

## Centers for Medicare and Medicaid Services Releases 2012 MCBS *Access to Care* Research Files: Are Medicare Beneficiaries Getting the Help They Need with Home-Based Care?

### Introduction

Americans are living longer with significant cognitive and physical disabilities,<sup>(1)</sup> and the number of Americans needing long term care will more than double by 2050.<sup>(2)</sup> Yet, there is a growing shortage of caregivers,<sup>(1, 3, 4, 5)</sup> and most Americans who need long term care receive it from unpaid family caregivers.<sup>(2)</sup> The estimated value of this unpaid work is \$375 billion a year.<sup>(6)</sup>

To mitigate these trends, there is a growing focus on home-based care to meet the needs of the elderly, including several initiatives in the Affordable Care Act aimed at increasing home-based care as a cost-saving measure that may also lead to improved health care quality.<sup>(7)</sup> In addition, there are calls to increase training and support provided to family caregivers,<sup>(3,6,8)</sup> as older adults who return home from a hospital event without needed assistance with an activity of daily living (ADL) have higher rates of rehospitalization.<sup>(9)</sup>

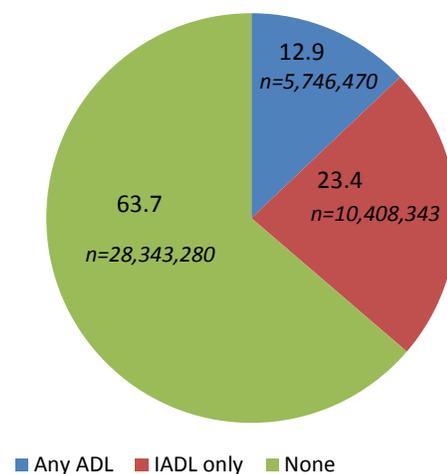
With almost 25 years of data on the health and well-being of the Medicare population, the MCBS is uniquely positioned to inform policy discussions about the care needs of Medicare beneficiaries, particularly for those receiving home-based care. This data brief uses the 2012 MCBS Access to Care Research Files to examine the characteristics of beneficiaries who have difficulty with normal daily activities and whether they are receiving help in performing these activities. It also examines whether the characteristics of beneficiaries receiving help have changed over time.

### Prevalence of Difficulty and Help

Over 16 million beneficiaries, or more than one third of the Medicare population, receive help with at least one instrumental activity of daily living (IADL) and/or at least one ADL (Figure 1). Examples of IADLs include housework, preparing meals, and shopping, whereas ADLs include basic activities such as walking, bathing, and dressing.

Table 1 describes the prevalence of Medicare beneficiaries reporting difficulty with specific ADLs and IADLs. The ADLs with which beneficiaries were most likely to report difficulty were walking, getting in or out of a bed or chair, and bathing. Among IADLs, beneficiaries most frequently reported having difficulty with heavy housework, followed by shopping, and light housework.

**Figure 1. Medicare Beneficiaries Reporting Difficulty, by Type of Difficulty: 2012**



Note: While beneficiaries with ADL difficulty may also have IADL difficulty, the three chart categories are mutually exclusive.

**Table 1. Percent of Medicare Beneficiaries Reporting Difficulty with Common Activities: 2012**

	<b>All Beneficiaries</b>
	Percent (95% CI) <i>n=44,498,093</i>
<b>ADLs</b>	
Walking	31.8 (30.8 - 32.8)
Getting in/out of bed/chair	16.8 (16.0 - 17.5)
Bathing	12.9 (12.4 - 13.5)
Dressing	10.1 (9.5 - 10.6)
Toileting	6.9 (6.4 - 7.4)
Eating	4.6 (4.1 - 5.0)
<b>IADLs</b>	
Heavy housework	37.6 (36.6 - 38.6)
Shopping	16.9 (16.3 - 17.6)
Light housework	15.2 (14.4 - 15.9)
Preparing meals	11.9 (11.3 - 12.5)
Paying bills	9.9 (9.3 - 10.5)
Using the telephone	7.8 (7.2 - 8.3)

Note: Excludes beneficiaries with end-stage renal disease or residing in a facility.

