

January 2, 2024

The Honorable Xavier Becerra, Secretary  
Department of Health and Human Services  
200 Independence Avenue, SW  
Washington, D.C. 20201

**RE: RIN 0955-AA05 - 21<sup>st</sup> Century Cures Act: Establishment of Disincentives for Health Care Providers That Have Committees Information Blocking**

*Submitted electronically via Regulations.gov*

Dear Secretary Becerra,

The US health care system is highly complex, difficult to navigate and increasingly unaffordable for millions of families and individuals across the nation. Ensuring that health information flows to the health care providers and patients who need it is critical to ensure an efficient health care system that delivers high quality care and improves health outcomes. As a leading national, non-partisan voice for health care consumers, Families USA appreciates the opportunity to comment on the “21<sup>st</sup> Century Cure Act: Establishment of Disincentives for Health Care Providers That Have Committees Information Blocking” proposed rule. Families USA supports the establishment of strong financial disincentives for data blocking through the 21<sup>st</sup> Century Cures Act and encourages CMS to continue to work to make sure that health care data flows throughout the health care system while also protecting the privacy and security of the American people, particularly as some states enact policies that criminalize some health care outcomes for certain populations. To that end, our comments focus on the following sections of the proposed rule:

III. C.: Appropriate Disincentives for Health Care Providers

III. B. 3.: Approach to Determination of Information Blocking and Application of Disincentives-  
Transparency for Information Blocking Determinations, Disincentives, and Penalties

**III. C.: Appropriate Disincentives for Health Care Providers**

Families USA supports CMS’s proposal to establish financial penalties for health care providers found to be engaging in data blocking including eligible hospitals and critical access hospitals (CAHs) participating in the Medicare Promoting Interoperability Program (MPIP); clinicians participating in the Merit Based Incentive Payment System Program (MIPS); Accountable Care Organizations (ACOs) and providers participating in the Medicare Shared Savings Programs (MSSP). Ensuring our nation’s families and individuals have the high quality, affordable health care and the improved health they deserve is contingent on better access to and flow of health care data, including- but not limited to- within these specific programs.

The proposed rule builds on a key provision in the 21<sup>st</sup> Century Cures Act that authorizes the Department of Health and Human Services (HHS) and the Office of the Inspector General (OIG) to evaluate claims of information blocking and apply disincentives to health care providers who are found to be engaging in information blocking. This proposed rule defines disincentives that will be applied to certain health care providers and establishes a public reporting process for violations.

Families USA supports CMS' proposal to enact the following financial penalties for certain providers found to be engaging in data blocking:<sup>1</sup>

- Reduce the annual market basket by three-quarters for eligible hospitals participating in MPIP;
- Reduce the reasonable cost payment adjustment by 100% for CAHs in MPIP;
- Apply a score of zero in the Promoting Interoperability performance category for clinicians in MIPS;
- Remove a health care provider and/or ACO from MSSP for up to a year.

Today, health care data are often inaccessible and nearly impossible to share for providers and patients.<sup>2</sup> The flow of well-managed and protected health care data is central to improving health care quality and driving down costs across the health care system, yet health care data blocking continues to be a major problem and is a significant barrier to ensuring our nation's families have the high-quality health care they deserve.<sup>3</sup> Information blocking practices - where providers or health IT vendors intentionally withhold information from being shared or becoming accessible - negatively impact the health and well-being of consumers and unnecessarily drives up the cost of care for consumers and the health care system overall.<sup>4,5</sup> For example, when patient records are not efficiently shared, patients can be forced to repeat expensive tests like MRIs, CT scans, or invasive procedures like blood draws. Because health care data are not considered a public good, it has been used to drive the business interests of some companies, instead of being used to drive better value across the US health care system.<sup>6</sup> As part of a multipronged strategy to improve health care quality and reduce unnecessarily high costs to our health care system, this dynamic must change. Access to interoperable and transparent data enables hospitals, clinicians, and payors to provide higher quality, less costly care. It is vital that data be made more broadly available and interoperable across the payment and delivery system. ***Families USA strongly supports CMS's proposal to implement financial penalties for health care providers engaging in data blocking.***

Although Families USA applauds the direction HHS is taking to reduce data blocking practices across the health care system, it is important to note that some providers that treat low-income, Black and brown, immigrant and largely Medicaid-covered patient populations tend to have fewer financial resources to implement data sharing systems.<sup>7</sup> These limited resources coupled with a robust financial penalty could disproportionately impact some providers who treat lower-income and historically marginalized populations. **As a result, Families USA recommends that CMS administer corrective action plans prior**

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<sup>1</sup> 88 FR 74947, <https://www.federalregister.gov/documents/2023/11/01/2023-24068/21st-century-cures-act-establishment-of-disincentives-for-health-care-providers-that-have-committed>

<sup>2</sup> Landi, Heather, "Fewer than 4 in 10 health systems care successfully share data with other hospitals, survey finds," Fierce Healthcare, August, 2019. <https://www.fiercehealthcare.com/tech/fewer-than-4-10-health-systems-can-successfully-share-data-other-hospitals>; and "Information Blocking: What is it and Why You Need to Care," Konica Minolta, January, 2023. <https://kmb.konicaminolta.us/blog/information-blocking>.

