

## EXECUTIVE SUMMARY

### In-Person Meeting of the Advisory Panel on Outreach and Education (APOE)

**APRIL 18, 2024, 9:05 A.M.–2:10 P.M. EDT**

#### **Open Meeting**

*Walter Gutowski, Designated Federal Official (DFO), Senior Advisor, Partner Relations Group (PRG), Office of Communications (OC), Centers for Medicare & Medicaid Services (CMS)*

Mr. Gutowski opened the meeting at 9:05 a.m. EDT, introduced himself as the Designated Federal Official (DFO), and reviewed housekeeping items to ensure compliance with the Federal Advisory Committee Act (FACA). He reminded APOE members to speak into the microphones so that all comments could be captured. He announced that APOE would hear public comments at the end of the meeting, noting that the time is set aside for comments only and that any person wishing to give public comment should sign up at the registration desk. Finally, he announced that in compliance with a White House directive, any lobbyists should identify themselves as such before speaking.

#### **Welcome and Opening Comments**

*Stefanie Costello, Director, PRG, OC, CMS*

Ms. Costello thanked the APOE members for joining the meeting and previewed the agenda. She introduced Neil Meltzer as the APOE Chair.

#### **Opening Comments and Panel Introductions**

*Neil Meltzer, APOE Chair*

Mr. Meltzer welcomed attendees and reminded them that this is an open meeting and everything said is on the record. He stated that the opinions expressed by panel members are their individual opinions and do not necessarily reflect the views of the organizations with which they are affiliated. Mr. Meltzer conducted a roll call. After each member introduced themselves, he turned the meeting over to Mr. Gutowski.

#### **Swearing-In of New Panel Members**

*Walter Gutowski, DFO, Senior Advisor, PRG, OC, CMS*

Mr. Gutowski introduced and administered the oath of office to two new APOE members: Matthew Fullen and Justin Gust.

## **CMS Response to APOE Recommendations**

*Stefanie Costello, Director, PRG, OC, CMS*

Ms. Costello informed APOE members that CMS' response to APOE's recommendations from the February 1, 2024, meeting was included in the meeting packet. APOE members did not have any questions. Ms. Costello turned the meeting back to Mr. Meltzer to introduce the first speakers.

## **Guiding an Improved Dementia Experience (GUIDE): Beneficiary Engagement and Alignment Strategy**

*Tonya Saffer, Director, Division of Healthcare Payment Models, Center for Medicare and Medicaid Innovation (CMMI), CMS*

*Charlotte Kaye, Social Science Research Analyst, Division of Healthcare Payment Models, CMMI, CMS*

Ms. Saffer introduced CMMI and explained that her office works on value-based care models and initiatives to improve the lives of people who are suffering from serious illness and chronic conditions. Ms. Kaye explained that GUIDE is a new innovation model launching on July 1, 2024. It is an eight-year voluntary model offered in all states, DC, and U.S. territories, and is scheduled to operate through 2032. Approximately 7% of Americans live with Alzheimer's Disease or dementia, and many are not receiving adequate care. The GUIDE model will test whether a comprehensive package of care will improve the quality of life for people with dementia and their caregivers while delaying avoidable long-term nursing home care and enabling more people to remain at home through end-of-life.

Ms. Kaye provided an overview of the GUIDE Model. Beneficiaries will receive care from an interdisciplinary team that manages the beneficiary's dementia and co-occurring conditions; provider participants are to provide a caregiver support program, including support groups; and a subset of beneficiaries are eligible to receive up to \$2,500 annually for respite services. Medicare Part B providers eligible to bill for the Medicare Physician Fee Schedule can apply to participate in GUIDE. If the participant cannot meet the care delivery requirements alone, they can contract with partner organizations or set up a new arm under a new Taxpayer Identification Number (TIN). There are two tracks: the Established Program track is designed for participants who are already providing comprehensive dementia care and are ready to launch in 2024, and the New Program track is for programs that will launch in 2025, after a one-year pre-implementation period for participants to establish their new programs.