(Table 3). Among beneficiaries ages 65 to 84 who reported difficulty with walking, 19.6% received help, compared to over 85% who reported difficulty with shopping. In general, beneficiaries received more help with IADLs than ADLs. Beneficiaries ages 85 and older were more likely to receive help across every ADL and IADL when compared to the 65 to 84 age group. Disabled beneficiaries had similar rates of help to beneficiaries ages 65 to 84, but were significantly less likely to receive help than beneficiaries ages 85 and older across every ADL and IADL, with the sole exception of getting in or out of beds or chairs.

**Table 2. Percent of Medicare Beneficiaries Reporting Difficulty with Common Activities, by Age Group: 2012**

	<b>Beneficiaries Under 65</b>	<b>Beneficiaries Ages 65-84</b>	<b>Beneficiaries Ages 85 and Older</b>
	Percent (95% CI) <i>n=7,285,372</i>	Percent (95% CI) <i>n=32,398,008</i>	Percent (95% CI) <i>n=4,814,713</i>
<b>ADLs</b>			
Walking	52.3 <sup>a</sup> (49.5 - 55.1)	24.5 (23.4 - 25.5)	50.5 <sup>a</sup> (48.4 - 52.6)
Getting in/out of bed/chair	33.2 <sup>a</sup> (30.4 - 35.9)	11.8 (11.1 - 12.6)	25.0 <sup>a</sup> (23.1 - 26.9)
Bathing	23.9 <sup>a</sup> (21.8 - 25.9)	8.6 (8.0 - 9.2)	25.8 <sup>a</sup> (23.7 - 27.8)
Dressing	21.2 <sup>a</sup> (19.0 - 23.4)	6.5 (6.0 - 7.1)	17.0 <sup>a</sup> (15.3 - 18.8)
Toileting	14.2 <sup>a</sup> (12.1 - 16.2)	4.4 (4.0 - 4.9)	12.8 <sup>a</sup> (11.5 - 14.1)
Eating	10.4 <sup>a</sup> (8.5 - 12.2)	2.9 (2.5 - 3.3)	6.9 <sup>a</sup> (5.8 - 8.1)
<b>IADLs</b>			
Heavy housework	65.5 <sup>a</sup> (63.0 - 68.0)	28.8 (27.8 - 29.9)	54.1 <sup>a</sup> (51.9 - 56.4)
Shopping	34.7 <sup>a</sup> (32.1 - 37.2)	10.7 (10.1 - 11.3)	32.2 <sup>a</sup> (30.1 - 34.4)
Light housework	34.5 <sup>a</sup> (31.8 - 37.2)	9.6 (8.9 - 10.2)	54.1 <sup>a</sup> (51.9 - 56.4)
Preparing meals	25.1 <sup>a</sup> (22.9 - 27.3)	7.3 (6.8 - 7.8)	22.5 <sup>a</sup> (20.7 - 24.4)
Paying bills	23.4 <sup>a</sup> (21.4 - 25.4)	5.3 (4.8 - 5.8)	20.3 <sup>a</sup> (18.6 - 22.1)
Using the telephone	11.0 <sup>a</sup> (9.1 - 12.9)	5.2 (4.7 - 5.8)	20.0 <sup>a</sup> (18.1 - 22.0)

Note: Excludes beneficiaries with end-stage renal disease or residing in a facility.

<sup>a</sup> Estimate was significantly different from the 65-84 age group at the p<.05 level using a Wald chi-square test.

Table 2 describes beneficiaries reporting difficulty with ADLs and IADLs by age group. Across all three age groups, the three ADLs with which beneficiaries were most likely to report having difficulty were walking, getting in or out of a bed or chair, and bathing. However, the percent reporting difficulty among both beneficiaries under age 65 and age 85 years and older was about twice as high as the levels reported by the 65 to 84 age group.

Among IADLs, beneficiaries most frequently reported having difficulty with heavy housework, followed by shopping, and light housework. As with ADLs, about twice as many beneficiaries under age 65 and age 85 and older experienced difficulty with most IADLs compared to the 65 to 84 age group.

