

Response to the Request for Information on

Social Security Administration's Plan for Increasing Public Access to the Results of Federally Funded Scientific Research

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Contents

Introduction	1
Response.....	1
1. Scope and Applicability—Our public access plan defines the scope of what research will be publicly accessible, including limitations to protect privacy of personally identifiable information. As we implement our public access plan, is there additional public access we should consider?	1
2. Digital Repositories—We will require that federally funded scientific research results are publicly accessible for free, including final scientific research reports, peer-reviewed scholarly publications, and the underlying scientific research data used to produce reports and publications, to the extent permitted by applicable law. We will require that final research publications are permitted to be available in an SSA-designated repository that we will select in 2024. Underlying scientific research data must be deposited in a repository and in a form that meets SSA’s requirements. What types of digital repositories do researchers prefer for providing public access to research data? What should SSA consider as we develop requirements for which data repositories researchers may use?	2
3. Costs—For the expenses that researchers incur for providing public access, we may allow reasonable costs as part of a contract, grant, cooperative agreement, or other research award. What information is available to help us estimate the costs associated with providing public access to scientific research publications and data? How can we minimize those costs to maximize the funds available for research awards?	2
4. SSA Research Information and Training—Our public access plan provides information about our existing website where we describe our research programs. We will consider providing a new web page as a single point of access for information about our research programs, including how to find publicly accessible research publications and data. What information, guidance, or training about public access could we provide to help researchers and their institutions, beginning with applying for a research opportunity through the time of final publication?	3
5. Equitable Research—How can we ensure equity in research opportunities and access as we implement public access requirements, and what challenges might certain institutions face with public access, including costs and publishing opportunities?	3

Response to the Request for Information on Social Security Administration's Plan for Increasing Public Access to the Results of Federally Funded Scientific Research

Introduction

Mathematica welcomes the opportunity to respond to the Request for Information on the Social Security Administration's (SSA's) Plan for Increasing Public Access to the Results of Federally Funded Scientific Research. We appreciate the tension between transparency, stewardship of public resources, and privacy protection. In what follows, we offer our thoughts in response to the specific questions posed by SSA as it works toward finalizing its public access plan.

Our responses are informed by our work as researchers on projects funded by SSA and by our considerations about how the work we do is made accessible to others in the research community. We believe that making data files available will be most salient to other researchers. Yet an important consideration for the access plan is making data available to the public, including program participants, practitioners, and media. SSA should consider ways not only to make data available but also accessible to members of the public.

Response

- 1. Scope and Applicability—Our public access plan defines the scope of what research will be publicly accessible, including limitations to protect privacy of personally identifiable information. As we implement our public access plan, is there additional public access we should consider?**

We recommend that SSA consider excluding individual-level qualitative research from the public access plan because the data may be difficult to store in a way that sufficiently protects respondent privacy. This exclusion would apply to interviews with beneficiaries, service providers, and SSA staff. Even removing personally identifiable information, responses during interviews might still leave a particular entity identifiable based on a pattern of data or information about its contextual factors. Additionally, we are concerned that plans to publicly release individual responses to surveys and interviews might make people less likely to participate in data collection efforts or less candid in their responses. It would be possible to include summary information from qualitative interviews after coding responses, but doing so would require careful assessment to make a determination about privacy protections before posting publicly.

It is unclear whether SSA's plan would require that researchers using secondary data release derivative files they used to conduct their analyses, or whether simply citing the source where other researchers can access the data publicly would be sufficient. For example, if a researcher conducted a study using the Current Population Study (CPS), would they be expected to post their final analysis file, limited to their study population and constructed variables, or would referencing the CPS be sufficient? If the former, researchers must understand the expectations for preparing data files as part of their research, and clear parameters will be critical for developing the resources necessary to support data file development. Additionally, some publicly available data sources may have limits on repackaging derivative files that will be important to consider when developing access plans.

Finally, SSA should establish expectations for research using linked survey-administrative records such as the Health and Retirement Study-Social Security Administration, CPS-Social Security Administration, or Survey of Income and Program Participation-Social Security Administration files. Researchers working with these files must abide by data sharing requirements set with the University of Michigan or Census Bureau and, based on those requirements, will not be permitted to release data files used for their analysis. There are other examples of files for which researchers have permission to conduct research and release deidentified summary statistics but not individual data; these types of cases will need to be accounted for in SSA's access plan.

- 2. Digital Repositories—We will require that federally funded scientific research results are publicly accessible for free, including final scientific research reports, peer-reviewed scholarly publications, and the underlying scientific research data used to produce reports and publications, to the extent permitted by applicable law. We will require that final research publications are permitted to be available in an SSA-designated repository that we will select in 2024. Underlying scientific research data must be deposited in a repository and in a form that meets SSA's requirements. What types of digital repositories do researchers prefer for providing public access to research data? What should SSA consider as we develop requirements for which data repositories researchers may use?**

The University of Michigan's Inter-university Consortium for Political and Social Research (ICPSR) is an established repository familiar to many researchers in the social sciences and related disciplines. SSA might consider storing data in the ICPSR repository. Alternatively, SSA might want to use the ICPSR requirements as a basis for their requirements for data file documentation and storage, and could work with ICPSR to cross-list data the agency houses so that they are searchable by researchers working with the ICPSR database. Posting in or cross-referencing with the ICPSR repository would increase the likelihood that other researchers would find SSA-funded data products and that the procedures to document the files would follow established practices that ICPSR has developed over decades.

