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December 14, 2023

Submitted electronically at: datascience.nih.gov/rfi-rwd

To whom it may concern:

On behalf of the members of the Population Association of America (PAA) and Association of Population Centers (APC), we are pleased to respond to a request from the National Institutes of Health (NIH) for public comments on the agency's use of Real-World Data (RWD), including Electronic Health Records, for Biomedical and Behavioral Research.

As you may know, PAA and APC are two affiliated organizations that together represent over 3,000 social and behavioral scientists and the over 40 population research centers that receive federal funding and conduct research on the implications of population change. Our members, which include demographers, economists, sociologists, and epidemiologists, conduct scientific and applied research, analyze changing health, demographic, and socio-economic trends, develop policy and planning recommendations, and train undergraduate and graduate students. Their research expertise covers a wide range of issues, including adolescent health and development, aging, health disparities, immigration and migration, marriage and divorce, education, social networks, housing, retirement, and labor. NIH is the primary source of competitive, discretionary grant funding supporting the population sciences. As a result, PAA and APC monitor and often respond to proposed changes governing NIH extramural research activities and resources.

We appreciate the NIH proactively seeking input from stakeholders regarding the opportunities and challenges that the use of RWD presents. Given the expertise population scientists possess about collecting, linking, disseminating, and storing data, our field is eager to be a resource on the complex administrative, scientific, and ethical issues facing the NIH with respect to the use of RWD in biomedical and behavioral research.

Of paramount importance to the population research community is the degree to which its health-related data platforms include RWD data that are population based and signify a well-defined community. NIH supported platforms should include linked data with a clear description of who they represent. Volunteer samples, clinic samples and cohorts recruited via social media campaigns, for example, are biased and, therefore, not representative of well-defined populations. In its platforms, we encourage the NIH to be transparent about the nature of its RWD and to clarify the origin of the data and their potential

limitations.

A major tenet of the population research community is its commitment to ensuring data are publicly available. We urge the NIH to follow our community's example and uphold data accessibility in any future guidelines governing the development and management of platforms housing RWD.

Thank you for considering our views. Please do not hesitate to contact us if our organizations can be of further assistance.

Sincerely,

Handwritten signature of Dr. Lisa Berkman in black ink.

Dr. Lisa Berkman
2023 PAA President

Handwritten signature of Dr. Jennie Brand in black ink.

Dr. Jennie Brand
2023-2024 APC President