharmacies. Prices can differ substantially from pharmacy to pharmacy, although no one pharmacy in a community seemed to have the lowest prices on all drugs. This strategy was mentioned primarily as a way to save during the coverage gap, although some beneficiaries mentioned it as a way to lower their total costs from the beginning of the year and thus postpone the coverage gap.

Many beneficiaries also found savings by using mail order. In most cases, these savings seemed to be in their out-of-pocket costs before reaching the gap; beneficiaries did not point to mail order as a way to postpone the gap.

Several beneficiaries mentioned lowering their drug costs by ordering drugs from Canada or buying them while traveling overseas. For most, this was a strategy for purchasing drugs at a lower price once they had reached the gap. At least one beneficiary, however, was ordering his most expensive medication from Canada throughout the year and was hoping to avoid the gap in 2009 by doing so.

A few beneficiaries mentioned the use of discount cards. One had tried to use them, but found she had to make sure she did not use them on drugs being reported to Part D. Another had acquired some discount cards and was going to try them.

**Changing medications.** The vast majority of beneficiaries said they had switched their drugs to generics whenever possible. For many, the practice of using generics whenever possible had pre-dated the coverage gap, particularly if they had physicians who were proactive about keeping drug costs low. About a fifth of the beneficiaries in our focus groups, however, mentioned reviewing their medications with their physician and asking to shift to more generics specifically as a result of reaching the gap. At least one beneficiary who had hit the gap in 2008 thought this change to generics would be enough to keep her out of the gap in 2009.

Some of the beneficiaries commenting on reviewing costs with physicians complained that their physicians seemed to have little understanding of what prescriptions cost. But physicians who brought up the topic in their groups reported that patients were increasingly embracing the use of generics as

cheaper alternatives. One physician also remarked that her patients were “coming in to change their medications because they just can’t afford it especially when they go into the doughnut hole.”

Beneficiaries reported not just switching to the generic version of a drug they were taking, but also switching to a similar drug to lower costs. Commonly mentioned examples included switching among statins, among PPIs, and from Niaspan to over-the-counter niacin. One beneficiary described his decision to stop taking Niaspan:

I just switched from my Niaspan which was \$434 for three months, I got over the counter Niacin... I've been on that for about two months and my cholesterol level and everything else is right where it's supposed to be...[the doctor] said "you probably don't get the same benefit that you would with the Niaspan," but you know...he ain't paying the \$434 every three months.

Most beneficiaries were able to make these cost-saving changes in their drug regimens without adverse consequences, although they may have required more monitoring and doctor's visits to ensure the drugs were working as intended. However, we did hear stories of some adverse effects. For example, one beneficiary told us:

I went to all of the physicians that I see and told them, the income that I have now as a widow, I couldn't handle it. So they had switched me into generics, which have created tremendous problems. I'm going to the hospital because of a generic that created terrible heart palpitations. I am now on a generic that is creating itching and peeling. So I have tried, but some of the generics just do not work like the others.

Some beneficiaries who experienced side effects simply tolerated them, while others chose to continue paying for the more expensive drug through the gap.

**Reducing or stopping medications.** About ten of our 54 respondents said they had stopped taking a medication entirely when they reached the coverage gap; eight said they had reduced the dose of a medication, or were skipping doses. One beneficiary said she was thinking of stopping her cancer medication, which cost \$935 per month, "because I'm angry, and I'm not sure it's worth it."

In one physician focus group where the coverage gap came up spontaneously, physicians confirmed that they were seeing this behavior in their patients. One said, “the people that fall into that crack are the people that have the more serious diseases and then they’re stuck. They don’t have money to buy their drugs and they wind up in a hospital.” Several other physicians agreed with his statement.

In some cases, beneficiaries worked directly with their doctors to wean themselves off certain drugs. One beneficiary reported that he had accidentally missed some doses of an expensive asthma medication while on vacation and asked his doctor whether he might not need so many medications anymore. The doctor worked with him on a plan to lower gradually the dose of two medications, and the beneficiary had dramatically lowered his costs. Similarly, another beneficiary worked hard to keep himself from needing a very expensive diabetes medication, but was concerned he might not be able to do so indefinitely:

My doctor suggested [Byetta], that it would practically normalize my diabetes. But I found it is so expensive, it would send me right into the void...I just didn't pick it up [at the pharmacy.]...[My physician] said, "How are you doing on that?" And I said, "I'm not taking it." ...I

increased my exercise and I'm taking the maximum of [Glucophage] and I'm monitoring my diet...but I recently injured my knee, and I don't think they make one-legged bicycles.

Some beneficiaries tried to stop taking a medication, but quickly discovered that they needed the drug. For example, one woman stopped taking a PPI for heartburn, thinking, "If I skip it once in a while, it's not like insulin." But she had a bad attack, "and that scared me enough not to want to fool with it." Another woman had a similar experience when she tried to stop Spiriva. Others did not see an immediate effect from stopping a drug, but their physicians convinced them to continue taking it, like the beneficiary who told us:

I went to my doctor...I felt pretty good. I just happened to have an appointment that next week. And I hadn't been taking it for about a month. And when I told my doctor, he looked at me and said, "No, you better go back." And I said, "Do I have to?" And he said yes. That was enough.

Fearing a similar interaction, one beneficiary was taking his medications every other day and did not want to tell his doctors, "because I know what they would say." This beneficiary emphasized that he and his doctors were closely watching his test results on a fairly frequent basis, so he felt comfortable with this course of action as long as his test results were acceptable.

Another beneficiary reduced the dose of a drug she took because she does not make saliva, without telling her doctor. This made a noticeable difference in her comfort:

BENEFICIARY: I found that – this was not smart – but the medicine I take three times a day, by November, I'm taking it twice a day because it's just getting too expensive.

MODERATOR: Did you discuss that with your doctor?

BENEFICIARY: No. I just did it, because I know he's going to say "take it three times, that's what I'm prescribing," and I just can't put out the \$300 or \$400.

MODERATOR: In January, do you continue taking it two times a day?

BENEFICIARY: Oh, no, I go right back to the three because I feel much better with that.

A few beneficiaries had turned this prescription-stretching strategy around and used it in consultation with their physicians, obtaining prescriptions for twice their actual daily dose of a medication. For example, if a physician believed a beneficiary should be taking a 100mg daily dose of a drug, the doctor might write a prescription for a 200mg daily dose. By splitting the 200mg pills in half, a beneficiary could make a three-month prescription last for six-months at 100mg per day. Beneficiaries using this strategy said it was a tremendous help, because pills of a larger dose (e.g. 200mg vs. 100mg) are often only marginally more expensive.

