MEDICARE RIGHTS CENTER
Getting Medicare right

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Shalanda Young
Acting Director
Office of Management and Budget
725 17th St NW
Washington, DC 20503

RE: Methods and Leading Practices for Advancing Equity and Support for Underserved Communities Through Government

Dear Acting Director Young:

The Medicare Rights Center (Medicare Rights) appreciates this opportunity to comment on the **Methods and Leading Practices for Advancing Equity and Support for Underserved Communities Through Government** request for information (RFI). Medicare Rights is a national, nonprofit 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. Each year, Medicare Rights provides services and resources to nearly three million people with Medicare, family caregivers, and professionals.

The need to address equity has never been clearer. The COVID-19 pandemic, entrenched economic exploitation, rising income inequality, and violent and systemic racism must be a call to action to build new pathways to equity and justice. We are glad to see this RFI's focus on ways to see, assess, and redress inequities throughout our governmental systems.

Medicare has aided the country before as we attempted to move past the horrors of Jim Crow and other segregation and racial and ethnic barriers.[1] But disparities persist, and more must be done to improve

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[1] Steve Sternberg, "Desegregation: The Hidden Legacy of Medicare," US News (July 29, 2015), https://www.usnews.com/news/articles/2015/07/30/desegregation-the-hidden-legacy-of-medicare.

access to health care and coverage, build well-being, support dignity, and enhance economic stability for all.

For Area 1, on equity assessments and strategies:

- How can community engagement or feedback from underserved individuals with lived expertise on a given policy problem be integrated meaningfully in an agency's use of equity assessment methods?

Feedback from underserved individuals must be compared with assessment tool population results and discrepancies must be explored. For example, within Medicare this could involve the use of focus groups or other consumer outreach strategies to discover how underserved individuals may diverge from better served individuals, including in how they would answer questions on survey instruments; elements of their treatment, communication, or access to care; interactions with providers and plans; technology gaps that impede access; and other potential hindrances. Such deliberate engagement is critical because while certain quality assessment methods may be accurate for well-served communities, they may have inherent biases or be missing elements that would better capture the lived experiences of underserved individuals and communities.

For Area 2, on barrier and burden reduction:

- Are there specific requirements or processes (*e.g.,* in-person visits, frequency of recertification of eligibility) that have been shown in rigorous research to cause program drop-off or churn by underserved individuals and communities? Similarly, is there rigorous evidence available that certain requirements or processes have little actual effect on program integrity?

By its nature as a program for lower income individuals, Medicaid provides care and coverage to many who are traditionally underserved. The office of the Assistant Secretary for Planning and Evaluation Office of Health Policy determined that common state policies, including frequent redeterminations, lead to widespread Medicaid churn.[2] This is an expected result, as increased redeterminations lead to more opportunities for paperwork error and missed deadlines. Were such policies to be replicated, so too would their harms.

- How can agencies best balance collecting demographic information about program applicants and participants with the potential effect on program participation that these questions may cause? What does rigorous research show about the effect of demographic questions on program participation?

Many communities have been and are still subject to discrimination and prejudice, including profiling, poorer or missing services, suspicion of wrongdoing, physical mistreatment such as involuntary sterilization or denial of pain treatment, hostility, and violence. Such a historical record may make attempts to classify individuals into demographic groups suspect, or even threatening. We urge the creation of focus groups and consumer-tested template documents that explain how demographic

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[2] Sarah Sugar, et al., "Medicaid Churning and Continuity of Care: Evidence and Policy Considerations Before and After the COVID-19 Pandemic," Assistant Secretary for Planning and Evaluation Office of Health Policy (April 12, 2021), https://aspe.hhs.gov/system/files/pdf/265366/medicaid-churning-ib.pdf.

information is collected, used, and shared, and how individuals may opt out or otherwise control that information if they seek to limit its scope. We also urge coordination with trusted organizations, churches and other religious institutions, and local media to disseminate information to communities and individuals in culturally competent and language-appropriate ways.

For Area 5, on stakeholder and community engagement:

- What processes should agencies have in place to engage proactively with the underserved individuals and communities that will be most affected by agency programs, policies, rules, processes, or operations? How can agencies design and implement community engagement practices that are accessible to underserved communities? How might affected communities be engaged pro-actively and early to shape agency policy priorities and strategies?

We urge the adopting of rigorous processes that focus on active and clear communication of all information to beneficiaries, consumers, citizens, and stakeholders and embedding consumer needs into policy design from the outset. These processes should take into account all internal and external avenues of communication, plain language, and consumer testing for readability and comprehension. They should also include relevant information, including potential benefits and potential consequences of a given policy, transparent funding information including any financial incentives for various participants and/or stakeholders, independent information and assistance through ombudsman programs where possible, and audit, quality, and evaluation results that capture the needs and interests of the consumer. For example, Medicare Rights partnered with AARP to develop a checklist for Center for Medicare & Medicaid Innovation models, outlining ways to better engage Medicare beneficiaries and improve model design and participation.[3] The recommendations include:

1. Develop standard consumer communication templates for CMS and providers. Templates should be developed jointly with focus groups and experts to include information about the model's design, how it affects consumers' cost and care, how it affects providers, and what consumer rights and options are.
2. Develop customized scripts for 1-800-MEDICARE.These scripts would help ensure that consumers can access model-specific information from a widely known and trusted source.
3. Develop model-specific training for State Health Insurance Assistance Programs (SHIPs). Trainings would capitalize on SHIPs' valuable individualized services and their connections to state-specific resources.
4. Ensure meaningful consumer participation in model design, monitoring, and evaluation. By building consumers' perspectives directly into new models and consulting regularly with consumers and providers, CMS can improve how models function for consumers.
5. Avoid unintended consequences of beneficiary incentives in model design. Incentives that increase patient costs may drive them away from needed care.

