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May 10, 2021

The National Institutes of Health
1 Center Drive
Bethesda, MD 20892

Response to: NOT-LM-21-005, Request for Information (RFI): Use of
Common Data Elements (CDEs) in NIH-funded Research

To whom it may concern:

On behalf of the Population Association of America (PAA)
(www.populationassociation.org) and Association of Population Centers
(APC), we are pleased to provide comments in response to the National
Institutes of Health (NIH) Request for Information regarding the use of
Common Data Elements (CDE) in NIH funded research.

The PAA and APC are two affiliated organizations that together represent
more than 3,000 population scientists, an interdisciplinary field that includes
demographers, sociologists, economists, epidemiologists, and statisticians,
who study the implications of population change. The APC is comprised of
the over 40 federally supported population research centers based nationwide
at universities and private research institutions. Population scientists have
made groundbreaking and meaningful contributions on a wide array of topics
relevant to society, including the social determinants of health, child and
adolescent development, aging, migration, fertility, economic well-being,
education, retirement, and post-disaster resiliency.

As population scientists, most of our data come from large, government-
collected or supported surveys or registries. Our members are very involved
in developing surveys, testing respondent strategies, and making
comparisons across large population surveys. Our scientists also value the
ability to compare across sub-groups of the population, time, and countries.
Our scientists both contribute towards and consult existing data repositories,
including the NIH Common Data Elements (CDE) Repository. For these
reasons, we are supportive of the dissemination and use of CDE.

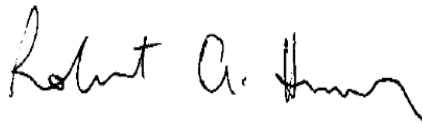
Our organization has recently demonstrated its support of sharing data
collection protocols, particularly for large, national studies. Early in the
COVID pandemic, we held large webinars with survey developers and asked
them to submit their instruments to the PhenX Toolkit: COVID-19 library
and NIH Public Health Emergency and Disaster Research Response (DR2)
so that scientists developing questionnaires could harmonize this new area of
work. This approach was very useful to the community and will lead to
more comparable data on COVID.

Because population scientists generally include elements in surveys that have been previously validated, they are likely to consult repositories like the CDE for new items in this process. However, existing questions do not always match the scientific needs for a given population being studied and the time requirements for existing batteries may be cost prohibitive in the context of a large survey with multiple content areas. As a result, our members often must develop new data elements to suit their scientific goals. This flexibility is essential for scientific progress. Therefore, we strongly urge that CDE content should not be proscriptive, but rather suggestive. Moreover, new CDE development should consider existing items in large representative studies to maximize comparative value.

In sum, the existing CDE has been of modest use for our community, but we support the idea of sharing protocols to facilitate use by the scientific research community in general.

Thank you for considering our views.

Sincerely,



Dr. Robert A. Hummer
President
Population Association of America



Dr. Sara R. Curran
President
Association of Population Centers