***Participants also reported tricks they use to improve their cash flow, but these were less common than strategies for reducing overall costs.***

**Choosing which prescriptions to claim.** A few beneficiaries reported that they were buying inexpensive medications without using their insurance card. For example, they might buy \$4 generics at Wal-Mart all year, and never report them to their Part D plan. For a beneficiary using many generics, this might slightly postpone when they reach the coverage gap depending on how the plan's price at the regular pharmacy compares to the Wal-Mart price. Most of the beneficiaries using this strategy reported that a pharmacist or physician had recommended it to them.

**Timing prescription refills.** Other beneficiaries described timing when they fill prescriptions to maximize their coverage. For example, a beneficiary in the gap at the end of the year might fill a one-month prescription at the beginning of December, rather than their normal three-month refill, knowing that they will have better coverage in January. Likewise, one beneficiary who had reached the catastrophic benefit reported "stocking up" at the end of the year, knowing their coverage would be worse in January. Another beneficiary reported a simpler type of timing – she switched from three-month to one-month refills during the gap, simply because she could not afford to pay for the three months' supply all at once.

***Beneficiaries sometimes face barriers to using these strategies.***

A few focus group participants voiced their concern for beneficiaries who might have cognitive impairments or other problems that would prevent them from using the strategies that might help to manage or avoid the coverage gap. One expressed his personal experience with these challenges:

If you're in the condition that I or some of the people in here have indicated that they are, it's a full time job...when you're going through surgeries and stuff like that, you're on pain medications, narcotics, dope, and your cognition is affected...your ability to sequence thinking and do logic and say, "I need to look at this or I need to look at that," is impaired dramatically. The system doesn't take that into account, and that is a big, big deal... you just stumble through and find your way...I wonder about the people that don't have the education or they're 90 and they're really, really sick. When I'm really ill, even though I've got the ability to do it, I'm not up to doing that stuff.

***Few beneficiaries reported having any coverage in the gap, even for generics; a majority of beneficiaries did not seek to compare Part D plans during the open season.***

Many beneficiaries were either unaware of the availability of coverage for generics in the gap, or didn't see it as helpful. But one or two had done the math and decided a plan with generic gap coverage was worth the extra premium.

Although all beneficiaries in our high-spender focus groups were engaging in activities aimed at lowering the price of their prescriptions, fewer seemed sensitive to the price of their Part D plans. A minority of beneficiaries reported comparing their plan options during open season. A few beneficiaries taking a large number of drugs reported that it was very difficult to shop for plans, even though they tried. One was not able to find a plan that covered all of his drugs.

***With these coping strategies, many beneficiaries could afford to continue taking their drugs in the gap, but some could not.***

Several beneficiaries reported saving carefully all year so that they would have the money to cover their prescriptions during the gap. After hitting the gap several years in a row, some of these beneficiaries found their drug costs fairly predictable. However, changes in medication needs could create major problems if they exceeded the budget these beneficiaries had set aside.

Some beneficiaries reported that their income had dropped significantly in recent years; they had stopped working partly because of the health issues that were causing them to have high drug costs.

The simultaneous drop in income and increase in drug costs was causing a hardship. One beneficiary said:

The doughnut hole wasn't nearly as difficult for me last year as it has been this year, because my income, with all of these things, and my business I had to close, and my income ceased...The doughnut hole is a real problem, and more so I would say as you progress with the prevailing illnesses that you've got...it just gets worse and worse and worse.

A handful of beneficiaries reported real hardship due to their drug costs. One beneficiary said her drug costs were "eating us alive...we have no recourse...there's no place we can go for any kind of help." Another said, "It's really awful. We don't have any income...and sometimes I just do without because we can't afford it...I just do things like have a can of soup at night for dinner. I don't go anywhere and I don't do anything. That's just my life."

One participant in particular reported (at the time of the session) being only a few days away from being unable to fill a prescription for diabetes medications that were critical to his health. He had tried numerous strategies already and was at a loss to know what to do next.

I'm a diabetic and so I have a lot of drugs that I take. I say a lot, really I only take 12, but that's still quite a bit. However, I'm alive. That's the nice side of it. However, I may not be by this time next year the way it's going. I hit the doughnut hole in April this year. My wife hit it just last week, and now my drug bill, right now, if I can raise the money, is \$2,100 a month. I do not have \$2,100 a month. I have a decent income as far as retirement, but I don't have enough to make my house payment and my drug bill and eat. So what do you do? You either eat, you take drugs, or forget it...I had \$8,000 set aside for emergencies. I thought that would take care of my wife and I...We thought we had good insurance. Uh-uh. I ate the whole thing up as of last year and this year. Now I'm down to where I can't do anything, so I don't know what to do...Up until this year, I drove community transit buses [but now] they won't let me drive, so I don't have that income...at 76 years old, I'm sitting here wanting to work and can't work, and want to pay my bills and can't pay my bills, what's left?

***Three beneficiaries had recently dropped employer-sponsored insurance and signed up for Part D; two had planned for the coverage gap, but one was blindsided.***

One beneficiary chose to drop his employer-sponsored insurance because the premiums had gotten too high. He had calculated his annual costs and decided that even with the coverage gap, he would come out ahead by not paying the extra premiums. Another reported being encouraged to leave a former employer's health plan. As a result of the switch, he was hitting the gap for the first time in 2009, but it was not a surprise:

My wife and I sat down and studied the whole thing before we switched from our former insurance to Medicare. But my wife's company is going to pay part of our expense. You know, when you get to be her age and my age, it raises the premiums for the whole company, and we were the two oldest, so they had agreed to pay us a certain amount.

One beneficiary's story was quite different.

I retired in '92 from [my company] after 37 years and I took the [the company's] medical insurance. Never heard of a doughnut hole until this year. Somebody from [a plan] came in and said "I can save you some money," [and I said,] "Okay, let's do it"...Within two weeks, they said, "oh, you're within \$1,400 of being in the doughnut hole." Well, what the hell is the doughnut hole? It was explained to me, which I found rather upsetting. I can't get back into the [company] plan, can't afford the meds. I am on about 13 meds and some of them are \$800 for three months...as I run out of the meds now, I just don't refill them.

#

***Despite their problems with the gap, all were glad to have the Medicare drug benefit – and Medicare.***

Particularly for those who had not had drug coverage prior to enrolling in the program, Part D was seen as a help, despite the gap. Beneficiaries ranged from being "hugely appreciative" for Part D to saying it was "better than nothing." Attitudes about Medicare in general were even more uniformly positive, with beneficiaries saying things like they were "just as happy as punch" to have it. One summed up the discussion by saying, "I can complain about it from now until doomsday but [Medicare] was a great gift for seniors, it truly is."

