



May 2022

Medicare Trends and Recommendations:

An Analysis of 2020-2021 Call Data from the Medicare Rights Center's
National Helpline

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Acknowledgements

The authors would like to thank Derek Ayeh, Rachel Bennett, Casey Schwarz, and Emily Whicheloe for their research and editorial support. The authors also thank the Medicare Rights Center staff and volunteers who field clients' 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 2020 and 2021, Medicare Rights staff and volunteers addressed nearly 42,000 questions and issues through the organization's national consumer helpline and professional email channel. In addition, Medicare Rights' free and independent online reference tool Medicare Interactive (MI), designed to help older adults and people with disabilities navigate the complex world of health insurance, answered more than 5.5 million questions for beneficiaries, their caregivers, and professionals. This report features select helpline trends and highlights the most commonly sought helpline and Medicare Interactive answers, providing a glimpse into the information and coverage needs of Medicare beneficiaries and their families in 2020 and 2021.

Helpline callers and Medicare Interactive users are diverse and seek information and answers related to a variety of complicated Medicare topics. Helpline callers include beneficiaries, caregivers, family members, and health care and community-based professionals. In 2020-2021, Medicare Rights served clients in all 50 states, Puerto Rico, and the U.S. Virgin Islands, as well as U.S. citizens living abroad. All told, 77% of beneficiary clients were Medicare-eligible due to age, 20% due to a disability, and 1% due to an End-Stage Renal Disease (ESRD) diagnosis. Caregivers assisting Medicare beneficiaries across all eligibility types accounted for 22% of helpline callers. Approximately 46% of helpline callers reported living on incomes below \$19,320 per year, which is 150% of the Federal Poverty Limit for single individuals, and 17% of helpline callers were dually eligible for Medicare and Medicaid.

Medicare Interactive users comprise Medicare beneficiaries, their families and caregivers, and the professionals serving them. The most frequently visited sections of Medicare Interactive in 2020-2021 are described in Figure 1.

Figure 1:
List of Medicare Interactive Sections Sorted by Number of Page Views, 2020-2021

Section Title	Page Views	Percentage of Total Page Views
1. Medicare-covered Services	2,134,020	23%
2. Medicare Basics	1,628,270	17%
3. Medicare Health Coverage Options	1,359,340	15%
4. Cost-saving Programs for People with Medicare	932,333	10%
5. Coordinating Medicare with Other Types of Insurance	617,667	6%
6. Medicare Prescription Drug Coverage (Part D)	555,409	6%
7. Medicare Denials and Appeals	297,902	3%
8. Types of Medicare Advantage Coverage	152,121	2%
9. Planning for Medicare and Securing Quality Care	82,178	<1%
10. Medicare Fraud and Abuse	27,368	<1%

Source: Calendar years 2020-2021 Google Analytics data for www.medicareinteractive.org.

During 2020 and 2021, counselors on Medicare Rights’ national consumer helpline fielded similar questions as in previous years, particularly related to Medicare enrollment, affordability, and appeals. But the COVID-19 pandemic added new gravity to perennial issues and brought into focus many of the inequities and disparities that beneficiaries face because of age and/or ability and that beneficiaries of color experience to a far greater extent than their white counterparts.

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. The report explores four top themes on Medicare Rights’ national helpline: 1) mitigating COVID-19’s impact on Medicare enrollment and affordability; 2) appealing Medicare Advantage (MA) and Part D denials of care; 3) accessing and affording prescription drugs; and 4) the need for a Medicare dental benefit.

Medicare Rights produces this report so that advocates, policymakers at the Centers for Medicare & Medicaid Services (CMS) and the Social Security Administration (SSA), elected officials, and other stakeholders can better understand the needs of beneficiaries and work toward greater accessibility and affordability in Original Medicare and Medicare Advantage.

Helpline Trend

Mitigating COVID-19's Impact on Medicare Enrollment and Affordability

Case Story— David, who is Medicare-eligible due to a disability, contacted the Medicare Rights Center because he was laid off early in 2020 due to the COVID-19 pandemic. He had previously declined Medicare Part B enrollment because he had primary coverage through his employer. He did not realize that he should have enrolled in Medicare Part B when he was laid off, instead opting to take COBRA. Months later, he realized the error, but by that time he was outside any Part B enrollment period. A Medicare Rights helpline counselor found that David was eligible for a Medicare Savings Program (MSP), a Medicare cost-assistance program for people with limited incomes. Enrolling in an MSP also enrolls someone in Medicare Part B outside of formal enrollment periods, and David was therefore able to enroll in Part B with some retroactive benefits.

