

## ASN Responds to CMS RFI on Research Data Request and Access Policy Changes

By Ryan Murray

With broad implications for kidney research using data from the Centers for Medicare & Medicaid Services (CMS), the agency issued a Request for Information (RFI) on a proposal on Research Data Request and Access Policy Changes on February 14, 2024, which was later updated on March 1, 2024. In its RFI, CMS announced a decision to discontinue the physical delivery of critical health care data in support of external research projects and to require researchers to use the Chronic Conditions Data Warehouse Virtual Research Data Center to conduct all research using CMS Research Identifiable File data. After soliciting feedback from its members, including those with direct experience with conducting research with data from federal agencies, ASN responded to CMS's RFI on May 15, 2024.

ASN shared how CMS's proposal jeopardizes the future of research on kidney diseases and will likely directly harm Medicare and Medicaid beneficiaries' access to and quality of care and specifically highlighted the following concerns:

- ▶ The lack of transparency regarding the future of CMS kidney-related data in light of this proposal
- ▶ The unique nature of the federal government's role in kidney care given Medicare's End-Stage Renal Disease program and thus, the potential for jeopardizing the real-time research necessary for policymakers to improve kidney care

- ▶ The impact that a future dearth of research will have on disadvantaged populations given the inequities faced by patients with kidney diseases and their families
- ▶ The impact of increased costs for researchers and their institutions, especially those at smaller, less financially endowed universities
- ▶ The potential to impede the future capacity of researchers across specialties but in particular, in the realm of kidney diseases

CMS data, especially kidney data, are an invaluable resource to policymakers, health care systems, researchers, and the millions of individuals impacted by the contribution of that research through improving outcomes and saving valuable resources. ASN urged CMS to pause the proposal to allow for time to address concerns of the kidney community, those of the broader health care community, and, most importantly, those of individuals living with kidney diseases. ASN will continue to advocate for transparent and open access to federal datasets and keep the kidney research community informed of any updates.

ASN will provide future updates as policy is refined. To read ASN's full response to the RFI, please visit <https://www.asn-online.org/policy/webdocs/05.15.24VRDCLetterFinal.pdf> or the ASN website at [www.asn-online.org/policy](http://www.asn-online.org/policy). ■

*Ryan Murray is the senior manager of Policy and Government Affairs at ASN.*

## ASN Responds to CMS Comment Period on Medicare Advantage Data

By Lauren Ahearn

The Centers for Medicare & Medicaid Services (CMS) issued a Request for Information (RFI) on Medicare Advantage (MA) data on January 30, 2024. This RFI is a part of the Biden-Harris Administration's efforts to promote competition in health care, which includes increasing transparency in the MA insurance market and strengthening programmatic MA data. CMS plans to use the information solicited by the RFI to support efforts for MA plans to best meet the needs of people with Medicare, for people with Medicare to have timely access to care, to ensure that MA plans appropriately use taxpayer funds, and for the market to have healthy competition.

ASN addressed the following topics related to MA data in a letter submitted to CMS on May 29, 2024:

- ▶ **Missing data on transparency:** Despite estimates of MA enrollment amongst Medicare's End-Stage Renal Disease (ESRD) beneficiaries exceeding 50%, exact data on enrollment from CMS have not been made available. In response to this issue, ASN urged CMS to collect and publish the annual number and percentage of ESRD enrollees who enrolled in an MA plan and the annual number and percentage of those who disenrolled.
- ▶ **Questions of transparency:** ASN has raised in previous comment letters concern that MA plans do not provide the same level of transparency as the Medicare Fee-for-Service program, which has a strong history of providing quality data to researchers and policymakers alike. ASN urged CMS to require MA plans to provide the ESRD enrollee data similar to the data collected for Fee-for-Service beneficiaries.
- ▶ **Medicare Chronic Condition Special Needs Plan:** Little is known about the impact of Medicare's Chronic Condition Special Needs Plan largely, in part,

because MA data have not been made available to researchers and policymakers. ASN urged CMS to publish these data.

- ▶ **Network adequacy:** MA network adequacy issues refer to the concerns regarding the sufficiency and accessibility of health care practitioners within the networks of MA plans. Network adequacy issues can have significant implications for patients with kidney failure who require specialized care and frequent access to health care services. Although CMS requires MA plans to submit data on their physician networks, much of these data remain undisclosed to researchers and the public.
- ▶ **Equity:** ASN stressed that improving data collection and transparency on MA coverage and enrollees is essential for promoting health equity and ensuring that patients with kidney failure have equitable access to high-quality health care services.
- ▶ **Prior authorizations:** Currently, MA insurers are not required to report prior authorization requests, denials, and appeals by types of service, for a specific plan within a contract, or reasons for authorization denials. ASN stressed that improving data collection and transparency regarding prior authorization in MA plans is crucial for ensuring patients with kidney failure receive prompt access to the care and treatments that they need to manage their condition effectively and maintain their health and quality of life.

ASN will provide future updates as policy is refined. To read ASN's full response to the RFI, please visit <https://www.asn-online.org/policy/webdocs/05.29.24MedicareAdvantageDataRFI.pdf> or the ASN website at [www.asn-online.org/policy](http://www.asn-online.org/policy). ■

*Lauren Ahearn is a quality and regulatory affairs associate at ASN.*



### Stay at the Forefront of Kidney Care

The ASN Podcast is at the frontline of nephrology and kidney care, connecting you to the newest advancements and insights. With over 85,000 downloads, join the conversation on the latest in kidney research.

**Join the Conversation Today!**  
[www.asn-online.org/podcast](http://www.asn-online.org/podcast)