### **3. Physicians' Views on Comparative Effectiveness**

In previous years, MedPAC has reported that little information is available that compares the clinical effectiveness of alternative medical treatments and has concluded that, because comparative effectiveness research would be a public good, a federal role is needed. The Commission recommended that the Congress charge an independent entity to sponsor and disseminate research on comparative effectiveness. As part of the American Recovery and Reinvestment Act of 2009, the Congress authorized \$1.1 billion to support this type of research. The Congressional Budget Office (CBO) has defined comparative effectiveness research as "...a rigorous evaluation of the impact of different options that are available for treating a given medical condition for a particular set of patients." It can compare similar therapies such as drug vs. drug or different therapies such as drug vs. surgery. Comparative effectiveness research can be based on clinical trials, analysis of available studies, and review of claims data.

In the 2009 focus groups, we asked physicians about where they currently get information on new medical treatments and whether they saw the need for more research on comparative effectiveness. We also asked them about how they might use such research, if more became available, as well the forms in which they would prefer to receive such information. The nature of focus group discussions does not lend itself to estimating the prevalence of views on these various issues, but allows us to get a sense of the variety of views expressed among physicians.

***Physicians point to a variety of sources they currently consult for information on new procedures or drugs.***

Physicians told us about a wide variety of different means for learning about new medical procedures or drugs. Most seem to use several different approaches, and the sources that participating physicians



mentioned varied based on such factors as their specialty and the type of practice setting where they work. One participant referred to a “constellation” of sources and the need to combine knowledge and evaluate across the different sources. Another suggested that often you see the “sources start [to] coalesce together [so that] you see some consensus.”

**Meetings and journals.** Professional meetings, continuing medical education sessions, and journals were regularly mentioned. These often included the meetings and journals sponsored by the main professional societies to which physicians belong. But in addition, many mentioned special review journals that focus on comparative reviews and are distinguished by offering independent analysis and avoiding advertising. Specific examples mentioned included *The Medical Letter*, which publishes review articles focusing on consensus and accepts no advertising; the Cochrane Library, which includes regularly updated evidence-based healthcare databases, and Hayes Reports, another independent group doing technology assessments. From the discussion, it seems likely that these review sources are consulted by only a minority of physicians, probably more so by academic-based physicians and by specialists than by primary care physicians. But others seemed aware of some of these sources and might consult them on an occasional basis.

**Websites and other electronic sources.** Internet, email, and other electronic sources have increasingly become a key component for information seeking. In the words of one participant,

I think that the Internet has been such an addition that is so beneficial to people, having easy access to all the printed information on what’s out there. It has made it so much easier to access this information to start this process of comparison, short of going to a meeting once a year.

Several physicians cited the websites of their professional societies as a valued source, while several others noted that certain subscription websites (e.g., UpToDate.com) have become important in their efforts to know about new medical treatments. Still others used programs such as Epocrates that offered information on a hand-held electronic device as a convenient means of retrieving information.

**Consultation with colleagues.** Informal and formal consultation with colleagues remains an information-seeking strategy for many physicians. Those in larger group practices sometimes convene meetings to share information and compare notes on new drugs or other treatments, while those in solo or small practices seek out advice from both local colleagues and friends from medical school or residency programs. Some physicians suggested, however, that they have lost certain kinds of opportunities to consult with colleagues. Because they do not see patients regularly in the hospital, informal consultation with colleagues in the doctor’s lounge at the hospital is becoming a lost opportunity. And others reported that busier schedules have made it harder for them to get specialist colleagues on the phone for advice on patients.

**Pharmaceutical and device manufacturers.** Drug company representatives also remain part of the constellation of information sources, although physicians sometimes seemed reluctant to admit it. One participant quipped that his colleagues talk to drug reps, “but of course none of *us* do.” A few physicians mentioned that their practices have taken steps to cut back on meetings with drug representatives and especially on accepting free meals and other perks.

***Many physicians spoke about the need to filter any information they receive, based on their perception of the bias of different sources.***

Overall, the physicians participating in our focus groups showed a high awareness of the potential for bias in the information they receive. As one participant suggested, the least biased source is someone who is not going to get any money out of what they recommend. But participants mentioned different approaches to addressing the biases. One primary care physician suggested,

If they're salesmen, of course, everything they say I take with two grains of salt. Whoever's presenting the information, how are they related? Are they totally independent? Are they sponsored by the company?...Just what in general is everybody doing? What are people using? If I hear ten independent people are using whatever and it's great...then I'd probably go with that.

A common approach is for physicians to listen to information from any source, including those with an obvious interest (e.g., drug representatives) and nonscientific sources, such as newspaper articles, television news reports, Internet sources, and so-called "throw away" newsletters. According to one, "[drug representatives] have a role because you can't filter that information if you don't have it." Once they know there is a drug or other treatment of potential interest, they may go to a more trusted source, either a literature compiler like Cochrane or to the original research, to learn more. Several pointed out that even the original study authors may be funded by a pharmaceutical manufacturer or other interested party, so they try to take that potential bias into account. Physicians also reported consulting with a variety of colleagues. Eventually they look to their professional societies and other groups for peer-reviewed guidelines that may indicate whether a new treatment is important to use.

Different physicians have different perceptions of bias. Although many physicians see drug representatives as helpful and timely sources of information, others view the information provided with some skepticism. "You have to filter the information as it relates to your own practice ..., but I learn a lot about new drugs from the drug reps."

More often than not, physicians cited peer-reviewed journals, government sources, and professional societies as trustworthy sources with little bias. One primary care physician suggested,

Information comes through different filters and different levels of validity. You know, something that you hear about in an e-mail from a rep [creates] awareness, but you're not really going to just believe it. Whereas if you read about it in a peer-reviewed journal, I think you're going to take it more seriously. If it's from the CDC, if it's something from the [American College of Physicians], one of those organizations where their primary objective is pure patient care then, I think it means a lot more.

Still, a few participants worried that even professional societies can be biased, especially if they get funding from manufacturers. And participants often warned that the government has its own sources of bias, especially the need to save money. One found herself more "more and more skeptical" about research studies after wondering who is funding what study and hearing about studies using data that were suspect in some way.

A number of participants emphasized the importance of their own experience in making judgments about what treatments work best. According to one participant,

Drug reps can come in or you could hear about a drug in a journal or a meeting but you don't really know the efficacy until you really try it on patients.... Some drugs work and some don't.... I can look at all the package inserts or studies that they want to show me but if I don't think the drug works in my patients, I don't use it.

Another in the same group agreed.