- 3. Costs—For the expenses that researchers incur for providing public access, we may allow reasonable costs as part of a contract, grant, cooperative agreement, or other research award. What information is available to help us estimate the costs associated with providing public access to scientific research publications and data? How can we minimize those costs to maximize the funds available for research awards?**

Although costs certainly should not preclude the release of information to the public, we have concerns about the costs and resource intensity. This could be especially true for Retirement and Disability Research Consortium (RDRC) and Analyzing Relationships Between Disability, Rehabilitation, and Work (ARDRAW) projects, which generally have modest budgets. Preparing files to be included in an online repository—with sufficient documentation to be useable by other researchers—is not a trivial undertaking, and the additional responsibility will likely increase per-project costs substantially. The same will be true for paying for open access to research publications in journals, where the fees associated with guaranteeing indefinite open access can be in the thousands of dollars. The current ARDRAW and many RDRC project budgets will not be sufficient to produce data files and cover open access fees, and increasing the per-project budget will mean that SSA will be able to fund fewer research studies.

To minimize costs, SSA should consider defining in advance the requirements for data documentation and disclosure review and, to the extent possible, identify definitive criteria for acceptable products. Currently, SSA's Program Data Disclosure Review Board (PDDRB) offers a checklist for consideration as a way to begin the disclosure review process, but meetings with the committee to verify that disclosure risk has been mitigated can be intensive. To be sure, this process ultimately protects privacy, but it is quite resource intensive for both researchers and SSA staff. If every study funded by SSA went through this process, PDDRB staff capacity would likely not be sufficient to meet demand, unless the criteria could be better defined in advance. Additionally, our understanding is that the current PDDRB guidelines are primarily focused on quantitative research. If SSA had a similar PDDRB review process for qualitative data, it would likely need a different checklist with separate criteria.

4. SSA Research Information and Training—Our public access plan provides information about our existing website where we describe our research programs. We will consider providing a new web page as a single point of access for information about our research programs, including how to find publicly accessible research publications and data. What information, guidance, or training about public access could we provide to help researchers and their institutions, beginning with applying for a research opportunity through the time of final publication?

SSA may wish to leverage its existing partner organizations as a way to disseminate information about public access. Across the RDRC and ARDRAW program, SSA could reach research staff in dozens of universities and research institutions, including a more recent effort to engage researchers from minority-serving institutions. SSA could also use its annual RDRC meeting to highlight opportunities and to learn about data access. Additionally, SSA may wish to partner with the National Institute on Disability, Independent Living, and Rehabilitation Research, which funds many researchers interested in disability policy through its Rehabilitation Research and Training Centers and Disability and Rehabilitation Research Projects. These researchers are often interested in SSA programs and policies and come from a range of institutions that do not fully overlap with SSA-funded institutions. SSA should consider the institutions that might not be included in its typical outreach efforts, including a broader range of minority-serving institutions and researchers with disabilities, and make deliberate efforts to reach these institutions. SSA's National Disability Forums may offer an avenue for broader dissemination and outreach as the access plan is solidified.

SSA should ensure that publicly available research products and files comply with best practices in digital accessibility, including alternative text for graphic elements, such as charts and graphs, and captions and ASL interpretation for videos and webinars. As accessibility to the public rests on plain language, SSA should consider helping researchers with plain and publicly accessible language that makes it easier for the public to read and understand the agency's programs.

5. Equitable Research—How can we ensure equity in research opportunities and access as we implement public access requirements, and what challenges might certain institutions face with public access, including costs and publishing opportunities?

Releasing data to comply with the new requirements will be onerous for researchers but will become easier with experience. Certain groups that already have a standing relationship with SSA will be able to meet the requirements with lower costs over time, whereas others may find meeting the requirements both challenging and costly. This disparity could reduce the likelihood that marginalized groups, institutions, and new researchers will seek to conduct research with SSA.

SSA could consider devoting resources to effectively subsidize or more fully support researchers new to the agency's processes to comply with the requirements. For example, researchers submitting an ARDRAW or RDRC project could increase their budget by a prespecified amount set by SSA to support documenting and posting their data files. The agency must also make accommodations available to support researchers with disabilities to comply with any public access requirements.

People with disabilities should be front and center in SSA's plan to increase public access, including researchers with lived experience of disability. This means ensuring that the materials needed to prepare data files are accessible by people with a range of disabilities, and that the processes and technology used to document and store data are also accessible.

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