### Which Beneficiaries Receive Help?

The percentage of beneficiaries reporting that they had a difficulty with an ADL or IADL and received help with it varies greatly by type of ADL and IADL

**Table 3. Percent of Medicare Beneficiaries Reporting Difficulty and Getting Help with Common Activities: 2012**

	Beneficiaries Under 65		Beneficiaries Ages 65-84		Beneficiaries Ages 85 and Older	
	Percent with Difficulty Getting Help (95% CI)	Frequency	Percent with Difficulty Getting Help (95% CI)	Frequency	Percent with Difficulty Getting Help (95% CI)	Frequency
<b>ADLs</b>						
Walking	23.5 <sup>b</sup> (20.5 - 26.6)	896,478	19.6 (17.9 - 21.4)	1,555,245	27.7 <sup>a</sup> (25.2 - 30.1)	671,833
Getting in/out of bed/chair	40.2 <sup>a</sup> (35.5 - 44.9)	970,592	28.2 (25.4 - 31.0)	1,080,186	38.1 <sup>a</sup> (34.0 - 42.1)	458,840
Bathing	45.7 <sup>b</sup> (40.1 - 51.2)	793,403	48.4 (44.6 - 52.3)	1,346,957	68.4 <sup>a</sup> (64.2 - 72.6)	848,363
Dressing	57.0 <sup>b</sup> (50.9 - 63.1)	880,934	61.2 (57.3 - 65.0)	1,297,034	74.4 <sup>a</sup> (69.4 - 79.5)	609,333
Toileting	30.1 <sup>b</sup> (23.6 - 36.5)	310,175	26.2 (21.5 - 31.0)	375,500	46.5 <sup>a</sup> (40.3 - 52.7)	286,335
Eating	26.0 <sup>b</sup> (18.3 - 33.8)	196,659	24.3 (18.3 - 30.3)	229,150	46.7 <sup>a</sup> (38.1 - 55.3)	155,531
<b>IADLs</b>						
Paying bills	77.9 <sup>b</sup> (73.4 - 82.3)	1,324,472	85.9 (82.2 - 89.6)	1,470,106	94.4 <sup>a</sup> (92.3 - 96.4)	923,446
Shopping	80.2 <sup>b</sup> (77.1 - 84.7)	2,042,686	85.8 (83.8 - 87.8)	2,969,103	94.4 <sup>a</sup> (92.6 - 96.2)	1,465,414
Light housework	82.1 <sup>b</sup> (78.5 - 85.8)	2,061,895	81.3 (78.5 - 84.2)	2,522,013	92.4 <sup>a</sup> (89.8 - 94.9)	1,041,888
Preparing meals	78.3 <sup>b</sup> (74.1 - 82.6)	1,432,104	80.9 (77.9 - 83.9)	1,916,522	90.6 <sup>a</sup> (88.2 - 93.1)	983,197
Heavy housework	78.7 <sup>b</sup> (76.2 - 81.2)	3,752,322	75.8 (73.8 - 77.7)	7,076,670	86.0 <sup>a</sup> (83.5 - 88.5)	2,239,129
Using the telephone	52.9 <sup>b</sup> (45.0 - 60.8)	424,923	60.9 (56.5 - 65.4)	1,035,233	67.6 (63.0 - 72.1)	651,467

Note: Excludes beneficiaries with end-stage renal disease.

<sup>a</sup> Estimate was significantly different from the 65-84 age group at the p<.05 level using a Wald chi-square test.