Ms. Kaye explained beneficiary eligibility and the voluntary alignment process. To be eligible to participate in GUIDE, the beneficiary must have a dementia diagnosis attested by a clinician practicing within a GUIDE program, must be enrolled in Medicare Parts A and B (and not enrolled in Medicare Advantage), must not reside in a long-term nursing home, and must not be enrolled in Medicare hospice or PACE. For voluntary alignment, the beneficiary or legal representative must actively consent to receiving services under the model. After the provider participant performs a comprehensive assessment and submits the beneficiary alignment form to CMS, CMS confirms eligibility. Participants must offer all eligible beneficiaries the opportunity to voluntarily align to the program but can deny the opportunity if the beneficiary lives outside of the participant's ZIP Code service area or if there are capacity issues—CMS expects most participants to have approximately 200 beneficiaries aligned within the first performance year.

Ms. Kaye discussed beneficiary recruitment and outreach efforts. GUIDE participants are responsible for conducting outreach and engagement to recruit beneficiaries by developing provider networks with primary care providers, neurologists, hospitals, community-based organizations, and other relevant groups in the area, and for using data provided by CMS to identify potential eligible beneficiaries. Starting in July 2024, CMS will mail letters to potential beneficiaries, providing them with the contact information for providers participating in GUIDE in their area. The outreach letter will also include information on how to voluntarily align to receive these services. APOE members can send feedback on the letter to [guidemodelteam@cms.hhs.gov](mailto:guidemodelteam@cms.hhs.gov).

### **Discussion of Recommendations Among APOE Members, Ms. Saffer, and Ms. Kaye**

The panel made a series of preliminary recommendations in these key areas:

Outreach Strategies for GUIDE Model Participants: The panel stressed the importance of building robust partnerships to enhance outreach efforts. Leveraging partnerships with organizations like the Area Agencies on Aging, which operate the National Family Caregiver Support Program, as well as associations like the Alzheimer's Association and the Case Management Society of America, is crucial for expanding the model's reach. These organizations have established trust and networks within the communities they serve, making them ideal partners for spreading awareness about the GUIDE model. Connecting with State Health Insurance Assistance Programs (SHIPs) was seen as vital for reaching a broader audience of potential beneficiaries. Direct phone outreach, in addition to mailed letters, was recommended as an effective method for increasing awareness and participation, given that many potential participants may not regularly open their mail. Educating primary care providers, especially those in small and rural practices, is essential since they are often the first to identify signs of dementia. Utilizing the experience of local Veterans Affairs clinics and healthcare systems can provide additional support and credibility to the outreach efforts. Integrating state programs that provide financial assistance to family caregivers into the outreach strategy ensures that those who are already in supportive roles are informed about the GUIDE model. Nutrition service programs like Meals on Wheels were identified as valuable sources for referrals, as these programs frequently interact with individuals who may benefit from the GUIDE model.

Communication Methods for Strategies to GUIDE Model Participants: To effectively communicate these strategies, the panel recommended a combination of peer-to-peer education and CMS-led presentations at professional association meetings across national, state, and local levels. Peer-to-peer education is particularly effective because it allows participants to hear firsthand experiences and best practices from their colleagues. Conducting a gap analysis after identifying and enrolling the beneficiary population helps focus communication efforts on areas most in need, ensuring that no community is left behind. Collaborating with associations like the American Academy of Family Physicians and organizing webinars and regional presentations were highlighted as effective methods for disseminating information. Participants conducting landscape analyses to identify local dementia service providers ensures that they are aware of and can collaborate with existing resources. Establishing an informational website tailored to participants' needs serves as a central resource, providing easily accessible information and updates about the GUIDE model.

**Model-Wide Beneficiary Recruitment Strategies:** The panel proposed a multifaceted approach for broader beneficiary recruitment, emphasizing the importance of targeted outreach in rural areas and promoting transportation benefits to facilitate access to providers. This is crucial as rural areas often face significant healthcare access challenges. Engaging first responders, including mental health responders and silver alert issuers, was suggested as a means to identify potential participants during crisis situations. This approach recognizes the pivotal role first responders play in the community and their potential to refer individuals to the GUIDE model. Tailoring messages to different stages of dementia and focusing on the respite benefits of the GUIDE model were seen as effective recruitment strategies, as they address specific needs and concerns of potential beneficiaries and their caregivers. The importance of educating community members through centers and churches, which naturally foster word-of-mouth marketing, was also noted. Translating outreach materials into multiple languages and collaborating with major employers to inform their employees about the GUIDE model were recommended to ensure inclusivity and broad reach. Providing information through large chain pharmacies like CVS and Walgreens, as well as small independent pharmacies, was suggested to maximize visibility and accessibility. Creating a website specifically targeting family caregivers and refining outreach letters based on feedback from potential beneficiaries were recommended to enhance the effectiveness of recruitment communications, ensuring that the messaging resonates with and is accessible to the target audience.

