



The PhenX Toolkit: Measurement Protocols for Assessment of Social Determinants of Health

Michelle C. Krzyzanowski PhD , Cataia L. Ives MS , Nancy L. Jones PhD, MA , Barbara Entwisle PhD , Alicia Fernandez MD , Theresa Cullen MD, MS , William Darity PhD , Mark Fossett PhD , Patrick L. Remington MD, MPH , Maile Taulii PhD, MPH , Consuelo H. Wilkins MD, MSCI , Eliseo J. Pérez-Stable MD , Nishadi Rajapakse PhD, MHS , Nancy Breen PhD , Xinzhi Zhang MD, PhD , Deborah R. Maiese MPA , Tabitha Hendershot BA , Meisha Mandal PhD , Stephen Y. Hwang MS , Wayne Huggins PhD , Lauren Gridley MS , Amanda Riley PMP, MBA , Erin M. Ramos PhD, MPH , Carol M. Hamilton PhD

PII: S0749-3797(23)00124-1  
DOI: <https://doi.org/10.1016/j.amepre.2023.03.003>  
Reference: AMEPRE 7110

To appear in: *American Journal of Preventive Medicine*

Please cite this article as: Michelle C. Krzyzanowski PhD , Cataia L. Ives MS , Nancy L. Jones PhD, MA , Barbara Entwisle PhD , Alicia Fernandez MD , Theresa Cullen MD, MS , William Darity PhD , Mark Fossett PhD , Patrick L. Remington MD, MPH , Maile Taulii PhD, MPH , Consuelo H. Wilkins MD, MSCI , Eliseo J. Pérez-Stable MD , Nishadi Rajapakse PhD, MHS , Nancy Breen PhD , Xinzhi Zhang MD, PhD , Deborah R. Maiese MPA , Tabitha Hendershot BA , Meisha Mandal PhD , Stephen Y. Hwang MS , Wayne Huggins PhD , Lauren Gridley MS , Amanda Riley PMP, MBA , Erin M. Ramos PhD, MPH , Carol M. Hamilton PhD , The PhenX Toolkit: Measurement Protocols for Assessment of Social Determinants of Health, *American Journal of Preventive Medicine* (2023), doi: <https://doi.org/10.1016/j.amepre.2023.03.003>

This is a PDF file of an article that has undergone enhancements after acceptance, such as the addition of a cover page and metadata, and formatting for readability, but it is not yet the definitive version of record. This version will undergo additional copyediting, typesetting and review before it is published in its final form, but we are providing this version to give early visibility of the article. Please note that, during the production process, errors may be discovered which could affect the content, and all legal disclaimers that apply to the journal pertain.

## Research Methods

## The PhenX Toolkit: Measurement Protocols for Assessment of Social Determinants of Health

Michelle C. Krzyzanowski, PhD,<sup>1</sup> Cataia L. Ives, MS,<sup>1</sup> Nancy L. Jones, PhD, MA,<sup>2</sup> Barbara Entwisle, PhD,<sup>3</sup> Alicia Fernandez, MD,<sup>4</sup> Theresa Cullen, MD, MS,<sup>5</sup> William Darity, PhD,<sup>6</sup> Mark Fossett, PhD,<sup>7</sup> Patrick L. Remington, MD, MPH,<sup>8</sup> Maile Taulii, PhD, MPH,<sup>9</sup> Consuelo H. Wilkins, MD, MSCI,<sup>10</sup> Eliseo J. Pérez-Stable, MD,<sup>2</sup> Nishadi Rajapakse, PhD, MHS,<sup>11</sup> Nancy Breen, PhD,<sup>2</sup> Xinzhi Zhang, MD, PhD,<sup>11</sup> Deborah R. Maiese, MPA,<sup>12</sup> Tabitha Hendershot, BA,<sup>1</sup> Meisha Mandal, PhD,<sup>1</sup> Stephen Y. Hwang, MS,<sup>1</sup> Wayne Huggins, PhD,<sup>1</sup> Lauren Gridley, MS,<sup>1</sup> Amanda Riley, PMP, MBA,<sup>1</sup> Erin M. Ramos, PhD, MPH,<sup>13</sup> Carol M. Hamilton, PhD<sup>1</sup>

