FORUM OF END STAGE RENAL DISEASE NETWORKS

June 3, 2019

Seema Verma
Administrator
Centers for Medicare & Medicaid Services
Department of Health and Human Services
PO Box 8010
Baltimore, MD 21244-1810

Re: CMS-9115-P: Medicare and Medicaid Programs; Patient Protection and Affordable Care Act; Interoperability and Patient Access for Medicare Advantage Organization and Medicaid Managed Care Plans, State Medicaid Agencies, CHIP Agencies and CHIP Managed Care Entities, Issuers of Qualified Health Plans in the Federally-Facilitated Exchanges and Health Care Providers

Dear Ms. Verma,

The National Forum of ESRD Networks appreciates the opportunity to comment on CMS-9115-P, Medicare and Medicaid Programs; Patient Protection and Affordable Care Act; Interoperability and Patient Access for Medicare Advantage Organization and Medicaid Managed Care Plans, State Medicaid Agencies, CHIP Agencies and CHIP Managed Care Entities, Issuers of Qualified Health Plans in the Federally-Facilitated Exchanges and Health Care Providers. We appreciate and agree with the ideas described in the proposed rule which seek to improve transparency of healthcare data for patients, and patient access to their own health information. We do appreciate the need to ensure security of any of this sensitive data between systems to protect the rights and privacy of patients. We believe that the End-Stage Renal Disease (ESRD) population of patients is an especially vulnerable population that is not specifically mentioned in this proposed rule.

We believe that ESRD patients on dialysis would greatly benefit from better access to their own healthcare data, and better sharing of healthcare data between systems. Dialysis patients often undergo transitions of care which render them vulnerable to errors due to erroneous or missing data. For example, when dialysis patients are admitted to hospitals, the hospital rarely has electronic access in real time to the patients' current medications. Consequently, it is possible that patients may be placed on medications they no longer take while in the hospital which can potentially be harmful to patients. In addition to medications, other important information for dialysis facilities to know about their patients to improve safety of patient care, includes recent transfusions, infections and vascular access procedures. Similarly, when ESRD patients move between dialysis facilities when traveling, the dialysis facilities often communicate the patient's health data by faxing large packets of paper. It is possible that some of the critical information needed for the accepting dialysis facility to best care for the patient, is missing.

We would encourage CMS to also consider promoting interoperability between dialysis facilities, and between hospitals, physician practices, nursing homes and dialysis centers. Dialysis facilities require that much of the patients' critical medical information be made available. Therefore, dialysis facilities may function as a central hub for ESRD patients' electronic data. However, we would caution against putting the financial burden of promoting this interoperability all on the healthcare providers. The Electronic Medical Record companies should also be held accountable by CMS to promote this interoperability and provide the necessary tools and software to Providers and Facilities to make this interoperability possible. Without Electronic Health Record vendors working with other vendors to provide the electronic connections to share data with other EMRs, healthcare Providers will never be able to accomplish interoperability as intended in this proposed rule. Furthermore, mandating interoperability to small Provider groups or small dialysis organizations could possibly lead to significant financial burden on the facilities which they cannot afford. We believe the focus should be on mandating the technology needed to promote interoperability to EMR vendors and insurance companies.

Thank you for your consideration,

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President, Forum of ESRD Networks

David Henner, DO
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