You have to make sure you reach your goals with that patient with medications you're using. And you don't have the luxury of doing analysis of your entire practice. You just hope that what is in the literature holds true.... So whether one drug works, you just become familiar with it.

***Physicians currently have little access to head-to-head comparative effectiveness information for drugs, devices, or procedures, but there was disagreement on whether more is needed.***

For the most part, physicians in the focus groups agreed that information offering direct head-to-head comparisons between competing treatments was often lacking. They generally understand that FDA approval is based on showing that a drug or device is safe and effective compared to a placebo. Some also noted that even when two drugs or devices are aimed at treating the same problem, new studies may be done with different parameters so that comparisons to other studies are difficult.

Some physicians were satisfied with the level of comparison or guidance available in the clinical guidelines they see from professional organizations or other sources and a minority of participating physicians questioned the need for more research. Some emphasized in particular that their own clinical experience was more important than any research study, emphasizing the uniqueness of each patient and the need to consider different treatments for different situations.

I think you can come up with all kinds of studies about certain drugs, about how well they work....But at the end of the day what really matters is what the physician feels with experience works. So I am going to prescribe something that works. If it does not work, I am not going to prescribe it. I do not care what the study says. If it does not work for my patient then I am not going to prescribe it.

But others challenged this view, arguing that physicians' opinions on what works can be disproportionately affected by one memorable case. One said, "...you get one patient with [a particular response] and you always remember that...[but] there's always a problem with anecdotal evidence."

A majority of participants thought more comparative effectiveness research would be helpful, pointing in particular to head-to-head randomized double-blind control studies. Two examples presented by physicians in our focus groups illustrate the kinds of situations where some believe comparative effectiveness information could be valuable to them in their practices. The first was for angiotensin receptor blockers (ARBs) used to control high blood pressure:

Head to head studies between two products are not out there. I think a lot of that is driven by money...I'll never forget when I saw Benicar compared to Diovan; [when it] seemed to

identify...the superior ARB, it made me want to use it all of the time...If we can remove some of the bias in head to heads, then I think you've got something.

The second was related to drugs that might be used to treat Methicillin-resistant *Staphylococcus aureus* (MRSA) infections:

We have almost no published data looking at old drugs [such as] trimethoprim sulfa or the tetracyclines to show whether they are equivalent, inferior, or superior to the newer drugs, which have been well studied, but, of course, not compared to those drugs, but compared to therapies that would be somewhat equally expensive. So oral linezolid will compare itself to IV vancomycin and hope to come up with equivalency. And people say we charge a lot for this drug orally because, in fact, it's not too much different in price from treating with an IV medication and it's easier. But would they compare it to oral doxycycline or trimethoprim? Those studies just don't get done; they are not that hard to do, but they're not going to be funded by industry.

Some physicians go a step further and suggest that cost comparisons should be a part of a comparative effectiveness analysis. One specialist wanted to know "where you do an intervention and you decrease the rate of cardiac events by 1 percent, and that's the lead article in the New England Journal, how much is that going to cost and really does it matter?" Cost effectiveness, however, was not brought up often by the physicians in our groups.

Still other participants expressed concerns about aspects of comparative effectiveness research, emphasizing the need for studies to include a focus on variations in side effect profiles as well as the differential effect of drugs or other treatments on particular subpopulations. They pointed out that a drug that is less effective overall could still be better for a subset of patients or could avoid side effects that may affect patient adherence. In fact some said they feared that inadequate attention to these issues could drive the drug rated less effective out of the market despite its value in the overall portfolio of options for physicians to consider.

***Physicians expect they will have to do the same sort of filtering for comparative effectiveness research that they do for other clinical information.***

There was a good deal of discussion and disagreement about the best source for comparative effectiveness information, paralleling the same arguments about bias in general. Much of the discussion concerned the role of government. Some see the government favorably as a research sponsor of comparative effectiveness research and one of the few potential sponsors with both adequate resources and the necessary neutrality.

Something like NIH...supporting a research project adds credibility to the results. In part because, rightly or wrongly, you feel that there's less bias and influence as a result of the safeguards that are there. So a study supported by...one of the large pharmaceuticals as opposed to NIH, I think you'd grant there is a credibility to a government funded study.

But that same physician also expressed the concern that the government as a research sponsor may bring a bias toward "therapies that may not be as effective but are less costly to the payer." We heard a mixture of views on this point. Some looked to the government as the most neutral sponsor, while others vigorously challenged the government's neutrality. One worried the government would say,

“Evaluate the drug, but I want the cheapest damn drug that’s going to save the most money, and that’s what got to be key in your evaluation, plus efficacy of course (we don’t want to hurt our reputation). But it damn well better be generic and cheap.” Some went even further, indicating their lack of faith in the government as a source of advice: “I’m not going to trust my government to tell me how to practice medicine, which drugs are better, or which doctor I should refer to.”

Different government sponsors may be seen as more or less trustworthy. For example, some physicians mentioned NIH as an unbiased research sponsor, with one recalling that “they came out with these blue-spined booklets on various disease states, they were excellent.” Another thought that the FDA could take the next step beyond approving a drug based on its safety and effectiveness to conclude that a group of drugs are equivalently effective or that one is relatively more effective. By contrast, we heard that CMS might be viewed as a biased source since it has payment responsibility in Medicare and Medicaid and thus a potential cost savings bias.

***There was some concern that comparative effectiveness research would lead to restrictive guidelines by government or health plans and that those guidelines would be biased toward cheaper treatments.***

Advocates of more comparative effectiveness research would prefer to see government and plan guidelines and formularies based on good evidence rather than factors such as prices. They emphasized the importance of transparency, with all researchers reporting any conflicts of interest and a full presentation of research design and methodology.

Some physicians in the focus groups feared that the “losing” drugs in a comparative effectiveness study – even one that was based purely on clinical effectiveness, not on price – would be eliminated from formularies or given non-preferred status on preferred drug lists. Similarly, they worried that “losing” procedures would not be eligible for coverage. It would be thus be difficult or impossible to prescribe these drugs or procedures. This concern was aimed most often at government decision-makers, but there was also the concern that private health plans would also restrict coverage. These physicians said it was critical for them to have multiple options available for treatment of their patients, and they did not want to be required to offer extensive evidence for why they want to use a “losing” treatment.

Some physicians went a step further to suggest that the inevitability of some drugs or devices being losers and thus excluded from coverage could discourage manufacturers from developing new treatments. One physician illustrated this concern with reference to a major comparative study of drugs to treat hypertension (the ALLHAT study) that showed that less expensive drugs (such as diuretics) are more effective in preventing cardiovascular disease than newer, more expensive drugs (such as calcium channel blockers or ACE inhibitors). He pointed out that although ACE inhibitors might be less cost-effective overall, they are critical for controlling microalbuminuria in people with diabetes; he did not want concerns over cost-effectiveness to shut down research that would lead to such drugs.

