

A driving force for health equity

Submitted via email to VRDCRFI@cms.hhs.gov

May 3, 2024

Chiquita Brooks-LaSure Administrator Centers for Medicare & Medicaid Services 7500 Security Boulevard Baltimore, MD 21244

Re: Request for Information on Research Data Request & Access Policy Changes

Dear Administrator Brooks-LaSure,

On behalf of OCHIN, we welcome the opportunity to provide feedback on the policy changes regarding Research Data Access for CMS data.

OCHIN is a <u>national nonprofit health information technology and research network</u> that offers technology solutions, informatics, evidence-based research, and policy insights. OCHIN serves nearly 2,000 community health care sites with 25,000 providers in 40 states, reaching more than 8 million patients. Our network is comprised of federally qualified health centers (FQHCs), community health clinics, Ryan White HIV/AIDS Program Health Centers, school-based health clinics, certified community behavioral health clinics (CCBHC), Tribal health clinics, local public health agencies, and critical access hospitals.

Importantly, OCHIN has a robust research department that includes over 60 staff members who partner with over 25 research partners across the country on nearly 60 active research projects. OCHIN also serves as the lead for the Accelerating Data Value Across a National Community Health Center Network (ADVANCE) one of the eight clinical research networks funded by the Patient-Centered Outcomes Research Institute (PCORI). Through this work, OCHIN frequently engages with data linkage to enhance the research studies led by our research scientists and research partners. These studies are critical to advancing health equity in the United States.

We are writing to express our concerns regarding the policy changes in requesting and accessing CMS data for research. We are concerned with the proposal that all CMS research data must be stored and analyzed in the Chronic Conditions Warehouse Virtual Research Data Center (CCW VRDC) and the added administrative costs driven by this change. Given the often-fragmented care for systemically disadvantaged patients, linking claims data with primary care electronic health record data is critical for health equity research. For OCHIN-led and support research studies that use CMS data the proposed policy would require that this EHR data be transferred and analyzed in the VRDC environment. In addition to the increased security and privacy efforts that would need to happen, the added technical storage needed for this volume of data will dramatically impact the cost of research studies.

As specifically requested in the RFI, we note that the analysis in the VRDC would be an added cost for OCHIN organizationally as it does not allow us to reduce any operational costs as some academic institutions may be able to through shifting costs from internal data centers to the VRDC. In addition to

this specific cost addition and the other VRDC costs (e.g., the seat fee for a researcher), the new Project Fee structure further places an economic burden on conducting this research that will result in a reduced ability to work with CMS data. Organizations like OCHIN that represent safety net organizations are primed to lead health equity research studies. The proposed changes will make it financially infeasible for us, and many other partners, to work with CMS data: hampering health equity research. We urge CMS to reconsider these policy changes and develop alternative pricing models for non-profit safety net organizations.

We would also like to take this opportunity to highlight OCHIN's continued encouragement of CMS-led, harmonized, up-to-date, national datasets. To advance health equity, there is a need for data that can help reflect the patient care continuum under a fragmented system. For example, being able to link OCHIN member patient's electronic health record data with national, up-to-date Medicaid claims would greatly bolster the ability to study care and outcomes for some of the most systemically underserved patients. Please do not hesitate to contact us with any questions.

Sincerely,

Jennifer Stoll Chief External Affairs Officer External Affairs OCHIN