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National Institutes of Health  
Office of Science Policy  
Building One  
Bethesda, Maryland 20892

Delivered to: <https://osp.od.nih.gov/rfc-draft-supplemental-information-to-the-nih-policy-for-dms/>

To whom it may concern:

On behalf of the organizations we lead, the Population Association of America and Association of Population Centers, we are pleased to submit comments in response to “Request for Public Comments on DRAFT Supplemental Information to the NIH Policy for Data Management and Sharing: Protecting Privacy When Sharing Human Research Participant Data” (NOT-OD-22-131).

Our organizations jointly represent about 3,000 individual population scientists—including demographers, economists, sociologists, and epidemiologists—as well as approximately 40 federally funded interdisciplinary research centers. Population scientists study the individual, societal and environmental implications of population change—and thus contribute key findings that help inform evidence-based policy making in the public and private sectors. Population research centers facilitate interdisciplinary research on a range of topics including mortality, morbidity, fertility, adolescent health, aging, population forecasting, immigration, labor and workforce policies, family dynamics, and human-environmental interactions. They also train emerging and early career scientists. We also have unique expertise regarding data collection, management, and archiving, and our field embraces data sharing as a central principle.

The National Institutes of Health is the primary source of competitive, discretionary grant funding supporting the population sciences. To that end, our organizations serve on NIH study sections, working group, and advisory councils and provide comments, both formal and informal, on a variety of NIH proposals, including its evolving data management and sharing policy.

We appreciate the opportunity to respond to this latest request for comments that NIH has issued to inform its goal of developing a set of principles and best practices for protecting the privacy of research participants when sharing data under the NIH Policy for Data Management and Sharing.

[from Roz] Please continue to speak up about deductive disclosure. Please also continue to speak up about the need for documentation and the effort (with corresponding costs) involved in producing it so that it serves the needs of junior investigators with less experience in secondary analysis. Finally, I would say that our researchers have particularly valuable insights into bringing together data from multiple sources, including administrative/government sources, mobile devices, social media, and biomarkers collected in community settings (e.g., outside clinical settings).

Sincerely,

Dr. Sonalde Desai

Handwritten signature of Sonalde Desai in black ink.

President  
Population Association of America

Dr. Sara R. Curran

Handwritten signature of Sara R. Curran in blue ink.

President  
Association of Population Centers