<sup>1</sup>GenOmics, Bioinformatics, and Translation Research Center, RTI International, Research Triangle Park, NC

<sup>2</sup>National Institutes of Health, National Institute on Minority Health and Health Disparities

<sup>3</sup>Department of Sociology, University of North Carolina at Chapel Hill, Chapel Hill, NC

<sup>4</sup>Division of General Internal Medicine, University of California, San Francisco, San Francisco, CA

<sup>5</sup>Regenstrief, Indianapolis, IN

<sup>6</sup>Sanford School of Public Policy, Duke University, Durham, NC

<sup>7</sup>Department of Sociology, Texas A&M University, College Station, TX

<sup>8</sup>Department of Population Health Sciences, University of Wisconsin–Madison, Madison, WI

<sup>9</sup>Center for Integrated Health Care Research, Hawaii Permanente Medical Group, Honolulu, HI

<sup>10</sup>Department of Medicine, Vanderbilt University Medical Center, Nashville, TN

<sup>11</sup>Center for Translation Research & Implementation Science, National Heart, Lung, and Blood Institute

<sup>12</sup>Division for Research Services, RTI International, Research Triangle Park, NC

<sup>13</sup>National Institutes of Health, National Human Genome Research Institute

Corresponding Author: Nancy Jones, PhD, MA, National Institute on Minority Health and Health Disparities, 6707 Democracy Blvd, Suite 800, Bethesda, MD 20892

([jonesna@nimhd.nih.gov](mailto:jonesna@nimhd.nih.gov))

**Credit\_Author**

**Michelle C. Krzyzanowski:** Software, Data Curation, Writing - Original Draft, Writing - Review & Editing, Project administration **Cataia L. Ives:** Writing - Original Draft, Writing - Review & Editing, Project administration **Barbara Entwisle:** Validation, Investigation, Resources, Writing - Review & Editing **Alicia Fernandez:** Validation, Investigation, Resources, Writing - Review & Editing **Theresa Cullen:** Validation, Investigation, Resources, Writing - Review & Editing **William Darity:** Validation, Investigation, Resources, Writing - Review & Editing **Mark Fossett:** Validation, Investigation, Resources, Writing - Review & Editing **Patrick L. Remington:** Validation, Investigation, Resources, Writing - Review & Editing **Maile Taulii:** Validation, Investigation, Resources, Writing - Review & Editing **Consuelo H. Wilkins:** Validation, Investigation, Resources, Writing - Review & Editing **Eliseo Pérez-Stable:** Conceptualization **Nishadi Rajapakse:** Conceptualization **Nancy Breen:** Conceptualization, Writing - Review & Editing **Xinzhi Zhang:** Conceptualization **Nancy L. Jones:** Conceptualization **Deborah R. Maiese:** Methodology, Writing - Original Draft **Tabitha Hendershot:** Conceptualization, Methodology, Supervision **Meisha Mandal:** Software **Stephen Y. Hwang:** Software, Data Curation **Wayne Huggins:** Conceptualization, Methodology **Lauren Gridley:** Software **Amanda Riley:** Project administration **Erin M. Ramos:** Conceptualization, Supervision **Carol M. Hamilton:** Conceptualization, Methodology, Supervision, Funding Acquisition

## Abstract

**Introduction:** Social determinants are structures and conditions in the biological, physical, built, and social environments that affect health, social and physical functioning, health risk, quality-of-life, and health outcomes. The adoption of recommended, standard measurement protocols for social determinants of health (SDoH) will advance the science of minority health and health disparities research and provide standard SDoH protocols for inclusion in all studies with human participants.

**Methods:** A PhenX (consensus measures for **Phen**otypes and **eX**posures) Working Group (WG) of SDoH experts was convened from October 2018 to May 2020 and followed a well-established consensus process to identify and recommend SDoH measurement protocols. The PhenX Toolkit contains data collection protocols suitable for inclusion in a wide range of research studies. The recommended SDoH protocols were shared with the broader scientific community to invite review and feedback prior to being added to the Toolkit.

