



Medicare Trends and Recommendations:

An Analysis of 2017 Call Data from the Medicare Rights Center's National Helpline

April 2019

Prepared by:

Fred Riccardi
Vice President, Client Services

Julie Carter
Senior Federal Policy Associate

Rachel Bennett
Vice President, Program & Product Development

Acknowledgements

The authors would like to thank Mitchell Clark and Anna Szilagyi for their research and editorial support. The authors also thank the Medicare Rights Center staff and volunteers who field client questions.

Disclaimer: All names and identifying details have been changed to protect the privacy of individuals.

Introduction and Summary

The Medicare Rights Center (Medicare Rights) is a national, nonprofit consumer service organization that works to ensure access to affordable health care for older adults and people with disabilities through counseling and advocacy, educational programs, and public policy initiatives. In 2017, Medicare Rights staff and volunteers addressed more than 15,000 questions and issues through the organization's national helpline. In addition, over 2.8 million questions were answered for people with Medicare, their caregivers, and professionals serving them through Medicare Interactive, Medicare Rights' free and independent online reference tool thoughtfully designed to help older adults and people with disabilities navigate the complex world of health insurance. This report will feature select helpline trends and highlight the most commonly searched for Medicare Interactive answers, providing a glimpse into the information and coverage needs of Medicare beneficiaries and their families.

As in previous years, helpline callers and users of Medicare Interactive were geographically and socioeconomically diverse, and needed help with a wide array of complex Medicare-related issues. Medicare Rights served clients in all 50 states. Approximately 30% of helpline callers were living on incomes of less than \$19,000 per year. This number includes people dually eligible for Medicare and Medicaid, who represented 10% of all callers. Caregivers helping to resolve issues and asking questions for family members accounted for 20% of helpline callers. And around 25% of helpline callers were under 65 and eligible for Medicare due to disability. Medicare Rights has less robust demographic data on users of Medicare Interactive but knows that these users represent both beneficiaries and the professionals serving them, and the most popular sections in 2017 included one on Medicare-covered services and one that introduces Medicare eligibility and coverage topics.

Figure 1: List of Medicare Interactive Sections Sorted by Number of Page Views in 2017

Section Title	Page Views
1. Medicare-Covered Services	1,591,138
2. Introduction to Medicare	1,074,031
3. How Original Medicare Works	508,308
4. Programs for People with Limited Income	451,800
5. Medicare and Other Types of Insurance	449,718
6. Medicare Prescription Drug Coverage	197,784
7. Overview of Medicare Health Coverage Options	196,995
8. Types of Medicare Advantage Plans	130,740
9. Filling Gaps in Medicare	118,459
10. Medicare Rights and Appeals	71,197
11. Caring for Yourself or a Loved One with Medicare	69,828
12. Medicare Fraud and Abuse	6,412

Source: Calendar year 2017 Google Analytics data for www.medicareinteractive.org.

People with Medicare and their families rely on the program for overall wellbeing and economic security. In 1963, two years prior to the advent of Medicare, an estimated 44% of Americans over 65 had no health insurance.ⁱ As one University of Pennsylvania historian notes, “In the early 1960s, the choices for uninsured elderly patients needing hospital service were to spend their savings, rely on funding from their children, seek welfare (and the social stigma this carried), hope for charity from the hospitals, or avoid care altogether.”ⁱⁱ Medicare fundamentally altered this reality, and today only around 2% of Americans over 65 have no health insurance.ⁱⁱⁱ Further, since Medicare’s inception in 1965, the average life expectancy for adults 65+ has increased by five years.^{iv} Statistics like these point to the twin need to protect Medicare and strengthen it for future generations.

Through client stories and data, this report seeks to put a face on the Medicare population today and the top issues facing people with Medicare and their families in Medicare’s 54th year. The report explores three top themes on Medicare Rights’ national helpline: 1) navigating Medicare Part B enrollment; 2) appealing Medicare Advantage (MA) denials of care; and 3) affording prescription drugs and related care. The report also summarizes the most commonly searched for answers on Medicare Interactive.

Medicare Rights produces this report so that advocates, policymakers at the Centers for Medicare & Medicaid Services (CMS) and the Social Security Administration (SSA), and other stakeholders can better understand the needs of beneficiaries and work toward

greater accessibility and affordability in Original Medicare and Medicare Advantage. For instance, in order to streamline and increase consumer awareness around Part B enrollment, the Beneficiary Enrollment Notification and Eligibility Simplification (BENES) Act, supported by Medicare Rights and further discussed in this report, was introduced in Congress in 2017. In 2018, additionally, Medicare Rights led advocacy efforts with CMS to extend the Medicare Part B time-limited equitable relief opportunity for Medicare beneficiaries who are enrolled in Marketplace health insurance instead of Medicare. Medicare Rights applauds CMS for extending and providing this relief opportunity through 2019 and beyond for those eligible in 2019 or prior years.