### **Medicare eResources**

*Erin Pressley, Director, Creative Services Group, OC, CMS*

Ms. Pressley explained that eResources is an initiative to encourage beneficiaries to opt into electronic versions of communications. By way of background, CMS mails the *Medicare & You* Handbook to approximately 50 million households annually, and 2.8 million have opted out of paper mailings as of February 2024. Similarly, CMS mails more than 200 million Medicare Summary Notices (MSNs) annually, and 3.2 million people have opted out of paper mailings as of April 2024. Under the current statutory authority, CMS must mail these documents by default, and beneficiaries must affirmatively elect a paperless option.

Ms. Pressley discussed previous promotion efforts to encourage the adoption of eResources. These efforts include messaging in the *Medicare & You* Handbook and MSNs, scripts for 1-800 call center employees, social media and digital ads, links from the [SSA.gov](https://www.ssa.gov) Medicare application, “Welcome to Medicare” messaging, and Earth Day campaigns. The Creative Services Group also conducts consumer testing of messaging in the field. Feedback was sought on strategies to increase electronic adoption.

### **Discussion of Recommendations Among APOE Members and Ms. Pressley**

The panel made a series of preliminary recommendations in these key areas:

**Outreach Strategies for Increasing Electronic Adoption:** The panel emphasized the need to learn from other industries that have successfully transitioned from paper to digital. Examples include restaurants using QR codes for menus, insurers encouraging digital communications, and medical organizations requiring opt-ins for paper communications. Libraries, which offer digital literacy classes and computer access, were identified as valuable partners in this effort.

Leveraging these insights and partnerships can provide practical strategies to enhance electronic adoption among Medicare beneficiaries.

**Messaging to Inspire Paperless Adoption:** The discussion highlighted several key messages that could motivate beneficiaries to go paperless. Emphasizing the convenience and organizational benefits of electronic resources can resonate with beneficiaries who spend significant time managing paper documents. For example, messaging can highlight how eResources make it easier to find information, reduce clutter during moves or downsizing, and allow beneficiaries to recycle old Handbooks confidently. Additionally, offering economic incentives, such as coupons, prescription drug discounts, or a free tote bag, could further encourage adoption. Promoting the environmental benefits by calculating and sharing the reduction in paper usage could also appeal to environmentally conscious beneficiaries. Including a pamphlet within the Handbook that provides an executive summary and information on opting out of mailings can serve as a transitional step toward full electronic adoption.

**Addressing Barriers to Electronic Adoption:** To overcome barriers to electronic adoption, the panel recommended several strategies. Educating plan navigators to discuss electronic options when assisting beneficiaries is crucial. While multifactor authentication may be seen as a barrier, it can be marketed as a data security measure to build trust. Partnering with fraud prevention and digital literacy organizations can enhance beneficiaries' confidence and skills in using electronic resources. Ensuring that documents are mobile-friendly is essential, as many beneficiaries rely on smartphones for internet access. Conducting targeted focus groups can provide insights into the specific reasons why beneficiaries resist opting into eResources, allowing CMS to tailor their strategies more effectively. Developing a Medicare app can significantly enhance usability and prevent email fraud by providing a centralized, secure location for all Medicare-related information. Marketing towards adult children who assist their parents with technology can also drive electronic adoption. Finally, utilizing online advertisements, including social media and popular apps, can reach a broader audience and promote eResources effectively.

### **CMS Sickle Cell Disease Toolkit**

*Michelle Oswald, Technical Director, Policy & Program Alignment Group, Office of Minority Health (OMH), CMS*

Ms. Oswald stated that OMH is interested in receiving feedback on a Sickle Cell Disease (SCD) Toolkit it plans to launch in summer 2024. Half of individuals with SCD are on Medicaid, and 11% are on Medicare. In September 2023, CMS launched an SCD Action Plan with four key areas of focus: expanding coverage and access, improving quality and the continuum of care, advancing equity and engagement, and examining data and analytics.