In 2020-2021, enrollment and affordability related to 52% of Medicare Rights' total helpline questions, a 21% increase over 2019. While enrollment questions have been common on the helpline since its launch in 1989, 2020-2021 brought a new urgency to the topic. Clients like David needed help enrolling in Medicare Parts A, B, and D through various enrollment periods and determining their eligibility for and enrolling in cost-saving benefits. In addition, and separate from the percentage cited above, enrolled beneficiaries had a variety of questions about pandemic-specific, temporary changes to Medicare, including on topics of telehealth, moving from a nursing home to another care setting, skilled nursing facility care, access to providers, and more.

The 2020-2021 increase in enrollment-related helpline questions is attributable to pandemic-related layoffs, reductions in work, and termination of employer-sponsored health benefits. Helpline callers who may have previously delayed Medicare enrollment because they had primary coverage through current employment, found themselves suddenly without job-based insurance and needing to enroll in Medicare. Medicare Rights frequently counseled clients on how to use the Part B Special Enrollment Period (SEP), a process that in 2020-2021 was accompanied by unique challenges. For example, Social Security offices were closed to the public during much of those years, and many callers required counseling around submitting enrollment paperwork. Additionally, many individuals had employers who had ceased operations or were closed temporarily due to the pandemic, which made it difficult to obtain the documentation required for the Part B SEP. All callers expressed concerns about the immediacy of their need to access coverage during a frightening and uncertain time when health care needs were high.

Medicare Rights' helpline also saw a pandemic-related increase in individuals seeking assistance with Medicare costs, driven in part by unexpected layoffs and reductions in income. There was a particular increase in inquiries surrounding the Qualified Medicare Beneficiary (QMB) program, which has the lowest income threshold of the Medicare Savings Program. In

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2019, 68% of Medicare Rights' MSP inquiries and referrals were related to the QMB program while in 2020, 74% of low-income inquiries were related to the QMB program.

Medicare Rights is committed to expanding access to its services for underserved populations. Of the clients the organization assisted with low-income benefits in 2020, for whom demographic information is known, 13% were Black/African American, 19% Asian or Pacific Islander, 28% Hispanic/Latino, and 37% white. This is in comparison to the general Medicare population, of which 10% are Black/African American, 4% are Asian or Pacific Islander, 9% are Hispanic/Latino, and 75% are white. Acknowledging and working to reduce disparities is crucial: compared to white beneficiaries, Black and Hispanic beneficiaries earn lower per-capita incomes, are more frequently enrolled in low-income programs such as Medicaid, and report higher rates of difficulty accessing quality care.ⁱ

Policy Recommendation

Enrollment and Affordability Improvements

While most people new to Medicare are automatically enrolled in Part A and Part B, a growing number are not, and these individuals can face significant challenges in knowing how and when to enroll. Managing the process is not simple. Currently, far too many people make honest mistakes when trying to understand and navigate Medicare's confusing enrollment system. The consequences of such missteps can be significant—including lifelong late enrollment penalties, higher out-of-pocket health care costs, and gaps in coverage and access. This problem has been exacerbated during the COVID-19 pandemic as Medicare-eligible individuals suddenly found themselves facing enrollment decisions—and sometimes making enrollment mistakes—during a time of great stress and upheaval. And the same disruptions—job loss, illness, increased caregiving obligations—reduced incomes, putting quality health care out of reach for many.

The consequences of these two factors can be dire. People who cannot access care, whether because they do not have coverage or because they cannot afford to pay for care, will avoid medical treatment—a dangerous result at the best of times, but especially troubling for public health and the safety of at-risk populations during a pandemic.ⁱⁱ

Medicare Rights supports providing a notice from the federal government to individuals approaching Medicare eligibility about basic enrollment rules, which would help prevent costly enrollment errors. In addition, we support increasing access to relief from mistaken delays in Part B enrollment, including through increased use of equitable relief, special enrollment periods for people whose enrollment was affected by the public health emergency, and limits to the duration of any late enrollment penalties.

To address costs, we support capping out-of-pocket costs for beneficiaries. Original Medicare and Part D have no out-of-pocket maximums, exposing beneficiaries to limitless financial risk. While Medicare Advantage (MA) plans do include an out-of-pocket maximum in their benefit

packages, this threshold is too high. We urge the establishment of a standardized, affordable, out-of-pocket maximum for Original Medicare and MA.

For people with lower incomes, Medicare Rights supports increasing eligibility for assistance programs by eliminating asset limits, raising income limits, and easing burdensome application processes.

Together, these policies will improve the access to and affordability of Medicare coverage and modernize the benefit for current and future generations.

