March 22, 2024

Allison Oelschlaeger
Chief Data Officer and Director
Office of Enterprise Data and Analytics
Centers for Medicare & Medicaid Services
7500 Security Boulevard
Baltimore, MD 21244

Re: Pricing Changes for Physical Delivery of Research Files

Dear Chief Data Officer Oelschlaeger:

On behalf of the American Cancer Society (ACS) and the American Cancer Society Cancer Action Network (ACS CAN) we write to express concern with the implementation of new pricing changes for physical delivery of research files. ACS is a nationwide, community-based, voluntary health organization dedicated to eliminating cancer as a major health problem by preventing cancer, saving lives, and diminishing suffering from cancer through research, education, advocacy, and service. The American Cancer Society, operating through its national office and 6 geographic regions throughout the United States, is the largest voluntary health organization in the United States. ACS CAN is the nonprofit, nonpartisan advocacy affiliate of ACS, supporting evidence-based policy and legislative solutions designed to eliminate cancer as a major health problem. ACS CAN is making cancer a top priority for public officials and candidates at the federal, state, and local levels, and empowering advocates across the country to make their voices heard and influence evidence-based public policy. **We strongly urge CMS to halt any pricing changes to the physical delivery of research files, which is slated to be implemented as of August 19, 2024.**

ACS and ACS CAN are concerned the new pricing structure for research files will have a devastating impact on the ability of entities like ACS to conduct vitally important research. CMS data are an essential resource for studying cancer screening, diagnosis treatment spending, survival, and quality of life after a cancer diagnosis. Access to CMS data is key to research that helps to develop policy solutions in line with the Administration's Cancer Moonshot initiative to prevent cancer and improve the lives of individuals touched by cancer.

ACS's department of Surveillance and Health Equity Science is among the hundreds of users of the linked SEER cancer registry data and Medicare claims data purchased from the National Cancer Institute. We routinely use these data to examine patterns of care before and after cancer diagnosis and associated spending. ACS's department of Population Science has the unique ability to answer important questions using Cancer Prevention Study-II cohort data together with Medicare claims data. Specifically, we are filling a gap within cancer survivorship research, aiming to understand the role of health behaviors, medications, health history, and demographics in the postdiagnosis development of various adverse health outcomes.

We believe that the proposed changes in the *Research Data Request and Access Policy* will seriously harm our research, if not halt it entirely. As a non-profit organization reliant on donations, **we will be unable to afford separate license fees for each researcher to access data on VRDC, and thus will be excluding many of our researchers from using CMS data**. As an evidence-based organization, this will have a profound, long-term impact on the quantity of research we publish. ACS is currently committed to making significant investments in grants for research projects using CMS data. These projects are focused on health equity and underserved populations. The pricing change could jeopardize this investment in researchers across the country.

We are further concerned that the proposed changes in the pricing structure will further drive inequity in research, as the burden of the new rules is even greater for students and junior researchers, who will undoubtedly be the first to lose access to CMS data. Thus, the pricing changes will significantly disrupt the training of the next generation of researchers, which will have a profound long-term impact on the field as a whole.

We share CMS' concerns about data privacy and security reviews. As stewards of sensitive Cancer Prevention Study-II participant data (including addresses, diagnoses, and social security numbers), maintaining the highest standards of data security is paramount. However, we are concerned that the new policy would likely prohibit the ability to conduct research combining data from the Cancer Prevention Study-II and Medicare data. Specific to our research, **a lack of physical access to individual-level data means that we would need to upload our participants' private information to the VRDC to use alongside Medicare claims data, which will be infeasible and potentially unethical due to the inadequacy and restrictions of the VRDC environment.**

Data accessibility and research productivity does not need to be sacrificed in the name of data security. **We strongly urge CMS to halt the imposition of any new changes related to imposition of the new pricing structure and the limitations on access to physical data files until such time as CMS has had an opportunity to consider the effect this policy would have on the long-term research projects.** We welcome the opportunity to meet with you and your staff to discuss our concerns.

If you have any questions, please feel free to contact us or have your staff contact Robin Yabroff, Scientific Vice President, Health Services Research at Robin.Yabroff@cancer.org or Anna Schwamlein Howard, Policy Principal, Access and Quality of Care at Anna.Howard@cancer.org.

Sincerely,

William Dahut, MD
Chief Scientific Officer
American Cancer Society

Lisa A. Lacasse, MBA
President
American Cancer Society Cancer Action Network