Ms. Oswald discussed resources that currently exist, including a video about SCD, an SCD infographic, a publication about SCD pain management, a report about the prevalence of SCD among Medicare Fee-for-Service beneficiaries, and September being Sickle Cell Awareness Month. The Cell and Gene Therapy (CGT) Access Model team has resources to support interested organizations. In November 2023, OMH held a roundtable with approximately 47 providers to receive feedback on the SCD Toolkit. Recommendations included: targeted versions for different audiences, focusing on individualized treatment plans, and prioritizing comprehensive care versus chronic care management. The draft outline for Toolkit topics includes a description of SCD; information on insurance coverage; comprehensive care and support services; screening, diagnosis, and treatment; barriers and opportunities; and

resources. The discussion sought feedback on what resources and information should be included in the toolkit, effective dissemination strategies, and additional tools needed to address barriers to care.

### **Discussion of Recommendations Among APOE Members and Ms. Oswald**

The panel made a series of preliminary recommendations in these key areas:

Resources and Information for the Toolkit: The panel emphasized the need for separate toolkits for providers and patients due to differing needs and perspectives. For providers, the toolkit should cover comprehensive care, support services, screening, diagnosis, and treatment protocols, with a particular focus on pain education and management. This is crucial given the stigma and barriers faced by SCD patients in accessing appropriate pain relief, especially during vaso-occlusive crises. Include tools, resources and/or strategies for coordinating multidisciplinary care, latest evidence-based practices, standardized procedures for diagnosing and managing SCD, and up to date information for billing codes. Create tailored content based on different medical disciplines and incorporate vital cultural considerations to address health disparities and improve patient-provider interactions.

For patients and their family/caregivers, the toolkit should provide basic information about SCD, symptoms, disease management, common complications, and impact on daily life. It should cover pain management strategies and address the stigma associated with opioid use for pain relief. Information on preventative care, including vaccination schedules, preventive dental care and the importance of regular health maintenance. Tailored guidance based on the patient's age with specific advice for managing the disease in infants, children, and adults, for example school aged children and sports. Resources explaining advanced treatments like gene and cell therapy, along with addressing common concerns and misconceptions. Include strategies for self-advocacy, such as tips on communicating effectively with healthcare providers and understanding patient rights within the healthcare system. Address health insurance literacy, helping patients understand their coverage, out-of-pocket costs, and how to navigate the healthcare system. The toolkit should offer support for family members, explaining how SCD can impact family dynamics and providing strategies for effective care and support. Include resources for mental health support, national organizations, and community partners.

Promoting and Disseminating the Toolkit: Effective dissemination strategies are essential to ensure the toolkit reaches its intended audience. Leveraging social media and public health campaigns can effectively target the younger demographic often affected by SCD. Partnering with organizations such as the American Academy of Family Physicians, Sickle Cell Disease Association, and other national and local chapters can enhance outreach. Utilizing commercials and collaborations with organizations that already have a strong media presence can also drive awareness. Ensuring the toolkit includes patient narratives and stories can make the information more relatable and impactful.

Addressing Barriers to Care: The panel highlighted several strategies to address barriers to care for SCD patients. Educating plan navigators and community health workers to discuss electronic resources and patient advocacy is critical. Creating a section on living with SCD, which addresses the various stages and severities of the disease, can provide tailored support and resources. Additionally, explaining advanced treatments like gene and cell therapy in clear, accessible language can alleviate fears and misconceptions. Providing tools for providers, such

as printable educational materials and patient-centered resources, can enhance patient engagement and understanding. The provider toolkit should include information on new treatments, access to medications, blood transfusions and the importance of pain management and disease management strategies. A patient/family centered toolkit would address barriers to care by offering tailored information and support that meets their unique needs, enhancing their understanding of SCD, mitigating misconceptions, and empowering them to become active participants in their healthcare. This approach helps patients/families navigate the complexities of SCD care more effectively, ultimately improving their overall care experience.

### **Inflation Reduction Act (IRA): Lower Out-of-Pocket Drug Costs in 2025**

*Stefanie Costello, Director, Partner Relations Group, OC, CMS*

Ms. Costello presented changes to the Medicare Part D benefit due to the passage of the Inflation Reduction Act (IRA). Currently, there is a cap on annual out-of-pocket costs on Part D drugs when a beneficiary reaches the catastrophic coverage phase. Most beneficiaries will contribute roughly between \$3,300 and \$3,800 before these kick in, resulting in paying \$0 for covered drugs for the remainder of the year.