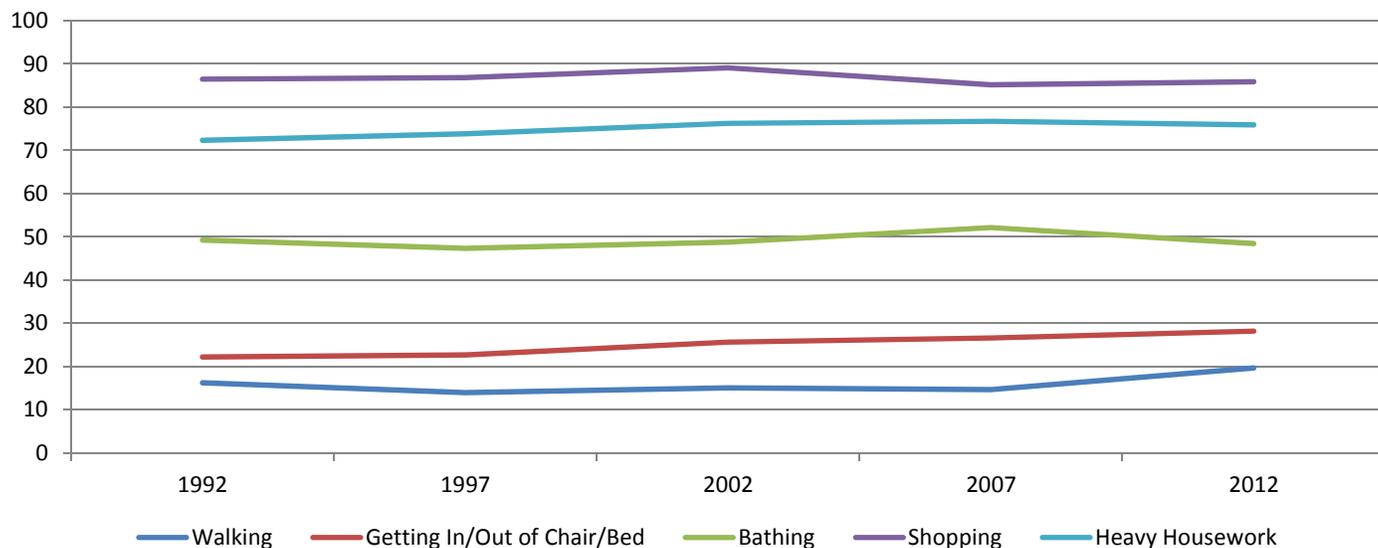
<sup>b</sup> Estimate was significantly different from the 85+ age group at the p<.05 level using a Wald chi-square test.

Figure 2 examines trends over time in the proportion of beneficiaries reporting help with select ADLs and IADLs. Among disabled beneficiaries, the percent receiving help decreased across selected ADLs from 1992 to 2007. Help with bathing and getting in or out of a bed or chair has stabilized in recent years, whereas help with walking has increased since 2007. However, help with the selected IADLs decreased. The percent of disabled beneficiaries receiving help with shopping decreased from 90.6% in 1992 to 80.9% in 2012, while the percent receiving help with heavy housework decreased from a high of 83.1% in 1997 to 78.8% in 2012. Despite a recent uptick, help with bathing has decreased since measurement began, from 54.3% in 1992 to 45.7% in 2012. Conversely, the percent receiving help with walking was higher in 2012 (23.5%) compared to 1992 (18.0%). Among beneficiaries ages 85 and older, the percentage receiving help remained stable or increased slightly over time for the selected ADLs and IADLs, with the exception of walking. In 1992, 31.6% of beneficiaries who had trouble walking received help; this decreased to a low of 23.4% in 2002 but has since risen to 27.7% in 2012.

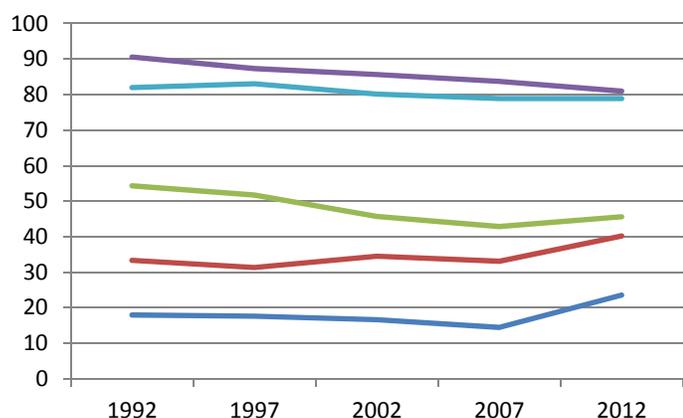
### Who Provides Beneficiaries with Help?

Figure 3 illustrates the relationship between beneficiaries and their helpers. For all three age groups, the largest proportion of the helper population consisted of relatives other than the beneficiary's spouse. This group includes children, children-in-law, grandchildren, siblings, nephews, nieces, and parents, among other relatives. The distribution of disabled beneficiary helpers differs from that of beneficiaries ages 65 to 84, with more 'other relative' helpers and fewer spouse helpers. The distribution difference is even more pronounced with beneficiaries ages 85 and older, who are more likely to have nonrelative helpers and less likely to have spouse helpers.

