



June 3, 2019

The Honorable Seema Verma, Administrator
Centers for Medicare & Medicaid Services
Department of Health and Human Services
Attention: CMS-9115-P
Mail Stop C4-26-05
7500 Security Boulevard
Baltimore, MD 21244-1850

Re: CMS-9115-P, RIN: 0938-AT79; Medicare and Medicaid Programs; Patient Protection and Affordable Care Act; Interoperability and Patient Access for Medicare Advantage Organizations 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

Submitted electronically via [Regulations.gov](https://www.regulations.gov)

Dear Administrator Verma:

Families USA, a leading national voice for health care consumers, is dedicated to achieving high-quality, affordable health care and improved health for all. We seek to make concrete and tangible improvements to the health and health care of the nation – improvements that make a real difference in people’s lives. In all of our work, we strive to elevate the interests of children and families in public policy to ensure that their health and well-being is foremost on the minds of policymakers.

Thank you for the opportunity to provide comments on this proposed rule. We support the Administration’s efforts to utilize technology innovations in the health care sector as a way to increase consumer’s access to their health care information and to promote transparency of critical health care data for consumers, payers, and providers. We applaud and encourage efforts that take steps towards the following: increasing the transparency of cost, pricing, and utilization of health care data; strengthening and standardizing interoperability standards of data systems and information sharing for consumers, payers, and providers; empowering consumers to be informed decision-makers; and enabling consumers to own their health care data. We believe that it is critical that the safety and privacy of consumers’ health care information and data is preserved and that consumers’ trust in the ability of health care entities to safeguard that information is not eroded or diminished in any way.

While this proposed rule is broad and includes several provisions in which other key stakeholders will comment, Families USA’s comments will focus on two areas that are particularly critical for consumers: *Open Application Programming Interfaces (APIs) for Medicare Advantage, Medicaid,*

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Children Health Insurance Program, Qualified Health Plan Issuers in Federal Facilitated Exchanges and Enrollee and Beneficiary Resources Regarding Privacy and Security.

Open Application Programming Interfaces (APIs) for Medicare Advantage, Medicaid, Children Health Insurance Program, Qualified Health Plan Issuers in Federal Facilitated Exchanges

We support the proposal to require payers to share the following data with patients through Application Programming Interfaces:

- Adjudicated claims (including cost);
- Encounters with capitated providers;
- Provider remittances;
- Enrollee cost-sharing;
- Clinical data, including laboratory results (where available);
- Provider directory data;
- Drug benefit data including pharmacy directory and formulary data.

A robust data system incorporating APIs will enable consumers to access health care data from multiple health care providers including hospitals, providing them with a comprehensive view of their health and health care.

However, we strongly recommend that CMS also consider requiring payers to share health care cost and pricing data through APIs. The Administration is keenly aware of the high and rising costs of health care in the United States. These uncontrolled costs threaten the affordability of care for families, seniors and children, and create unsustainable budget pressures on the federal government and state governments. As the largest single payer, Medicare rates are often used as a standard upon which private payers and providers negotiate prices *without* transparency and oversight by the public. Payment rates in private insurance are often substantially more than what Medicare pays for services. Further, we know that payment rates not only vary by payer but also that there is considerable variation in payment rates across geographic areas and within health care markets.

There are several actions CMS could take to address price distortions which fall outside the scope of this proposal. Within the scope of this proposal, however, CMS could mandate substantially improved price transparency. Requiring payers to include price and cost data through APIs would be a groundbreaking development that would not only enable consumers to be more informed purchasers of health care but would also unveil critical information that policymakers, researchers and other stakeholders need to inform better payment policies.

Enrollee and Beneficiary Resources Regarding Privacy and Security

We support the rule's requirement that health plans make available to beneficiaries information about safeguarding their data and submitting complaints. However, we have serious concerns about the oversight over third-party apps to ensure that consumers privacy is protected and preserved, and that public trust and confidence in health information technology and health

information exchanges are not eroded. Third-party apps are notorious for their lackluster effectiveness in protecting and securing consumer data. With the rapid proliferation of health technology innovations over the last decade, it is critical that third-party apps and any other entities that may be involved with consumer health data are subject to the highest standards of protection and security for consumer health data. **We recommend that CMS use HIPAA as a framework for a comprehensive privacy structure for third party apps and any new entities that would create, store or transfer health care data.**

Strengthening the regulatory framework for the health technology innovations of today, and the future, must clearly define who governs and controls health data; who has access to it; which entities are responsible for protecting and securing the data; and the extent to which these data and data systems will be interoperable with the health data systems within the health care system. Federal laws and regulations have not kept pace with rapid innovations in health technology. The existing health data regulatory infrastructure already contains significant gaps in the privacy and protection of patient-generated and personally identifiable data. Decisions about whether or not these data are subject to HIPAA's privacy and security protections is dependent on the role of a covered entity in creating or storing the data for a particular patient. The emergence of new health technology innovations will continue to challenge the existing regulatory framework. **We urge CMS to consider strengthening the regulatory framework and infrastructure needed to operate an efficient, effective, interoperable health care data system that protects and secures consumers health data and maintains the highest level of public trust in health care data systems and information exchanges for the 21st century and beyond.**

Thank you for the opportunity to submit these comments. Should you have questions, please don't hesitate to reach out to Sophia Tripoli, Director of Health Care Innovations, at STripoli@familiesusa.org or 202-626-3030.

Respectfully submitted,

Sophia Tripoli
Director of Health Care Innovations