**Results:** Nineteen SDoH protocols were released in the PhenX Toolkit (<https://www.phenxtoolkit.org>) in May 2020 to provide measures at the individual and structural levels for built and natural environments, structural racism, economic resources, employment status, occupational health and safety, education, environmental exposures, food environment, health and health care, and sociocultural community context.

Conclusions: Promoting adoption of well-established SDoH protocols can enable consistent data collection and facilitate comparing and combining studies, with the potential to increase their scientific impact.

## Introduction

Social determinants are the circumstances in which people are born, grow up, live, work, and age, and these circumstances are shaped by economic and social policies.<sup>1</sup> Social determinants are drivers of population health and health disparities that influence an individual's health behaviors as well as their experiences with the health care system.<sup>2,3</sup> The National Institute on Minority Health and Health Disparities (NIMHD) identified social determinants of health (SDoH) as a cross-cutting theme to advance the science of minority health and health disparities research and initiated a project to establish standardized measures for SDoH for use by the scientific community.<sup>4,5</sup>

The PhenX (consensus measures for **Phen**otypes and **eX**posures) Toolkit

(<https://www.phenxtoolkit.org>) is a web-based catalog of recommended measurement protocols of phenotypes and exposures suitable for inclusion in genomic, clinical, and translational research studies involving human participants.<sup>6</sup> The Toolkit contains data collection protocols (also known as instruments or measures) that are recommended using an established PhenX consensus process.<sup>7</sup> In the PhenX Toolkit, protocols provide a standard, reproducible approach (Table 1) for either collecting new data, such as by self-report or interviewer-administered questionnaires, physical measurements, and bioassays; or for performing secondary data analysis to derive information from available datasets.

Since its launch in 2009, the PhenX Toolkit has added protocols for measures of demographics, social environments, and health conditions including cancer, cardiovascular disease, diabetes, and obesity. In addition, the Toolkit has Specialty Collections that focus on in-depth assessment of topics such as Mental Health, and Substance Abuse and Addiction.

The National Institutes of Health (NIH) promotes standardizing and sharing data produced by biomedical research.<sup>8</sup> In support of this strategy, the PhenX Toolkit provides content to encourage data sharing across 30 research domains. This article introduces the SDoH Collections of the PhenX Toolkit to clinical, population, and translational researchers for use in their investigations. The methods used to create the SDoH Core and Specialty Collections and the scientific rationale for the SDoH Collections of measurement protocols are presented.

## Methods

In 2015, NIMHD began a scientific visioning process of minority health and health disparities research.<sup>9</sup> As a result, NIMHD prioritized three research strategies to address SDoH and health disparities: (1) understand protective and resilience factors; (2) examine multilevel discrimination, including structural racism; and (3) elucidate mechanisms of SDoH influence on health behaviors.<sup>4,10</sup> In 2017, NIMHD staff developed a multidimensional framework that spans different domains of influence (Biological, Behavioral, Physical/Built Environment, Sociocultural Environment, Healthcare System) as well as different levels of influence (Individual, Interpersonal, Community, Societal) within those domains to examine the complexity of the factors that contribute to causal pathways of health disparities.<sup>3</sup> In 2018, the

NIMHD Director Dr. Eliseo Pérez-Stable called on staff to lead an effort to identify consensus measures for SDoH that could be recommended in NIH funding opportunity announcements and empower collaborative health disparities research. The NIH-wide WG on SDoH defined a framework with 10 scope elements (Table 2) that were deemed important for assessing health disparities. The elements encompass the Built and Natural Environment, Educational Attainment, Employment, Health and Health Care, as well as the Sociocultural Community Context. These scope elements—built on definitions from the World Health Organization (WHO), the NIMHD Research Framework,<sup>3</sup> and the Healthy People 2020 SDoH objectives that state health starts in our homes, schools, workplaces, neighborhoods, and communities<sup>11</sup>—were used to define the scope of the PhenX SDoH Working Group (WG).