These concerns were among the most vigorously articulated in the discussions, and they were especially strong in one of our six physician groups. This perspective was less widespread in the other five groups. Unfortunately, the nature of focus groups makes it hard to assess whether any particular perspective is held by a majority of physicians.

Some participants offered the hope that they might have some protection from liability claims if they used guidelines based on good research. Several were concerned that evidence on what is most

effective would not in and of itself protect them from lawsuits if they followed the research rather than practicing more defensively. They felt that some policy change would be needed to give them that protection.

***If there are new comparative effectiveness research results, physicians want results in a form that is concise and easy to read.***

We asked focus group participants how they would prefer to receive information about comparative effectiveness studies, regardless of who produces the studies. While some participants seem willing to invest the time for reviewing research studies in journals and at conferences, others feel they lack the time and are looking for shortcuts. Several mentioned that there were already mechanisms available (e.g., from their professional societies) to get email alerts that call attention to new research findings, and they would like to see more such mechanisms.

I think that if there were an oversight committee that was looking at these medications and these various machines...saying this is number one in our test, this is number two in our test, and giving it to me either by e-mail or in a letter to every physician in that particular field, that would help things a lot. You'd feel comfortable that the government was behind you in using these new procedures, that you're going to get paid, and that if you buy it would not be a waste of money.

While some physicians would look to subscription journals and databases (referenced above) that compile and report on effectiveness studies, others pointed out the importance for public sources, since not everyone can afford access to subscription journals or databases. These public sources could include both those sponsored by the government or by professional societies.

Participants also emphasized the importance of timely research and timely dissemination of the results. In particular, some noted that patterns of treatment, once established, can be hard to break. In this view, comparative effectiveness information should be published as soon as possible after a new treatment becomes available so that physicians can make informed decisions about a new treatment, especially one this is more expensive than its alternatives.

Finally, we asked physicians in some of the groups whether they talk to their patients about comparative effectiveness studies when recommending treatments or when asking patients to make a choice among alternatives. One physician did so regularly, citing the example of patients asking for brand-name Boniva as a treatment for osteoporosis. "I say to the patients every day 'gee whiz, I can show you a half of a dozen studies that show that generic Fosamax is just as good as this.'" Making the case this way does not always work, with this physician suggesting he thought it worked about half the time. Another cited a current example about which treatment a patient should select.

Just this afternoon I was seeing a patient with atrial fibrillation and we talked about the options. "We can control your heart rate and put you on a blood thinner or we can try to get you out of this rhythm. There have been comparative studies that have looked at that, and the likelihood that you'll be alive without a stroke in five years is the same. So what do you want to do? How much does it bother you?"...That was an instance where having comparative outcomes data was very helpful, because I can tell the patient "if you're asymptomatic and no bleeding risk, we'll just do path A. And even though that seems to you like we're not treating your underlying problem, in fact, when we've looked at it in three big randomized studies the likelihood you're

going to do okay with that approach is as high as the likelihood you're going to do okay with trying to get rid of the rhythm."

Another physician in the same group agreed, saying that it can be helpful if you can present in a way the patient can digest it.

In the view of these physicians, good information allows the patient to make a more informed choice. But not all physicians agreed that this would be a good approach for talking to their patients, and others thought it would depend on the particular patient. They suggested that some patients do not want to hear about research; in fact some seem more interested in the views of celebrity endorsers such as Oprah Winfrey or Sally Field. But some also suggested that their patients may prefer to assume the physician is reviewing relevant research and want to know what the physician recommends rather than being told about the research.

## **4. Beneficiaries' Experiences with Access to Physicians**

One of the goals of the focus groups was to learn about Medicare beneficiaries' experiences with physician access. Both the low-income and high-spender beneficiary groups were asked about the difficulty of finding new doctors who accepted Medicare, average wait times for appointments, the experiences of their friends and family, and the trend over the past few years. Our groups included dual eligibles and other low-income beneficiaries who were eligible for subsidies but not for Medicaid. However, it was difficult in some cases to ascertain whether a beneficiary was a dual eligible or not. Overall, access to physician services does not appear to be a major problem in any of the three locations selected for this study, although we heard at least a few reports of access issues in each of our focus groups. We heard the fewest reports of access issues in Baltimore, and about the same number in Chicago and Seattle. However, these city-to-city comparisons are limited by the relatively small number of beneficiaries in groups in each city.

***We heard relatively few concerns about access to physicians in the three locations selected for this study.***

Most of the beneficiaries who participated in the focus groups reported no issues with physician access. Many of them had long-standing relationships with a particular doctor or a practice, and had not recently needed to search for a new doctor. A few beneficiaries said that their primary care doctors had recently stopped accepting Medicare, but had not stopped seeing them because of the relationship they had developed over the years. For example, a beneficiary in one group said that when she went on Medicare, her internist kept seeing her only because she had been seeing her for 15 years. Another beneficiary said of her doctor, "He no longer sees Medicare patients, period. But he continues seeing me because his mother's a friend of mine."

Several beneficiaries said that they had not had any problems with Medicare, and a few even preferred having Medicare over private insurance. One beneficiary, who had private insurance prior to having Medicare, reported being happier with Medicare, and described his experience as "completely trouble free." Another dual eligible beneficiary talked about her positive experiences with Medicare and Medicaid:

Yeah, I've had a wonderful experience. The physician is a wonderful person. And he keeps telling me what things should I do to continue improving my health. So I have seen several specialists. And we have been working with them as a follow-up which is wonderful. I have had a wonderful experience with Medicare and Medicaid. It's wonderful. I feel better than ever now.

One grateful beneficiary said that when she lost her Social Security disability benefits a year ago, her doctors were very considerate:

And, this has been a really horrible year. So I'm just grateful I'm back on it. And I can tell you three out of my four doctors have been consistently good to me...as a matter of fact, my psychiatrist told me that she would wait until the process went through...She doesn't take Medicaid, but she didn't drop me. And that's the kind of doctors that I know are here.

Most of the beneficiaries felt that they did not have to wait an unreasonable amount of time to get an appointment with their doctors, especially their primary care doctors. Most people reported that they could usually get an appointment within a few days. Some had set up a regular appointment schedule with their primary care doctor. Furthermore, most said that they could usually get an appointment right away in case of an emergency, or were directed to go to the emergency room if it was after hours.