<sup>3</sup> HealthIT.gov, "Information Blocking," The Office of the National Coordinator for Health Information Technology, November, 2023. <https://www.healthit.gov/topic/information-blocking>.

<sup>4</sup> HealthIT.gov, "Information Blocking," The Office of the National Coordinator for Health Information Technology, November, 2023. <https://www.healthit.gov/topic/information-blocking>.

<sup>5</sup> "Information Blocking: What is it and Why You Need to Care," Konica Minolta, January, 2023. <https://kmb.konicaminolta.us/blog/information-blocking>.

<sup>6</sup> "Evidence on the Costs and Benefits of Health Information Technology," Congressional Budget Office. <https://www.cbo.gov/sites/default/files/cbofiles/ftpdocs/91xx/doc9168/maintext.3.1.shtml>; and Adler-Milstein, Julia and Eric Pfeifer, "Information Blocking: Is It Occurring and What Policy Strategies Can Address It?," The Milbank Quarterly, March, 2017. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5339397/>

<sup>7</sup> Yearby, R., Clark, B., & Figueroa, J. F. (2022). "Structural racism in historical and modern US health care policy." Health Affairs, 41(2), 187–194. <https://doi.org/10.1377/hlthaff.2021.01466>

**to administering financial penalties for certain providers who disproportionately serve low-income, Black and brown and immigrant populations.**

Importantly, we also encourage CMS to take additional steps to avoid unintended consequences that could lead to patient harm if appropriate patient privacy and security steps are not taken. The Supreme Court's decision to overturn *Roe v. Wade* has led to several states imposing laws and regulations that increase the surveillance and criminalization of pregnancy outcomes.<sup>8</sup> As a result, there is a significant risk that sharing health care data about a patient's sexual and reproductive health care could put the patients' health and safety at risk or even lead to prosecution, detention, and convictions in some cases. Similar to legal requirements under 42 CFR Part II that protect patient substance use disorder treatment data, and some state privacy laws that protect mental health and HIV status data, we believe it is critical to also protect patients' reproductive, sexual and gender affirming health care data. Given that the Health Insurance Portability and Accountability Act does not sufficiently protect patient health care data in states that have criminalized abortion and gender affirming health care, **we recommend that HHS and CMS take steps to protect patient privacy for sensitive health care data- including information related to abortions, sexual and reproductive, and gender affirming care- to ensure the exchange of this data between providers cannot be used in a discriminatory or criminal manner.**<sup>9</sup>

### **III. B. 3.: Approach to Determination of Information Blocking and Application of Disincentives- Transparency for Information Blocking Determinations, Disincentives, and Penalties**

Families USA supports CMS's proposal to establish a process for the Office of the National Coordinator (ONC) to publish information on their website and disclose the names, business addresses, and level of penalty for health care providers, health information networks and exchanges, and health IT developers found to have engaged in information blocking. We believe disclosing this information to the public is a key step in not only unveiling the degree to which health care data is currently being blocked but it also creates an additional incentive for these health care entities to refrain from engaging in health care information blocking. This level of transparency around data blocking will also help to further inform future policymaking to ensure that health care data is flowing and driving high value care across the health care system. **As a result, we support CMS's proposal to increase transparency into the actors participating in information blocking.**

We thank CMS for the opportunity to comment on this proposed rule and are encouraged by the Department's work to address this critical issue to drive towards higher value health care for our nation's families, workers, and employers. If there are any further questions, please contact Sophia Tripoli, Senior Director of Policy at Families USA, at [stripoli@familiesusa.org](mailto:stripoli@familiesusa.org).

Sincerely,



Sophia Tripoli  
Senior Director of Health Policy

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<sup>8</sup> Deal, Laura, "State Laws Restricting or Prohibiting Abortion," Congressional Research Service, March, 22, 2023, <https://crsreports.congress.gov/product/pdf/LSB/LSB10779>

<sup>9</sup> Boodman, E., Bannow, T., Herman, B., & Ross, C. (2022, June 24). "Hippa won't protect you if prosecutors want your Reproductive Health Records." STAT. <https://www.statnews.com/2022/06/24/hipaa-wont-protect-you-if-prosecutors-want-your-reproductive-health-records/>