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[3] Julie Carter, "Consumer Protections in New Medicare Payment and Deliver y Models: A Checklist," Medicare Rights Center & AARP (November 2017), https://www.aarp.org/content/dam/aarp/ppi/2017/11/AARP1206_RR_MRCchecklist_Nov20v5.pdf.

6. Establish an independent ombudsman program. Such a program or programs would assist with consumer issues and questions and help monitor model successes and challenges.
7. Publicize all audit and evaluation results and incoming data in a timely manner. These transparent data would permit consumers, their families, and third parties to assess success and challenges with models, plans, and providers.
8. Share with consumers meaningful information about financial incentives included in model designs. Understanding their providers' incentives will allow consumers to trust the model.

- What tools and best practices might agencies deploy to establish advisory boards, task forces, and commissions that are inclusive of underserved communities?

We suggest building upon the work done in patient and consumer engagement in health care, including on the creation and nurturing of an advisory board for patients and families interacting with the health care system.[4]

- How can an agency assess the accessibility of the agency's rulemaking and policymaking commenting and engagement processes, including for individuals that experience barriers to participation? Examples of barriers may include limited language access assistance, online-only engagement, and minimal proactive notification of opportunities to provide comment.

Focus groups, polling, and other surveying may be useful to determine if communities are aware of and likely to engage with opportunities for comment and other feedback. We also recommend making materials available in as many formats and languages as possible.

- Do feedback mechanisms for customers, beneficiaries, and communities affected by Government programs exist to inform policy research and evaluation processes? If so, are these feedback mechanisms accessible to underserved communities? If not, what are best practices that agencies should consider?

Feedback mechanisms, in our experience within Medicare, are quite limited and not fully understood by beneficiaries and others who seek assistance. We encourage the creation of more resources, such as ombudsman programs, to assist consumers and beneficiaries in seeking and receiving help for their concerns. The availability of such mechanisms should be widely advertised in coordination with trusted organizations, churches and other religious institutions, and local media to disseminate information to communities and individuals in culturally competent and language-appropriate ways.

- What tools could agencies develop for expanding stakeholder input into programmatic and regulatory changes to minimize barriers and burden? How may existing processes (*e.g.,* notice and comment on information collections) be enhanced to improve accessibility by stakeholders?

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[4] Agency for Healthcare Research and Quality, "Working With Patient and Families as Advisors: Implementation Handbook" (last accessed June 30, 2021), https://www.ahrq.gov/sites/default/files/wysiwyg/professionals/systems/hospital/engagingfamilies/strategy1/Strat1_Implement_Hndbook_508_v2.pdf.

Many opportunities for stakeholder engagement rely on dissemination of information through formal channels and require expertise in regulatory jargon simply to understand the commenting or feedback opportunity. While it is understandable that much communication from the federal government requires language specificity that it not always amenable to plain speech, we recommend the development, where possible, of plain language guides to major regulatory proposals and actions, as well as considerable outreach to affected communities, especially those that are underserved. We recognize the sheer size of the government means many thousands of opportunities for comment, and that this makes any such outreach a major undertaking. But the average citizen is unaware of if, when, and how they can be heard.

We always urge agencies to approach consumers where they are, where they work, live, learn, shop, play, and pray. We again urge coordination with trusted organizations, churches and other religious institutions, and local media to disseminate information to communities and individuals in culturally competent and language-appropriate ways. Doing so will spur more input and greater opportunities for growth and engagement.

- What tools can agency offices, including communications, civic engagement, enforcement, and policymaking offices, use to better engage or reach underserved communities?

We urge the use of focus groups and consumer testing to develop plain language documents, as well as coordination with on-the-ground organizations who can help disseminate information.

- What are some of the barriers or factors that challenge underserved communities' interactions with Federal agencies and programs?

If a community lacks institutional knowledge of governmental functions, opportunities to be heard, or methods of communication, or if they do not have the resources to translate from complex and legalistic jargon into language they can better understand, they may not be able to effectively engage. We urge greater attention to plain language, multiple language translation, and identification of and coordination with trusted local organizations.

- What practices should agencies put in place to reach underserved communities in rural areas or underserved communities that otherwise are not able to visit Washington, DC, to engage with policymakers?

We urge agencies to identify organizations who can effectively disseminate information to underserved communities and spur and facilitate comments and other engagement. We also suggest tailoring outreach strategies and materials to best meet communities and individuals where they are.

Conclusion

Thank you again for this opportunity to provide comment on this important work. For further information, please contact Lindsey Copeland, Federal Policy Director at LCopeland@medicarerights.org or 202-637-0961 and Julie Carter, Senior Federal Policy Associate at JCarter@medicarerights.org or 202-637-0962.

Sincerely,

Fred Riccardi

Fred Riccardi
President
Medicare Rights Center