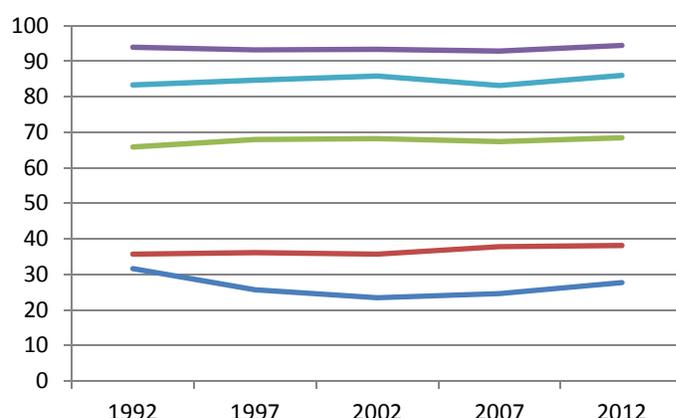
**Figure 2. Percent of Beneficiaries Ages 65-84 Who Receive Help, By Select ADLs and IADLs: 1992-2012**



**Beneficiaries Under 65**



**Beneficiaries Ages 85+**



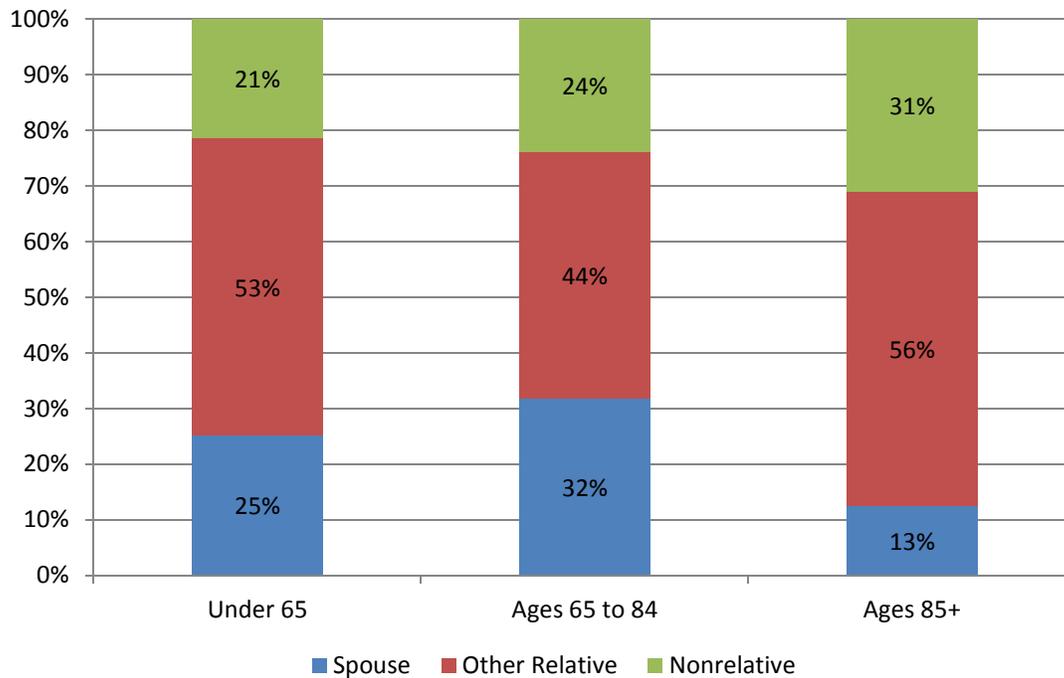
Note: To receive help with an ADL or IADL, a beneficiary must have reported difficulty with the ADL or IADL.

## Conclusion

Medicare beneficiaries report difficulty with several common activities, such as walking, bathing, and housework. More than one third of the Medicare population receives help with IADLs or ADLs, underscoring the critical need for caregivers as this population increases due to demographic changes. Among beneficiaries who report a difficulty, the percent receiving help ranges from about 20% to 90%, depending upon the activity. While rates of help in the overall Medicare population and among beneficiaries ages 85 or older have remained relatively stable over time, the proportion of disabled beneficiaries receiving help for reported difficulties has steadily decreased across multiple IADLs since 1992, with a recent improvement in help provided for ADLs. Disabled beneficiaries have the highest rate of difficulty with both ADLs and IADLs.

The findings in this brief highlight an important issue for Medicare beneficiaries and identify areas of possible unmet need. For example, future research should focus on whether the needs of disabled beneficiaries are being adequately met. Additionally, due to the projected shortage of caregivers, unmet need should be examined across the overall Medicare population, as well as the impact of help on overall healthcare costs.