This scope guided the selection of nine SDoH experts from academia and health care institutions to form a PhenX SDoH WG (Appendix Table 1). The WG included experts in social demography, language and literacy barriers in health care, socioeconomic and racial/ethnic disparities, health technology, residential segregation, health equity, public policy, and economics to recommend protocols for SDoH. The goals of this WG were to assess existing content relevant to SDoH that was already in the Toolkit, including protocols in domains such as Demographics, Social Environments, and Environmental Exposures, and propose measurement protocols based on the NIH-wide WG scope elements (Table 2).

The PhenX Steering Committee (SC), which provides overarching guidance to the project, defined the criteria for inclusion of protocols in the PhenX Toolkit. These criteria are that the



protocols are clearly defined, well established, broadly applicable, validated, reproducible, generally low burden to participants and investigators, and preferably publicly available.<sup>7</sup> Protocols are evaluated for requirements that indicate burden to investigators and participants when using the protocol: major equipment, specialized training, specialized requirements for biospecimen collection, and average time of greater than 15 minutes in an unaffected individual.

WG members were assigned 2 to 3 SDoH scope elements corresponding to their areas of expertise. They reviewed the literature to identify well-established protocols that meet the PhenX selection criteria. During an in-person meeting, the WG prioritized 12 to 15 specific topics to address. The WG did not prioritize the following topics: liquid assets, housing insecurity, overall economic hardship/insecurity, perceived social support, water pollution, and soil pollution.

In some cases, a WG member was able to identify only one well-established and broadly validated protocol to recommend (i.e., covering topics such as air pollution, environmental justice, social vulnerability, food insecurity, and food swamps), and the WG recommended each of them for inclusion in the Toolkit. In other cases, WG members identified multiple protocols for consideration (e.g., Health Literacy). After considerable discussion, the WG decided to recommend the Short Assessment of Health Literacy–Spanish and English (SAHL-S&E) because it was well established and broadly validated, available in English and Spanish, low burden, and was endorsed by the Agency for Healthcare Research and Quality.

Based on discussions,<sup>6</sup> the WG identified 19 protocols relevant to the scope that complement the existing Toolkit content. The recommended protocols were shared with PhenX Toolkit registered

users and NIMHD grantees through an outreach effort to invite review and feedback prior to the final deliberation of the WG. Respondents were asked to indicate with a Yes/No response whether they support including the protocol in the PhenX Toolkit and provide specific comments. Fifty people responded to the outreach email, providing feedback on the proposed protocols. Outreach responses indicated broad support for the protocols. In response to public comment, the WG recommended an additional protocol for Spirituality, the WHO Quality of Life and Spirituality, Religiousness and Personal Beliefs instrument. The PhenX SC approved the 19 SDoH protocols for the PhenX Toolkit.

## Results

The protocols selected by the SDoH WG reflect the breadth of population health and health disparities research and, if widely adopted, have the potential to impact the future of SDoH research. These protocols complement the SDoH-related protocols already in the PhenX Toolkit and were released in the PhenX Toolkit in May 2020

(<https://www.phenxtoolkit.org/collections/view/6>) (see Table 3). The NIHMD staff organized the SDoH Collection into a Core Collection and two Specialty Collections (Individual and Structural).

The Core Collection is deemed relevant to advance minority health and health disparities research. In October 2020, the NIMHD, together with five other NIH Institutes and Centers, issued a Notice Announcing Availability of Data Harmonization Tools for SDoH via the PhenX Toolkit. The notice strongly encourages investigators to incorporate the measures from the Core and Specialty Collections available in the Social Determinants of Health Collections of the

PhenX Toolkit ([www.phenxtoolkit.org](http://www.phenxtoolkit.org)) whenever possible.<sup>12</sup> PhenX SDoH protocols are designed to become the standard protocols for all primary data collection of SDoH for NIMHD funded investigators.<sup>12</sup> The Core Collection includes 16 protocols recommended for primary data collection including five protocols assessing demographic characteristics, two protocols assessing perceptions about the physical and social environment, and four socioeconomic protocols, as well as Health Insurance Coverage, Health Literacy, Access to Health Services, English Proficiency and Food Insecurity<sup>13-15</sup> (see Table 3). It takes about 30 minutes to administer the entire Core Collection of protocols.