Around two-thirds of Americans receive their Medicare benefits through Original Medicare, and it is critical to protect Original Medicare as an important coverage option, even while Medicare Advantage may be the right choice for some beneficiaries.^v Medicare Rights expressed its concerns with CMS education and outreach materials prepared for the 2018 Medicare Annual Coordinated Election Period, which many perceived promoted Medicare Advantage over Original Medicare. CMS listened to Medicare Rights' and other advocates' concerns, and the final version of the 2019 "Medicare & You" handbook—the primary educational resource for those new to Medicare—was more balanced and accurate. Medicare Rights hopes that additional recommendations made in this report to increase Medicare's responsiveness to beneficiary needs will be similarly heeded and acted on.

Helping Clients Navigate Medicare Part B Enrollment

Case Story: Alice called Medicare Rights because her husband Larry, age 67, has Medicare Part A (inpatient/hospital insurance) and is without Part B (outpatient/medical insurance). Larry has retiree insurance, and his benefits department told him that this insurance would cover him and that he would not need to enroll in Part B.

After previously being healthy, Larry was suddenly diagnosed with cancer and had to undergo costly tests and procedures. Alice and Larry were shocked when he began receiving medical bills for thousands of dollars. This is because Larry's retiree insurance only paid secondary on claims and, without Part B, Larry did not have any primary coverage for outpatient care.

Meanwhile, Larry still needed chemotherapy and surgery. If Larry had Part B, it would cover the chemotherapy and pay for needed physician services. But because Larry had not enrolled in Part B when first eligible, owing to poor advice from his benefits department, he now faced a several month waiting period before Part B

would take effect, and he would also have a lifetime Part B late enrollment penalty (LEP).

Larry had to decide whether to wait several months before beginning cancer treatment, or to start immediately and go deep into debt. A Medicare Rights Center counselor explained to Larry and Alice that, given current Medicare rules, all Larry could do was to talk to his employer, explain that they had misinformed him, and ask them to cover him as primary until he was eligible for Medicare coverage. Medicare Rights also referred Larry to a cancer foundation that could possibly offer him cost-saving assistance.

The consequences of Part B enrollment mistakes like those Larry made are significant—including late enrollment penalties, higher out-of-pocket health care costs, and gaps in coverage that can present barriers to accessing needed services. In 2017, an estimated 701,000 people with Medicare were paying a Part B LEP, with the average LEP amounting to nearly a 30% increase in their monthly premiums.^{vi} Through its helpline—on which around 26% of questions in 2017 had to do with Part B enrollment—Medicare Rights hears that people are very confused about how, when, and whether to enroll in Medicare. Many, like Larry, did not enroll in Medicare Part B when they should have owing to incorrect advice from employers, benefits departments, and health insurance companies—and they had little or no recourse to undo costs associated with coverage gaps and penalties.

For tens of thousands of people today—including those who work past age 65—transitioning from other types of health insurance coverage to Medicare is not an automatic process. Medicare Rights' clients often do not realize that Medicare should be paying primary, instead relying on retiree benefits or a Marketplace plan or COBRA. Contributing to the problem is the lack of a universal written notice about the need for people to actively enroll in Part B, or the availability of information about the Part B Special Enrollment Period (SEP), a right available to certain individuals under specific circumstances. To address the latter needs, Medicare Rights advocates for the passage of the BENES Act now.

BENES Act and Other Enrollment Improvements

While most people new to Medicare are automatically enrolled, a growing number are not, and can face significant challenges in knowing how to enroll and when to do so. Currently, if a person is receiving Social Security benefits as they reach Medicare eligibility, they are automatically enrolled in Medicare Part B. But as many people work later in life and defer their Social Security benefits, they may not be aware that such a deferral means they must make an active enrollment choice, taking into consideration Medicare's complex enrollment rules and timelines. If this transition is mismanaged, individuals new to Medicare may face lifetime late enrollment penalties, higher health care costs, gaps in coverage, and disruptions in care continuity. Medicare Rights continues to support the bipartisan Beneficiary Enrollment Notification and Eligibility Simplification (BENES) Act, which would help prevent these costly errors by providing a universal written notice about the enrollment requirements and by streamlining and simplifying the Part B enrollment process.