**Figure 3. Helper Relationship to Beneficiary: 2012**



## References

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- (2) Rousseau, D et al. A Short Look at Long-Term Care for Seniors. *JAMA*. 2013;310(8), 786-787.
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This data brief was written by Jessie Parker and Paul Guerino in the CMS Office of Information Products and Data Analytics (OIPDA), with editorial feedback provided by Kim Lochner. To learn about OIPDA, visit [www.cms.gov/Research-Statistics-Data-and-Systems/Research/ResearchGenInfo/OIPDA.html](http://www.cms.gov/Research-Statistics-Data-and-Systems/Research/ResearchGenInfo/OIPDA.html). For more information about the MCBS, visit [www.cms.hhs.gov/mcbs](http://www.cms.hhs.gov/mcbs). To purchase MCBS files, contact the Research Data Assistance Center (ResDAC) at [www.resdac.org](http://www.resdac.org) or (888) 973-7322.

## Technical Notes

The Medicare Current Beneficiary Survey (MCBS) collects data from the total Medicare population, whether aged or disabled, living in the community or a facility, or served by managed care or traditional fee-for-service. The MCBS is an in-person, longitudinal panel survey. Respondents are interviewed three times a year over a period of four years to form a continuous profile of their health care experience. Two types of interviews are conducted in the MCBS: a community interview done in the home, and an interview of knowledgeable staff on behalf of beneficiaries in a facility setting.

This data brief is based upon the MCBS Access to Care (ATC) research files, which represent cross-sectional data captured in the Fall round (September – December) interviews. The ATC research files include demographic and health insurance data as well as information on access to care, satisfaction with care, usual source of care, and health status and functioning. In addition, the ATC files are enhanced with available CMS administrative data and Medicare claims data for survey participants who received services through traditional fee-for-service Medicare.

The 2012 ATC files represent a point-in-time snapshot of the Medicare population. They capture the “always-enrolled” Medicare population, or those Medicare beneficiaries that became eligible before January 1, 2012, continued to be enrolled in 2012, and were still alive for their Round 64 (Fall 2012) MCBS interview. In 2012, there were 14,189 community interviews and 928 institutional interviews, representing an “always-enrolled” population of 46,869,000.

The study population for this analysis excludes beneficiaries living in a facility and those with end-stage renal disease and represented 44,498,093 beneficiaries. We examined three age groups: (1) disabled beneficiaries, who were under age 65 and were entitled to Medicare benefits by either receiving two years of Social Security or Railroad Retirement Board benefits, or who had a qualifying disability; (2) beneficiaries ages 65 to 84, who were enrolled in Medicare, regardless of their original reason for Medicare enrollment; and (3) beneficiaries ages 85 and older, who were enrolled in Medicare, regardless of their original reason for Medicare enrollment.

Information on a beneficiary’s ability to perform common activities is located in the RIC 2 file. A beneficiary having difficulty with an ADL or IADL was defined as someone who either reported difficulty with an ADL/IADL or reported not performing an ADL due to a health problem. Information on whether a beneficiary was receiving help for these activities is located in the RIC 2H file. A beneficiary receiving help was defined as someone who had difficulty with either an ADL/IADL and also received help with the ADL/IADL from another person. An additional question in the MCBS captures whether a beneficiary who is not helped with an ADL has a person nearby when they perform the activity. This was not included in the definition of help for the purposes of this data brief.

The 2012 ATC file contains cross-sectional weights that reflect the overall selection probability of each sample person. Survey weights were adjusted to account for non-response and post-stratified to control totals based on when beneficiaries became eligible for Medicare, age, sex, race, region, and metropolitan area status. The weights inflate the pool of survey respondents so they accurately represent the 2012 “always-enrolled” Medicare population. All estimates presented in this data brief were calculated using the cross-sectional weights, and all differences discussed in the brief or presented in tables were tested at the  $p < .05$  level.

### Other MCBS Data Files

The MCBS Cost and Use files capture survey-reported data for an entire year (up to three interviews per survey participant), include utilization and cost information (regardless of payer), and link Medicare claims data to survey-reported data. The Cost and Use files represent the “ever enrolled” population, or anyone who was enrolled in Medicare that year for any length of time, including beneficiaries who have died.