For the most part, the beneficiaries felt that access issues had not changed for them over the past several years, although a few reported that it had become more difficult to find a doctor and to get appointments. They felt that this was because there were fewer primary care providers, as well as fewer doctors who would accept Medicare. Some felt that things had improved. These were mostly beneficiaries who had not been forced to look for new doctors, or were in relatively good health and had not needed to look for specialists.

***Although there were few reports of access issues in any city, there were fewer in Baltimore than in Chicago or Seattle.***

There was some variation across the markets in which the focus groups were held. Although we did not hear widespread access issues in any of our focus groups, we heard the least number of concerns in Baltimore. One Baltimore beneficiary commented:

I've been in a long discussion on this on the Internet. And, Baltimore, we don't seem to have any problem at all. Texas, Washington State, Alaska, everybody there complains that they can't get doctors...I don't know anybody here who has had a problem with anybody with original Medicare. The individual plans are something else. And, everybody that we talk to is amazed. You mean...you don't have trouble finding doctors?

There does not appear to be a significant difference in access issues in Chicago and Seattle based on our focus groups.

***Most beneficiaries have no trouble finding doctors, but there were a few more reports of issues with access to specialists than for primary care.***

In general, beneficiaries in our focus groups had a harder time finding specialists and getting appointments with them, compared to primary care physicians. Several beneficiaries said that they



would have to shop around for a while before they could find a specialist who accepted Medicare. One Chicago beneficiary said:

I had to shop around for an orthopedic spine specialist and spine fellow for my fusion surgery. So I went to like maybe four or five different groups of doctors that do that. And some, they just didn't take Medicare, because the Medicare negotiated amount for this kind of a procedure was so much less than they could get from a non-Medicare person... And so in that search I found that there are neurosurgeons and spinal specialist surgeons whose offices just said "we don't take Medicare," because they just can't bear having to do a \$200,000 procedure and they get paid like \$8,000 or \$12,000.

Physical therapy, rheumatology and dermatology were the specialties that were brought up most often in all three locations as those where it was particularly hard to get appointments. One beneficiary mentioned that it took several months to get a physical therapy appointment for routine checkups. Another beneficiary said she had to wait three months to get an appointment with a rheumatologist. One Baltimore beneficiary talked about her experience of trying to get an appointment with a dermatologist:

I had an incident and I happened to mention it to my dentist...it was something that I was afraid it might be a cancerous something or other. And they said, "Oh, we'll take you down to the dermatologist at the end of the hall" and when I went - she walked down with me and she tells the receptionist the situation, and they didn't have any openings. And she said, "Well, when we get an opening, we'll call." And weeks passed, and I felt the situation wasn't improving. I wasn't getting any help, so I mentioned it again to the dentist and she again walked down with me and they still wouldn't do anything - would not give me an appointment - and she says "Look, this is not something - this is a physical problem - this isn't just, you know, like a pimple on the skin, or something. This could be serious." And they didn't have any openings - "We'll call you."...After weeks and weeks and weeks, I decided "This is ridiculous", so I called another dermatologist who took me almost immediately. It was a problem - it was pre-cancerous and they had to dig something out of my skull.

Although there were at least one or two reports of issues with access to specialists in all our focus groups, most beneficiaries were not having problems finding specialists and getting appointments with them, especially when referred by their primary care doctor.

***There were a few more reports of access issues with the low-income participants than with the higher-income beneficiaries.***

One frustrated low-income beneficiary in Baltimore spoke of her experience trying to find a specialist and a primary care doctor:

I have been flat turned down altogether, on more than one occasion, when I have said "Well, I have Medicare." And this was during the transition time that I was trying to get all these figured out. And I've just been turned away totally, completely.

Beneficiaries who are dually eligible for Medicare and Medicaid appeared to have the most access issues, although it was difficult to identify clearly the dual eligibles in our focus groups. A few beneficiaries reported that it was often difficult to find physicians who would accept Medicaid. Several

low-income beneficiaries also felt that they were treated differently because of the type of insurance they carried. One dual eligible beneficiary in Chicago said:

You have to find where to go and who to go to. And you have to find a place that treats you right because every place is different. But I'll tell you what, I've been on Medicare, Medicaid, [private plans], and I've been with cash. Your medicines that they give you, they will do it according to your insurance because they know what insurances will and will not pay for... you're treated according to your insurance.

***Some beneficiaries were concerned about different treatment because they were on Medicare.***

One low-income beneficiary in Baltimore told us he felt that “doctors overlook sometimes certain things because you’re on Medicare...it’s like they don’t want to see more than what they have to because they get paid less.” Some beneficiaries also felt that there was a stigma associated with Medicare, and few a handful of people said they felt embarrassed to be on Medicare. One Chicago beneficiary said:

When I was still working I had [private] insurance. And then when I switched over, when I went on disability and on Medicare, I was really - it was almost - I was embarrassed. I felt the stigma going in, and, my doctors or new doctors or new providers or whatever, I felt like I was taking something I did not deserve.

Another beneficiary in the same group agreed with her:

There have been times I felt like that also. Not necessarily by my primary but by specialists that he referred me to. And they are specialists that do take Medicare but...the first time you go in to see them and you are a new patient and they ask what insurance you have, “It is Medicare.” “Do you have anything else?” “No.” “Oh.” And it is like, “Oh, God, here we go again. He is not going to pay his bill.” You know, to me they are unnerving.

## **5. Physicians’ Views on Medicare Access**

In addition to asking beneficiaries about their access to physician services, we also asked physicians about both their willingness to accept new Medicare patients and their ability to get referrals for their patients. In addition, we ended most groups with a broad question on what they liked most and least about Medicare. Although almost all the physicians in our focus groups were accepting new Medicare patients, they raised some serious concerns about Medicare payment rates and billing policies.

***Most physicians were accepting new Medicare patients, but a few were not.***

The physicians in our focus groups all had some relationship with Medicare. As a condition of participating in the focus groups, physicians were required to have at least 10 percent Medicare patients in their practice, although many reported having a much higher percentage. For instance, one physician mentioned that Medicare patients made up 40 percent of his practice and at least 35 percent of his income. Another primary care physician said that 60 percent of his patients were on Medicare. During

the groups, we asked participants whether they were accepting new Medicare patients, had set a limit on the number of Medicare patients they saw, or had stopped taking new Medicare patients.

Several physicians said that they would have preferred not to accept any new Medicare patients. One frustrated physician said, "I'm not crazy about taking it but I can't exist without it." Another physician commented, "You cannot survive if you do not take Medicare. You *have* to take Medicare." A few physicians, however, cited moral reasons for continuing to see Medicare patients. One primary care physician in Seattle commented:

Well we continue to do it because it's not a business decision or we would be gone a long time ago. I don't think anybody here is thinking that's a business decision. It's ethical. It's your commitment to what you're doing in your profession in taking care of people that you've been [seeing]. "Okay, sorry you're 62 or 65 or whatever. It was nice knowing you, you know, for 20 years. Good luck." You know, you can't do that.