Despite the significant consequences of delaying Part B enrollment, federal assistance for those who make this mistake is quite limited. One pathway, known as equitable relief, allows some individuals to request immediate or retroactive enrollment into Part B and the elimination of their late enrollment penalties. However, equitable relief is only available to those who errantly delayed Part B due to their reliance on misinformation from a federal employee, such as a Social Security or 1-800-MEDICARE representative. This leaves individuals who rely on misinformation from other sources, like an employer or a health plan, with no opportunity for recourse.

Medicare Rights supports strengthening the avenues for relief from mistaken delays in Part B enrollment. Congress should expand the Social Security Administration's authority to grant equitable relief to individuals who receive and rely on incorrect information from non-federal sources, such as employers, employer-sponsored or individual market health plans, and insurance brokers.

At the same time, more people new to Medicare should have access to a Special Enrollment Period (SEP), allowing them to more easily enroll in Medicare after their existing coverage ends. Currently, federal law only grants an SEP to individuals with employer-sponsored group coverage based on active employment and for eight months after that coverage ends. Congress should make SEPs more widely available to help prevent enrollment errors that often result when people transition to Medicare from other, non-employer coverage. Medicare Rights urges Congress to establish SEPs for people with pre-Medicare coverage other than employer-sponsored group health plans, such as COBRA, retiree insurance, and Marketplace coverage.

Helping Clients Appeal Medicare Advantage Denials of Care

Case Story: Maria's daughter reached out to Medicare Rights after Maria was unable to get prior authorization from her Medicare Advantage Plan for Medicare-covered cancer treatment to eradicate a tumor. The surgical oncologist received prior authorization for pre-surgical procedures to prepare Maria for treatment, but the plan would not approve the surgery itself, despite Maria's doctor stating that it was medically necessary. Maria did not receive a denial in writing from her plan. After receiving Maria's daughter's call, a Medicare Rights counselor contacted Maria's plan, which struggled to locate their coverage determination and failed to explain why they approved the pre-surgical treatments but not the surgery. The plan reported that no formal appeal was on file, even though Maria's doctor had been in communication with the plan.

Days later, Maria received a coverage determination from the plan, noting that they considered the cancer treatment to be unsafe, ineffective, or not of value. Again, she questioned why the plan approved the pre-surgical procedures but not the surgery itself. Medicare Rights advised Maria to ask her doctor to file an expedited appeal. The doctor's office submitted a letter of support and research to support coverage. They won the appeal, and the initial denial was overturned by the plan within 72 hours.

Around one in three helpline callers have questions about accessing care through Medicare Advantage. Many of these calls relate to appealing denials of care. A recent Office of Inspector General report stated that only 1% of Medicare Advantage enrollees appeal their denied claims. And yet for those who do appeal, the report found that plans reverse an estimated 75% of their own decisions.^{vii} Plans have two opportunities to either approve or deny care for their members: at the coverage determination—which can be appealed—and at the reconsideration of the coverage determination, which can also be appealed. Medicare Rights advises beneficiaries to appeal and ask for help from their doctors. Unfortunately, clients like Maria report that Medicare Advantage denials can be confusing, with incomplete information available to members about why a service has been denied. Plans frequently cite a reason such as “not medically necessary,” with no individualized information to help the beneficiary understand the reason for non-coverage.

In addition to asking appeal-related questions, Medicare Rights' clients sometimes seek help switching Medicare Advantage plans or enrolling into Original Medicare when Medicare Advantage is not meeting their needs. Medicare Advantage provider

networks are more limited than Original Medicare, so some clients switch in order to have access to more doctors. Unfortunately, too, some individuals think that their providers are in network for Medicare Advantage only to find out later that they are not. In a 2018 review of around one-third of Medicare Advantage plan provider directories, CMS found that nearly half of listings contained an error, for instance wrong contact information or incorrect information about whether the provider is accepting patients.^{viii} Such misinformation can lead individuals to make choices that can later result in difficulty accessing needed doctors or obtaining other services and care.

Medicare Advantage

Medicare Advantage plans are becoming more complex, and beneficiaries are facing ever tougher decisions when it comes to choosing between Original Medicare or Medicare Advantage, or among various Medicare Advantage plans. To help people with Medicare make optimal health care choices in this increasingly complicated environment, the federal government must provide beneficiaries with comprehensive, easy-to-understand, and unbiased tools and resources. Currently, Medicare Plan Finder is the primary federal resource available to help people with Medicare make coverage comparisons and decisions. However, the tool is inadequate to meet the needs of current and future beneficiaries. It lacks vital information—such as accurate plan provider directories and personalized cost data—and is ill-equipped to incorporate the expanded information that beneficiaries will need to consider as plans adopt new flexibilities and expand their benefit offerings. Plan Finder must be updated to give beneficiaries the accurate information they need to make good decisions for their personal circumstances.

