

March 27, 2024

Chiquita Brooks-LaSure, M.P.P.
Administrator
Centers for Medicare and Medicaid Services
7500 Security Boulevard Baltimore, Maryland 21244

RE: Research Data Request and Access Policy Changes

Dear Administrator Brooks-LaSure:

I am writing on behalf of Research!America, a national, nonprofit, and nonpartisan organizational alliance that spans patient organizations, research universities, scientific societies, the pharmaceutical and medical device industries, independent research institutions, academic health centers, and philanthropies. We advocate for the funding and policy environment needed to accelerate scientific, medical, and public health progress. Thank you, Administrator Brooks-LaSure, for your considered stewardship over Medicare, Medicaid, and the Children's Health Insurance program. We appreciate your decision to expand the request for information on the Center for Medicare and Medicaid's proposed research data request and Access policy changes to include data access fees and timing of these fees, and we offer our input below.

Research! America is deeply concerned that the proposed changes with have a significant negative impact on the volume, reach, scope, and pace of research critical to continuous improvement in health and health care.

The implications of compromised access to data bear on the fundamental goals of healthcare quality, access, and affordability. Our nation is needlessly forsaking lifesaving healthcare quality improvements and urgently sought healthcare savings by underutilizing health services and health economics research. It is estimated that our nation could simultaneously reduce health care expenses by \$1 trillion per year and improve healthcare quality and outcomes if research is put to work to optimize healthcare delivery. In addition to the need for a greater federal funding commitment to health research, our nation cannot tackle this trillion-dollar challenge unless researchers have access to the data they need to understand and identify potential refinements to the current system.

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Further, despite disturbing crosswinds, the research community is committed to expanding and deepening the societal impact of research by fostering racial, ethnic, socioeconomic, and geographic diversity in the research ecosystem. Affordable access to data is a critical piece of this puzzle, and we are concerned that the proposed policy changes will create steep obstacles to data access that disproportionately affect communities currently and counterproductively underrepresented in the health research community.

We are confident that working collaboratively, CMS and the research community can identify a positive path forward. We respectfully request that the Centers engage the community to forge this consensus approach rather than moving forward with the current proposal.

Thank you for considering our views, Administrator Brooks-Lasure. Please call on Research!America if we can be of assistance going forward.

Sincerely.

Eleanor Dehoney

Senior Vice President

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Policy & Advocacy

Research!America