

February 3, 2020

Submitted via email (feedback@phenx.org)

National Institute on Minority Health and Health Disparities

Re: Social Determinant of Health (SDOH) Measures Proposed for Inclusion in the PhenX Toolkit

To Whom It May Concern,

The Association of American Medical Colleges (AAMC) appreciates the opportunity to comment on the National Institute of Minority Health and Health Disparities' proposed 'social determinants of health' (SDOH) supplement for addition to the PhenX Toolkit. The AAMC applauds the effort to standardize the collection of social factor data in order to build the evidence base of solutions to health inequities and facilitate population and community health science. The AAMC is a not-for-profit association representing all 154 accredited U.S. medical schools, nearly 400 major teaching hospitals and health systems, and more than 80 academic and scientific societies. These institutions conduct over half of the research funded by the National Institutes of Health (NIH), and through these institutions and organizations the AAMC represents nearly 173,000 faculty members, 89,000 medical students, 129,000 resident physicians, and more than 60,000 graduate students and postdoctoral researchers in the biomedical sciences.

In lieu of specific feedback on each proposed survey tool and questionnaire, we are pleased to provide the general comments below.

1. The AAMC encourages NIMHD/PhenX to separate measures that assess community-level SDOH from those that assess individual level health-related social needs (HRSN).

Some of the proposed measures assess social factors at an aggregate, geographic level (for example, environmental justice, air quality index, social vulnerability, etc.) while others focus on individual-level social risk factors known to be related to a person's health or health care outcomes (for example, numeracy, job insecurity, food insecurity, etc.). Epidemiologists and population health scientists refer to the former as SDOH and the latter as HRSN. Importantly, some variables can be assessed at either the HRSN or SDOH level (for example a person's household income versus his/her community's median income) and each can have direct and independent impacts on health and health care outcomes. For clarity's sake, we encourage NIMHD/PhenX to separate these measures into two distinct categories.

2. The AAMC strongly supports the identification of measures that are accessible to, and useful for, measurement across diverse communities.

In our review of the proposed measures, we noted that most are only available in English. This will significantly curtail applicability of the measures to non-English speakers, limiting research participant diversity and therefore external validity. Similarly, some of the proposed tools are grammatically or numerically complex (the numeracy measure and the household wealth measure, in particular.) We strongly urge the Working Group to redouble efforts to identify and include tools and survey items that have been validated in multiple languages and that require no more than a 6th grade level of comprehension.

3. The AAMC suggests attention be drawn to the geographic unit assessed by the proposed SDOH measures.

While we are pleased that aggregate, SDOH measures are to be included in PhenX, we are also mindful that the geographies to which they aggregate are distinct and potentially of varying scientific benefit. Ideally, all SDOH measures would map on to geographic units meaningful to the study participants ('neighborhoods' or 'blocks', for example). While some of the proposed SDOH measures are available at the census tract or block level and therefore might accurately reflect the lived experience of potential research participants, others are only available at the 5-digit zip code or county level, limiting their relevance – particularly in population-dense areas wherein a zip code might contain multiple neighborhoods with diverse and distinct SDOH and HRSN profiles. We encourage NIHMD to prioritize SDOH measures available at the census block or tract, and, at the very least, indicate for PhenX users some of the potential limitations of zip code- or county-bounded measures.

4. The AAMC strongly encourages that NIMHD/PhenX develop and disseminate guidance concerning the ethical imperative researchers may have to refer participants who screen positive for serious HRSN and SDOH.

The AAMC is mindful that research participants screening positive for food insecurity and other proposed social factor measures may need immediate referrals and/or assistance in order to be safe. Researchers have an ethical obligation to ensure, to the best of their abilities, the health and well-being of their study participants. We ask for the inclusion of specific guidance and resources to assist researchers using the PhenX database in making appropriate, timely referrals for social and other services for participants who report health harming social needs or determinants.

The AAMC's Health Equity Research and Policy team would be happy to discuss these comments and other aspects of SDOH and HRSN data collection. Please feel free to contact me directly or my colleague Philip M. Alberti, PhD, Senior Director, Health Equity Research and Policy, at palberti@aamc.org.

In addition, should PhenX and/or NIMHD find it useful to engage health equity scientists and scholars more broadly in this work – and with greater focus on specific measures – we would be more than willing to provide you an opportunity to discuss this effort with participants in AAMC’s Collaborative for Health Equity: Act, Research, Generate Evidence (CHARGE) group.

Sincerely,

A handwritten signature in blue ink, reading "Ross McKinney, Jr., M.D." The signature is stylized with a large "R" and "M", and a small "Jr." and "M.D." at the end.

Ross McKinney, Jr., M.D.
Chief Scientific Officer

cc: Philip Alberti, Ph.D.