Helpline Trend

Helping Clients Appeal Medicare Advantage and Part D Denials

Case Story— Rita suffered a fall and several severe injuries and was transferred to a skilled nursing facility (SNF) for rehabilitation. Shortly after she arrived, her Medicare Advantage plan denied coverage, even though she was still in need of daily physical therapy, occupational therapy, and speech therapy. A Medicare Rights Center helpline counselor assisted Rita’s caregiver in understanding Rita’s right to appeal and how to navigate the appeals process. When the initial appeal was denied, the Medicare Rights counselor guided Rita and her caregiver as they continued to the next level of appeal, advising on what documentation to provide and how to include appropriate evidence of medical necessity. Rita’s family ultimately won the appeal through a hearing at a higher appeal level, and the MA plan reimbursed Rita for all the expenses she had paid out of pocket.

In 2020-2021, 31% of questions on Medicare Rights’ helpline related to denials and coverage of medically necessary care. Of these, 44% were on how to appeal a Medicare Advantage plan’s denial of coverage for a service or item.

As Rita’s and her caregiver’s experience demonstrates, many beneficiaries do not understand all the rules and timelines to appeal a denial of coverage, which can be particularly burdensome during a time of medical need. During the pandemic, callers frequently expressed frustration in their inability to appeal on a timely basis per deadlines, given that many providers and doctors’ offices were temporarily closed or reduced in hours of operation. Other reports have found that only 1% of Medicare beneficiaries appeal while 75% of those appeals are successful.ⁱⁱⁱ

Policy Recommendation

Increase Oversight of Plan Denials

While the rules and timelines for appealing can present a challenge, some Medicare Advantage and Part D plans also engage in behaviors that exacerbate an already complicated process. Among the most egregious instances are those in which plans deny coverage for insufficient and incorrect reasons, forcing beneficiaries to appeal bad decisions and go without needed care

or medications in the interim. Troublingly, CMS plan audits have not increased to meet the need for aggressive oversight, and sanctions for bad behavior, including inappropriate denials, are far too rare.

In addition, Medicare Rights supports a stepping up of oversight and audits of plan denials and more significant sanctions for patterns of inappropriate denials. Medicare Advantage and Part D plans must not be permitted to gain financially by denying necessary and appropriate care.

Helpline Trend

Helping Clients Navigate Part D Access and Affordability

Case Story— Mari contacted the Medicare Rights Center’s helpline because her doctor had recommended a brand-name drug to treat multiple sclerosis, but the drug is new and was not on the formulary of her Part D plan. Mari has a low income, was not able to afford this prescription out of pocket, and wanted to know about possible strategies to access the drug. A Medicare Rights helpline counselor explained the Part D process for requesting a formulary exception. Specifically, Mari’s doctor could request that the plan cover the recommended drug because it is medically necessary and no other drugs on Mari’s Part D plan formulary can treat her condition. Mari was enrolled in full Extra Help, the federal program that helps eligible beneficiaries afford drug costs, so successfully navigating this process would also mean that Mari could access the drug at Extra Help prices.

Many callers contact Medicare Rights with questions about Medicare Part D. In 2020-2021, 12% of questions on Medicare Rights’ helpline related to Part D enrollment, coverage, and appeals. A subset of these Part D-related inquiries related to affordability for prescriptions that were costly due to formulary issues, high drug tiers, and a variety of other issues. Like Mari, more than 5 million Medicare beneficiaries struggle to access and afford medically necessary prescriptions and over half of them forgo needed prescriptions because of the cost.^{iv}

In many instances, successfully navigating the Part D appeals process is the key to accessing and affording prescription drugs. As noted in the previous section, in 2020-2021, 31% of questions on Medicare Rights’ helpline related to denials and coverage of medically necessary care. Of these appeal questions, 21% were on how to appeal a Part D plan’s denial of a prescription drug.

Policy Recommendation

Prescription Drug Access and Affordability Improvements

Medicare coverage appeals are complex processes, but some of the complexity, especially in Part D, is unnecessary. Currently, beneficiaries may learn at the pharmacy counter that their Part D plan will not cover their medication—but they will not learn why. Pharmacists tend not to have details about the coverage decision, and they can only provide the required standard

notice, which directs enrollees to contact the drug plan for an explanation. As a result, affected beneficiaries often have no choice but to leave the pharmacy without their medication or a clear understanding of why it was denied. Confused about what to do next, some may bypass the appeals process—knowingly or not—returning later to pay what they can or deciding to forgo the medication altogether. Those who do take action must embark on a tedious fact-finding mission, winding their way through a multi-layered, burdensome system, often with little help.

