

DRAFT PAA/APC Responses to NICHD STRIVE Idea Scale

1. What obstacles impede advancing health disparities research for NICHD populations?

- Data shortcomings severely limit health disparities research for NICHD populations. These shortcomings include and are not limited to: limited funding for prospective large-scale, population-level, longitudinal surveys of children, mothers and families; and, limited access to, and availability of, integrated administrative data about infant and child, mother and family health behavior, care, conditions, and outcomes. For the former, many surveys are not sufficiently large in sample size to afford significant observation of health disparities, as well as unable to afford detailed investigations of the complex set of mechanisms explaining health disparities. For the latter, limited information about social disparities is captured in administrative data and these data are not consistently available and accessible across the country to allow for high quality scientific investigations to inform population health disparities insights.
- Demographers and population researchers can provide valuable methodological and substantive expertise to multi-investigator teams and are rarely included or called upon. This is a major obstacle to advancing health disparities research, since demographers understand well how to measure social disparities and to model its causes and consequences.
- Omission of gender disparities, as part of the overall health disparities research portfolio, severely hampers advancing health disparities research. Gender, race, and ethnicity intersect. This means that black men's health care, conditions, behavior and outcomes are significantly different from white men or black women. Ignoring these differences by not collecting large enough samples that allow for these comparisons then limits research advancement. Research initiatives should encourage scientists to develop proposals that recognize these intersections and important population variation.
- As with gender, income, wealth, educational attainment, and family structure are measures that NICHD should be encouraging scientists to use to advance greater understanding of structural health disparities.

2. What innovative or novel approaches to research could be leveraged to mitigate health disparities in NICHD populations?

- Population-level, demographic analyses are needed to address underlying causes and consequences of health disparities. Longitudinal and multi-level analyses of prospective large-scale, population-level, longitudinal surveys of children, mothers, and families, as well as longitudinal analyses of integrated administrative data about infant and child, mother and family health behavior, care, conditions, and outcomes. There is rapidly developing analytic tools for this research being developed by demographers, economists, and geographers that should be put to the task of this effort.
- Need the social, behavioral, and economic sciences working jointly with the biomedical sciences, as co-leads on research projects, to ensure our expertise is tapped. Mechanistic changes are needed to stimulate and sustain these interdisciplinary collaborations.

3. What are the best opportunities to broaden community engagement in the research process?

- Communities are often asking for access to data to use to understand their communities. We can partner with people doing community engaged work to determine how to collect these data (e.g., understanding COVID infection rates in prisons and jails and spread to communities). Demographers are regularly part of teams developing visualization tools for seeing data from different perspectives and these tools can be made available to communities.
- Additionally, mechanisms might be developed to support the time of community members and researchers to collaborate on asking research questions, compiling and analyzing data, and translating results for broader dissemination. For example, it would be invaluable to develop supportive mechanisms for understanding racial disparities in genetic testing and timing of genetic testing.

4. What are some examples of community engagement models to strengthen health disparities research efforts (such as models for partnerships, collaboration)?

- PAA has a built-in organizational relationship with the Federal and State Cooperative for Population Estimates (FSCPE) and they already do community work by mandate. This is the type of internal org that PAA can leverage on behalf of the STRIVE initiative.

5. What resources (e.g., tools, technology, human capital) are needed to advance the field of health disparities research for NICHD populations?

- Increase support for large-scale data collection, improve data access, support visualization tools, support applications that explicitly include demography in the development of health disparities research, and include demographers in the development of major new health disparities research initiatives.
- NICHD should support the development of a collection of broad literature reviews that address the need and shortcomings in health disparities research. These reviews should be peer reviewed and conducted before more initiatives are developed, to fully understand the existing knowledge base and identify gaps in our scientific knowledge and community engagement. We understand NICHD may have the funds, internally, to support this activity.