Starting in 2025, people with Medicare prescription drug coverage will benefit from a yearly cap (\$2,000 in 2025) on what they pay out-of-pocket for covered prescription drugs. Additionally, some beneficiaries will have the option to pay their prescription costs over 12 months rather than all at once. Drug manufacturers will be required to provide discounts on certain brand-name drugs and biosimilars, offering a 10% discount during the initial coverage phase and a 20% discount during the catastrophic phase. The session aimed to gather ideas for effectively communicating these changes to beneficiaries, specifically the \$2,000 yearly cap.

### **Discussion of Recommendations Among APOE Members and Ms. Costello**

The panel made a series of preliminary recommendations in these key areas:

Effective Communication and Outreach Strategies: To effectively inform beneficiaries about the \$2,000 out-of-pocket cap, the panel emphasized leveraging pharmacies, particularly independent ones, as they have strong relationships with patients and can directly communicate the benefits. Pharmacists play a crucial role since they are often the ones explaining costs to patients. Utilizing national pharmacy associations to distribute materials and training to pharmacists about the new changes was suggested. Additionally, mail-order pharmacies should be included in the outreach to ensure all beneficiaries receive the information. For broader outreach, public health campaigns via social media platforms like Facebook can effectively target the senior demographic. Leverage and collaborate with existing partnerships such as State Health Insurance Assistance Programs (SHIPs), Area Agencies on Aging (AAA), 340B providers, national organizations and non-profits can further amplify the message. SHIP counselors, like ACA navigators, can become trusted messengers within their communities. Partnering with grocery store pharmacies, which are frequented by seniors, was also recommended for disseminating information.

Targeted Education and Simplification: Providing clear, simplified explanations of the changes is vital to ensure understanding among beneficiaries. This includes creating FAQs, infographics, mailers, and using plain language to explain the benefits and mechanisms of the \$2,000 cap. Developing scenarios to illustrate the before-and-after impact of the changes can help beneficiaries comprehend the practical benefits. Television ads and public service

announcements (PSAs) can reach a wide audience, including caregivers and family members who assist beneficiaries. Comprehensive outreach should include materials available in multiple languages to reach a diverse beneficiary population. Identifying opportunities such as Open Enrollment and starting educational efforts early, well ahead of the 2025 implementation, are also critical.

Reaching Specific Subgroups: Special attention should be given to subgroups with high medication costs, such as cancer patients, individuals with chronic conditions like diabetes, Crohn's disease, and those requiring biologics. Creating partnerships through organizations that serve low-income populations as well as outreach through navigators, social workers, and specialty pharmacies within cancer centers and hospitals can effectively reach these groups. Engaging disease management nonprofits and patient advocacy organizations, such as the American Diabetes Association and Crohn's & Colitis Foundation, can extend the reach to patients especially those with rare diseases, who would benefit most from these changes. Additionally, targeting long-term Medicare Part D enrollees who may not be aware of new changes and partnering with organizations that serve low-income populations and patients with rare diseases will ensure comprehensive outreach.

Challenges for Partners: One significant challenge is ensuring that partners can accurately and clearly explain the changes. The complexity of the IRA provisions requires that information be distilled into digestible chunks. It is crucial to address potential misconceptions, minimize misinformation and emphasize the automatic enrollment aspect, which means beneficiaries do not need to take any action to benefit from the \$2,000 cap.

### **Public Comment**

*Neil Meltzer, APOE Chair*

Mr. Meltzer recognized individuals who signed up to provide public comment:

Amy Niles, Chief Mission Officer of the PAN Foundation, recommended that CMS conduct broad and far-reaching education and outreach to make beneficiaries aware of the changes to the Medicare Part D program brought by the IRA. She recommended that the outreach be written in plain English and be clear that these are new, government-mandated programs and not a new offering from their prescription drug plan. She recommended that CMS use cumulative costs paid by beneficiaries to identify the target population of these efforts. Finally, she urged CMS to do more outreach and education to enroll individuals in Extra Help.

### **Final Comments**

*Neil Meltzer, APOE Chair*

Mr. Meltzer stated that the next APOE meeting is scheduled to be held virtually on June 27, 2024.

### **Meeting Adjournment**

*Walter Gutowski, DFO, Senior Advisor, PRG, OC, CMS*

Mr. Gutowski adjourned the meeting at 2:10 p.m. EDT. The next APOE meeting will be announced in the Federal Register.