A few others, however, felt differently. Of the 32 primary care doctors and 32 specialists in our focus groups, three primary care providers and two specialists said they had stopped accepting new Medicare patients. One physician, who had made the decision eight or nine years ago, said that it was because of the "reimbursement issue." For others, the decision had been more recent. They cited the same reason for stopping, along with frustration with the overall system. One physician said, "It's just so incredibly frustrating that I gave up." Another said, "They change their guidelines, they change their coverage, and it's a nightmare."

Among the five physicians who had stopped accepting new Medicare patients, three were from Seattle, and one each came from Baltimore and Chicago. One Chicago physician elaborated:

I think the situation in the Chicago area is a little better than some areas of the country. I don't know if it's the best, probably not, but it's much better than Florida. I've had patients move back from Florida because they can't stand the medical.

One of the physicians in our Seattle focus groups was not yet at the point of refusing new Medicare patients, but said that he and his partners discussed the issue "all the time." They had decided to set a limit: "We have right now 13 percent [of our panel is Medicare], and we've set a ceiling of 15 percent and feel as if we're pretty generous."

### ***Physicians perceive a problem with access to certain specialties.***

The physicians in our focus groups named several specialties for which Medicare access was a consistent problem. These included, among others, psychiatry, rheumatology and dermatology. They based these observations both on what they hear from colleagues generally and from attempts to get referrals for their patients. Many primary care providers reported that they sometimes had difficulty finding specialists for referrals of their Medicare patients.

Psychiatry was mentioned most often in all three locations as being a specialty where many doctors did not accept Medicare patients. One Seattle psychiatrist told us:

Before I started working with a mental health center, for most of this decade, I was specializing primarily in geriatric psychiatry, so I was working with Medicare. And I eventually changed the

focus of my practice because I just got tired of some of their limits on psychiatry. They would have certain fees that they would pay us, and they had an automatic cutback where they would just limit the amount of fees.

And the last straw that we had was, we were running this service providing psychiatric consultations to nursing homes, which most nursing homes will say they don't get enough of this stuff, and we had this fairly large consultation group. And at one point Medicare was auditing every single note for every single bill that came their way... and they were making it more difficult for us to do our work, and then I finally had enough.

One Baltimore physician suggested that it is particularly difficult to find specialists in network for a patient who is enrolled in a Medicare Advantage plan.

I found that if a patient has straight Medicare, who is becoming a rarity right now, then it's not as difficult. But if they do have one of the Medicare HMOs then you've got to do some calling around to find out who takes what. And that they may take them this month...[Then] they've seen them once...and they write them back and say we no longer take your insurance.

***The acceptance of other types of insurance varied, with Medicaid being the least accepted.***

Some physicians in our focus groups indicated that they did not accept Medicare Advantage plans although they accepted traditional Medicare. One Seattle physician explained his decisions to drop a Medicare Advantage plan.

[Plan X] is my worst enemy. Because people pay Medicare premiums, Medicare Part B, it pays to somebody, then somebody pays to somebody, and then they pay to [Plan X]. And [Plan X], I get a check from [the parent company], and with all those steps something will go wrong. So I get paid for a year or two and then usually get a letter from [Plan X] "give me the money back because patient didn't have coverage for those two years." You call the patient they say "what the hell, I've been paying premiums." So we don't accept any [Plan X] whatsoever now.

But another Seattle physician reached the opposite conclusion with regard to the same Medicare Advantage plan:

PHYSICIAN: [Our policy] is a hybrid, we'll take certain plans like Medicare Advantage or [Plan X] but not straight Medicare.

MODERATOR: What's the basis for that decision?

PHYSICIAN: Reimbursement.

MODERATOR: You're getting better reimbursement from Medicare Advantage plans.

MALE SPEAKER: We're not losing money yet.

A few physicians did not accept certain private insurance plans. One Baltimore participant dropped a particular plan because "they were substantially below every other payer, including Medicare for us." A Seattle physician similarly described refusing to see patients with a plan that paid less than Medicare.

Medicaid was by far the least accepted insurance source among the physicians. About 16 physicians, out of the 64 in our focus groups, said that they no longer accepted new Medicaid patients. Physicians felt that while it was sometimes difficult to refer Medicare patients to specialists, it was far more challenging

to find specialists who accepted Medicaid. A couple of physicians said that they preferred to not submit bills for their Medicaid patients because the hassle was not worth the payment. One Chicago physician commented:

I see a lot of them, but the only new ones I take are people or family members or whatever, because for just primary care, Medicaid when they come in the office, it's what the lawyers call pro bono, I don't even submit a bill, because it takes more time and energy for my staff to work up a bill to get the lousy ten bucks or whatever, it's just not worth it, I'll just see them gratis.

***Physicians named predictability, the pleasure of treating older patients, and the absence of preapproval requirements as the things they liked most about Medicare.***

**Reliable payer.** When we asked physicians an overall question about what they liked most about Medicare, the most consistent response was “predictability” and “reliability.” One physician noted, “I like that the rules are standardized. Those rules apply for Medicare; for everything. You know, the rules are rules and that's it. Very predictable.”

**Lack of preapproval requirements.** Physicians also liked the absence of preapproval requirements with Medicare. One physician, who appreciated the lack of restrictions, said:

The thing for surgery is that we don't have to get any preapproval like with HMO's and other insurance companies where you have to wait to decide if you can do a procedure on someone. With Medicare patients you can just go ahead. You don't have that restriction.

**Coverage for the elderly population and pleasure in treating them.** Some physicians also appreciated the universal coverage that Medicare provides for the elderly. One physician saw it as an “effective delivery model that is expandable to the entire population.” Another noted:

As a cardiologist I have a lot of patients who are over 65, and I think what I like best about Medicare is that, and this tells you where I stand on universal healthcare, I don't have to worry that my Medicare patients are going to lose their insurance and not be able to come see me. They're secure and I'm not going to stop seeing Medicare patients any time in the foreseeable future. So the fact that they have coverage and they can go to the hospital and they can come to my office is a very good thing.

Another physician felt grateful towards the elderly population:

It's that segment of the population, I think, who have made major contributions [to] the fact that I am where I am and able to practice, and I feel I owe these folks the best medical care that they can have and to know that they're not going to fall through the cracks because of availability of coverage is important.

