



Service to those affected by chronic kidney disease

May 28, 2024

The Honorable Chiquita Brooks-LaSure
Administrator
Centers for Medicare & Medicaid Services
200 Independence Avenue, SW
Washington, DC 20515

Re: CMS–4207–NC: Medicare Program; Request for Information on Medicare Advantage Data

Dear Administrator Brooks-LaSure,

On behalf of myself and the Renal Support Network (RSN), I am writing to bring up concerns for people on dialysis who are enrolled or may enroll in Medicare Advantage (MA). RSN helps people who have kidney disease, whether they are in the early stages of the disease, are on dialysis or have received a transplant. I have had kidney disease since age 2, spent 13 years on dialysis and now doing well with a kidney transplant. I founded Renal Support Network 30 years ago, with the goal of empowering people with kidney disease and their families to advocate for the best care.

MA offers an option for people who have kidney failure, particularly for those without access to Medigap policies or Medicare Secondary Policy. However, despite some of the benefits MA plans provide, there is a need for improvement to meet the needs of people who have kidney failure.

Network Adequacy & Transparency

Each plan's network should include a sufficient number of dialysis facilities, nephrologists, and other dialysis-related specialists. This way, Centers for Medicaid and Medicare Services (CMS) can effectively monitor any potential barriers faced by enrollees in accessing renal dialysis services, considering the recent unfortunate decision to exclude dialysis services from the network adequacy rule.

It is troubling that people on dialysis who enroll in MA may have to switch dialysis facilities, change doctors, or transplant centers. This can cause immense stress and negatively impact people's care and overall well-being. People should have access to information about available centers and doctors. Insufficient network adequacy, especially for vascular surgeons, is disrupting care and even posing a threat to people's health. We have received numerous reports from our audience stating that the only way they could see a surgeon for an outpatient vascular access procedure was by going to the emergency room.

The annual possibility of changes in networks pose challenges, especially for those seeking a kidney transplant. If your network changes, you have to undergo the process of transferring to another transplant facility, which can take several months. During this period, you are put on hold on the wait list and unable to proceed with the transplant. Also, it is important that MA insurers share their outcomes so patients can make an informed choice when they choose a plan.

Medicare Advantage Data Collection that Patients and HealthCare Professionals Need

The data reported by Medicare for its monitoring programs, which includes outcomes data collected by the Chronic Care Policy Group, the ESRD QIP, and the ESRD Networks, should adhere strictly to the definitions of data format, fields, and

An illness is too demanding when you don't have hope!

Renal Support Network

content used in traditional Medicare or the info will not benefit people who have to make choices. The U.S. Renal Data Systems should also follow the exact definitions of data format

Same Level of Care and Innovation

CMS needs to track to annually count the percentage of individuals enrolling in an MA plan, as well as the annual count and percentage of those disenrolling, segmented by the reasons for disenrollment. These data will help monitor disenrollment trends and identify any barriers that may impede access to healthcare.

People on dialysis who enroll in MA do not have access to the same level of treatment as those on Medicare fee-for-service, which contradicts the spirit of the law and the program's intention. It is crucial that people on dialysis have equal access to care, regardless of whether they are on fee-for-service or MA. Patients should not have to compromise their health and well-being due to limitations imposed by their insurance plan. Many of our members have informed us that they have to be told they have to take a least expensive drug until it becomes ineffective or fail. We do not understand the definition of "ineffective or fail" and this kind of practice, which prioritizes the company's interests over the quality of care for patients, is greatly concerning and needs to be addressed.

Marketing tactics used to entice patients into enrolling:

Marketing tactics are being used to attract patients to enroll in MA plans. It is worrying to witness some dishonest marketing practices that deceive people into thinking they will only have benefits from enrolling. This misleading marketing can lead to patients signing up without fully understanding the consequences of their decision. Once enrolled, patients are discovering that their care is significantly changed. These exploitative practices not only harm people by potentially limiting their access to appropriate care but also undermine trust in the healthcare system. It is crucial to address these unethical marketing tactics and ensure that patients are given accurate and transparent information when considering their healthcare options.

Ensuring people who enroll have access to networks of care that offer a wide range of healthcare providers and can provide continuity of care is crucial. The availability of choice and transparency is vital in promoting patient-centered care and empowering people to actively engage in their healthcare decision-making, it also contributes to better health outcomes and overall satisfaction with the healthcare experience.

Thank you for your attention to this critical issue to improve access for people living with kidney failure. Please let me know if you have any questions or need additional information. An illness is too demanding when you don't have hope.

Warmest Regards,



Lori Hartwell
President & Founder