Medicare Rights supports a simplification of the Part D appeals process, starting with customized notices at the pharmacy counter that explain the reason for the denial (e.g., prior authorization, step therapy, quantity limits, off-formulary, non-covered) and a requirement that a refusal at the pharmacy counter function as the plan’s initial coverage determination. This would allow the enrollee to obtain actionable information in real-time and initiate the appeals process sooner, significantly reducing frustration and delays.

As with hospital and medical costs, Medicare Rights supports the establishment of a standardized, affordable, out-of-pocket maximum for Part D. To both lower costs for beneficiaries and the system, this change must be coupled with efforts to address the underlying problem of high drug prices, such as drug price negotiation and penalties for manufacturers that refuse to negotiate.

Beneficiaries with Part D can currently request, through a “tiering exception,” that their plan allow them to pay less for high-cost medications when a similar, lower-cost medicine is available on the plan’s formulary but medically inappropriate for them. But this right is not available to beneficiaries whose prescription drugs are placed on the plan’s specialty tier, which has some of the most expensive medications. This frequently leads to high out-of-pocket costs. In addition, the cost threshold for drugs to be included on the specialty tier is too low, leading to an expansion in the number of drugs that are eligible for this tier. Medicare Rights supports Medicare beneficiaries having the right to request tiering exceptions for specialty tier medications or, at a minimum, policymakers raising the cost threshold so that fewer drugs are given this more restrictive treatment.

Helpline Trend

Lack of Dental Coverage

Case Story— Regina has Original Medicare and contacted the Medicare Rights Center’s helpline regarding dental coverage. Regina has osteoporosis, and two of the medications she needs to treat the disease put her at a higher risk for dental complications and jaw injuries. As a medically necessary preventive service, Regina requires regular dental care and at times removal of teeth. Regina’s dental providers have been unsuccessful in getting Medicare to provide coverage for her dental needs, leading her to seek coverage through a charity care program. Unfortunately, she maxed out the benefits for which she would be covered, leaving her to pay for dental services completely out of pocket. Because Medicare does not provide robust coverage for most dental care, a Medicare Rights counselor was not able to help.

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The need for dental coverage is a topic in around 5% of questions on Medicare Rights' helpline. Original Medicare provides little to no dental coverage, and although Medicare Advantage plans can provide such coverage as a supplemental benefit, it often only includes basic services such as cleanings and x-rays. As such, beneficiaries are frequently left with expensive dental bills or forced to forego medically necessary care due to unaffordability.

Policy Recommendation

Comprehensive Oral Coverage within Medicare Part B

A lack of dental and other oral care can lead to increased oral disease, exacerbated chronic conditions, and lessened quality of life. Among Medicare beneficiaries, 70% of people who had trouble eating because of their teeth did not go to the dentist in the past year. Currently, Medicare Advantage plans can offer dental, vision, and hearing coverage, but these benefits are largely very limited, and their availability is generally denied to beneficiaries with Original Medicare.

Medicare Rights supports legislation to provide comprehensive oral—as well as vision and hearing—coverage within Medicare Part B. This coverage should not be offered as a standalone or supplemental benefit akin to the Part D prescription drug benefit because separate, stand-alone coverage blunts the effectiveness and universality of coverage and can cause payment issues when it is unclear which part of Medicare should be covering a service. Rather, Medicare Rights encourages policymakers to add dental coverage as a core Part B benefit.

Conclusion

The Medicare Rights Center's 2020-2021 national consumer helpline data provide insight into the challenges people with Medicare faced to a unique degree during the year that COVID-19 emerged and spread globally. While the urgency and gravity of questions was intensified by the pandemic, counseling themes remained consistent with previous years, illustrating that work remains to be done to improve Medicare for all beneficiaries. This report provides actionable policy recommendations to simplify the Medicare enrollment process, increase Medicare affordability, decrease the complexity and challenges of navigating denials, make prescription drugs more affordable, and add dental coverage as a core benefit to the Medicare program. Medicare Rights looks forward to continuing to work with CMS, the Social Security Administration (SSA), fellow advocates, and beneficiaries to strengthen and protect the Medicare program.

Citations

ⁱ Kaiser Family Foundation, “Racial and Ethnic Health Inequities and Medicare” (Published February 16, 2021), <https://www.kff.org/medicare/report/racial-and-ethnic-health-inequities-and-medicare/>

ⁱⁱ Centers for Disease Control and Prevention, “If You Are at Higher Risk” (last updated January 4, 2021), <https://www.cdc.gov/coronavirus/2019-ncov/need-extra-precautions/people-with-medical-conditions.html>.

ⁱⁱⁱ US Department of Health and Human Services, “Medicare Advantage Appeal Outcomes and Audit Findings Raise Concerns About Service and Payment Denials” (Published September 2018), <https://oig.hhs.gov/oei/reports/oei-09-16-00410.pdf>

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