When we asked physicians what they liked most about Medicare, a few said they enjoyed treating older patients. One physician said that he loved seeing his elderly patients and looked forward to seeing them every day. Others said they liked that age group in general and found the elderly patient population “interesting.”

***Physicians said they disliked Medicare's level of payment, and they were concerned about some of Medicare's coding and billing policies.***

**Level of payment.** One of the most common replies to our question about what physicians liked least about Medicare was that payment rates are significantly lower than private insurance rates. Some physicians felt inadequately compensated for the time they spent with their Medicare patients, most of whom had more complex medical problems than other patients. According to one physician in our focus group:

[Medicare is] not a great payer in terms of the amount of reimbursement. As I said, most of our other insurances pay us more than Medicare. So that - and despite the fact that generally Medicare patients are more complicated and older by definition. So they're older and so they're more complicated yet we're paid less for them.

One primary care physician said:

For me the difficulty with Medicare is the multiple problems that [beneficiaries] have that we're trying to manage in a...patient who really doesn't want to hear from any other doctor but you. So they may go to all the other doctors but they're coming back to you to have them understand, "Why do I need a colonoscopy?" and "What about my breast lump?" and, like a 75-year-old that was HPV positive, "Why do I have to go to GYN?" And so you're actually spending more time if you care for your patients explaining what all the other specialists put them in or put them out and sent them to do. And they're coming to visit just so you can explain what's going on in their life. That may not be a Medicare issue, but I'm not being reimbursed *per se*.

Almost all the physicians suggested that they were better compensated by private insurers. The physicians generally felt that private insurance rates were 20 to 30 percent higher, although a few reported they were up to 50 percent higher than Medicare payment rates. The physicians who had stopped taking new Medicare patients cited low payment rates as the motivating factor behind their decision.

A couple of physicians from our two groups in Seattle also commented on the geographical variability of Medicare payment rates. They felt that the Medicare payment rate was unfairly low in Seattle compared to other states.

**Coding and billing policies.** Several physicians expressed their frustration with Medicare coding issues and the billing system, especially the coding of longer physician visits. The threat of audits and reviews for fraud is a constant source of worry for some physicians in our focus groups. Several mentioned that they were afraid of ending up in jail for a simple mistake. According to one physician:

They're the only insurer that can put you in jail, if you think about that. Now, I've been blessed that in 27 years of practice I've only been reviewed by them once, and that was about 27 years ago and they were satisfied with my records. So that was a good thing. But I've heard some cases where apparently innocent doctors have gone to jail for fraud...the other insurers can't do that.

Others were frustrated by the complexity of the coding system, and felt that the amount of time and money spent on billing was a waste.

**Other concerns.** Some of the other things that the physicians disliked about Medicare were poor coverage of preventive care, the Part D coverage gap, and other coverage issues for specific procedures. One physician noted:

I think the bad thing is they don't cover any preventive things. People come in and it has to be a problem. You cannot do a cholesterol screening if there is not a reason. Now how would you find a reason? Would they be feeling something?

Others brought up concerns about the doughnut hole and other coverage issues. One physician said, "Well the doughnut hole is preposterous, but then also I hate that every year they keep threatening and they do cut rates and it's like, you get this annual anxiety attack from Medicare. "

## 6. Concierge Care

Since MedPAC has been interested in the topic of concierge care, we discussed this recent trend in eight of our twelve beneficiary groups and four of our six physician groups. Interestingly, the topic came up spontaneously in six of our focus groups. We heard about how the recent trend of physician practices going into concierge care was affecting beneficiaries. In addition, we heard physicians' views on concierge care practices.

### *Some beneficiaries were aware of concierge care, but it did not seem widespread.*

Many beneficiaries in our focus groups were aware of concierge care but most were not directly affected by it. Most of the beneficiaries who were aware of it had read about it in the news, had heard it on television, or had heard about it from friends and family. Two beneficiaries from the high-spender groups mentioned that they had signed up with a concierge physician and were generally happy with the experience, despite having to pay a fee. One of them said:

We went concierge, mainly because of the doctor we had...We would've had to change. Well, it's a lot of money, but you get four long consultations a year. A complete physical, and...then you do something different every time, and I go four times a year. And he says, "Look I had all these patients, and I was working through lunch, and if you got 15 minutes with me, you were lucky." Now, you get a minimum of half an hour, usually 45 minutes, and you can talk about "I've got this problem," talk about things that should be problems. So we've been very satisfied with it. But it's expensive.

The other beneficiary also chose to stay with his doctor when the doctor's practice went concierge:

He offered to the patients that he took care of in this multi-practice the opportunity to come with him. He said he was limiting his practice. I don't know whether he did or not. But this is my third year that they've billed me for concierge service.

Several beneficiaries, whose physicians were considering converting a practice, said that they did not want to pay the extra fees and were generally unhappy with the development. One beneficiary said that after her husband's doctor converted to concierge practice, only a few of his original patients stayed with him:

I only know one out of maybe a dozen people who stayed with him, although he's an excellent doctor. But they didn't want to pay those fees. [The one person who stayed] is a little bit older and has a lot of problems. I'm sure she's working him [with all of her health issues].

In general, concierge care does not appear to be widespread. For the most part, beneficiaries in our groups were not experiencing problems with access to physician services as a result.

***Concierge care was modestly familiar to most physicians in our groups.***

The topic of concierge care came up in four out of the six physician focus groups. None of the physicians were in a concierge care practice, although one had previously worked in such a practice. Most physicians did not view the trend as a positive development. One physician dismissed it as a "passing fad." Others raised more serious concerns about patients abusing the doctors' time and doctors charging an unfairly large fee. One physician found concierge practice unethical. Another physician told us:

My partner keeps saying "why don't we go out for doing concierge practice in [a high-income suburb] or something like that?" And I said, "It's just a bunch of rich snobs there. They're just going to want all your time." I don't think I'd enjoy that.

Several physicians in our focus group also noted that they were already providing the same type of care as a concierge practice, especially for their elderly patients. One physician felt that primary care doctors were already providing the same service as a medical home or a concierge service:

But I think all primary care doctors are providing medical home care. We are providing concierge service...I'm doing all that stuff for free, you know. How come that guy's charging \$3,000 a month?...I think we're giving people a great deal because I think everybody here likes what they're doing. I think we're good people. We're not in it to make \$500,000 a year.

Only a few physicians saw concierge medicine as a positive development. One physician felt that it provided better care for patients: "They come in whenever they need to. There is really no wait. They get superior care and they are happy and able to pay." One person said that although he had not considered turning concierge at this stage in his career, he might be tempted to at a later stage in life when he wanted less work. Another physician mentioned a friend who had started providing concierge care and seemed to be happy with her decision.