Medicare Rights also urges CMS to provide much more robust oversight of Medicare Advantage plans to ensure they are not inappropriately denying care, publishing error-riddled provider directories, or steering lower-cost beneficiaries into their products while dissuading others with more complex needs from enrolling. CMS should also strengthen and streamline the Medicare Advantage appeals process, and protect beneficiaries by holding them harmless if plans fail to comply with all notice rules and requirements.

In addition, the plan selection process must be simplified. Medicare Rights supports efforts to standardize Medicare Advantage plans and to reinstate guardrails that prohibit multiple plan offerings with minor differences. These important safeguards are vital to preventing beneficiaries from being overwhelmed by deceptive and prolific choices.

Helping Clients Afford Prescription Drugs

Case Story: A caregiver called the Medicare Rights Center on behalf of her father, Steven. A week before, Steven had visited his oncologist for a monthly injection to treat his cancer, but Steven was unable to afford the 20% Part B coinsurance. A Medicare Rights counselor screened Steven for assistance programs, but he was not eligible, though he lives on less than \$1,400 per month. Steven is also unable to afford a Medigap, which is supplemental insurance that pays for Medicare cost-sharing. His options increasingly limited, Steven was left to search for help from charitable organizations, in the meantime going without his cancer treatment.

The unaffordability of prescription drugs and related care remains a top trend at Medicare Rights, and one that can have heartbreaking consequences—as Steven’s story illustrates. Given that half of all people with Medicare live on incomes below \$26,200—and one quarter have incomes below \$15,250—it is not surprising that around 20% of Medicare Rights’ callers express frustration about the unaffordability of their medicines and other care.^{ix} In 2017, further, there were 281,185 visits to a single page on Medicare Interactive that describes differences between Medicare and Medicaid, which numerous Medicare Rights clients turn to for help affording care.

And Medicare Rights’ call data shows that it is not just lower-income beneficiaries who are affected by increases in Medicare costs. In 2017, over 40% of helpline callers screened for Part D assistance programs, such as Extra Help, did not qualify. At the same time, the amount people with Medicare are spending on health care is disproportionate to that of the rest of society. Consider that in 2016, for instance, Medicare households spent around 41% more on health care than non-Medicare households.^x And 20% of beneficiaries’ out-of-pocket spending (not including premiums) is for prescription drugs, whether covered by Part D or, as in Steven’s case, Part B.^{xi}

Prescription Drug Pricing

Prescription drug affordability is a growing concern that requires a careful balancing of two issues: access and cost. More must be done to contain costs without impeding beneficiary access to care. Measures to be considered include increasing access to Medicare low-income assistance programs such as the Extra Help drug subsidy (also called the Low-Income Subsidy, or LIS), as well as imposing a cap on out-of-pocket beneficiary spending in the Part D prescription drug program and in Part B, which pays for drugs that are generally administered by providers.

Maintaining access to prescription drugs means rejecting proposals that seek to maximize utilization management strategies, such as prior authorization and step therapy. While warranted in some circumstances, when applied broadly or inappropriately these tools can prevent prescribers from choosing the best therapies for their patients, and can keep beneficiaries from obtaining the care they need in a timely manner. Maintaining or improving drug access also means improving deeply flawed appeals and exceptions processes, including by allowing beneficiaries to request a tiering exception for drugs on the Part D specialty tier. The current policy, which restricts this practice, can put many cutting-edge medications out of reach for people with Medicare.

Medicare Rights supports efforts to lower drug prices and overall Medicare costs through common-sense legislative and regulatory changes, such as allowing Medicare to negotiate Part D drug prices, increasing transparency in how prices are set, realigning incentives to better encourage low-cost, high-efficacy treatments, and employing adequate oversight to prevent patent abuses and industry gaming.

Conclusion

Medicare is a(n) essential/critical and popular/beloved program, and the Medicare Rights Center is focused on protecting the current program while improving it for future generations. The 2017 call data summarized in this report points the way to policy changes that would make it easier for people to enroll in Medicare, appeal Medicare Advantage care denials, and afford their medicines and related costs. Medicare Rights looks forward to continuing to work with advocates, CMS, SSA, and others to make policy recommendations a reality. In the meantime, Medicare Rights' national helpline is open for business.

For helpline assistance, call 800-333-4114. For online Medicare assistance, visit Medicare Interactive at <https://medicareinteractive.org/>. For policy updates, visit <https://blog.medicarerights.org/>.

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