Table 3 shows the SDoH Individual and Structural Specialty Collections that provide researchers with options of protocols to conduct in-depth assessments on single SDoH topics. An investigator may choose protocols from the Specialty Collections as needed for their study design and research needs. Eight protocols in the Structural SDOH Specialty Collection are ascertained for geographic areas with data from the U.S. Census or the American Community Survey (ACS).<sup>14,16</sup> Protocols in the Individual SDoH Specialty Collection collect data from individual respondents. Individual-level data may be aggregated to reflect the population of interest. Of the 19 protocols added to the Toolkit by the WG, 7 are available in Spanish and 2 in Chinese.

Structural protocols measure Air Quality,<sup>17</sup> Concentrated Poverty,<sup>18</sup> Community Educational Attainment,<sup>19</sup> Environmental Justice,<sup>20</sup> Food Swamp,<sup>21</sup> Percent Unionized of the Non-Agricultural Labor Force,<sup>22</sup> Race/Ethnic Residential Segregation,<sup>16,23</sup> and Social Vulnerability.<sup>24</sup>

All these community assessments are for specific geographic areas such as states, counties, metropolitan areas, or census tracts using secondary data from well-established government sources such as the U.S. Census, the ACS, and the Environmental Protection Agency. The SDoH WG also recommended a composite measure of social vulnerability and selected the Centers for Disease Control and Prevention (CDC) Social Vulnerability Index (SVI).<sup>25</sup>

Individual protocols measure English Proficiency,<sup>26</sup> Food Insecurity,<sup>27</sup> Job Insecurity,<sup>28</sup> Occupational Prestige,<sup>13-15</sup> Spirituality,<sup>29</sup> and Wealth.<sup>30,31</sup> Other measures assess an individual's interaction with the health care system and access to health information. These include Access to Health Services,<sup>32</sup> Access to Health Technology,<sup>33</sup> Disparate Health Care Quality,<sup>34</sup> Health Literacy,<sup>35,36</sup> and Health Numeracy.<sup>37</sup> These protocols come from international, federal, and state surveys, including the WHO Quality of Life, the General Social Survey (GSS), the National Health Interview Survey, the Panel Study of Income Dynamics, and the California Health Interview Survey. Also included in the Individual SDoH Collection is a protocol for Discrimination from the Major Experiences and Everyday Discrimination Scale to measure discrimination at the interpersonal level for interactions with employment, housing, and education.

Because health insurance benefits are often linked to employment, the SDoH WG chose questions from the GSS that ask whether a person thinks they will be laid off or lose their job and whether they will be able to find another job with the same income and fringe benefits. This Job Insecurity protocol provides an important assessment tool during times of high unemployment, such as during the novel coronavirus (COVID-19) pandemic, and more generally

with the U.S. gig economy.<sup>28</sup> The Access to Health Technology measure,<sup>33</sup> from HINTS, assesses use of tablets, smartphones, and electronic monitoring devices to track and share health information with health care providers. With the expanded use of telemedicine, this protocol can measure whether individuals have access to the technology that allows them to interact with clinicians.

The release of the SDoH Collections was timely amid the global COVID-19 pandemic that revealed the magnitude of racial/ethnic disparities in the United States.<sup>2</sup> In October 2020, COVID-19 Research Collections were released in the PhenX Toolkit, with the recommendation to include the SDoH Core Collection of protocols.<sup>38</sup> In addition, several related protocols selected by the SDoH WG were included in the COVID-19 Research Collections, including Access to Health Services,<sup>32</sup> Access to Health Technology,<sup>33</sup> Disparate Health Care Quality,<sup>34</sup> Food Insecurity,<sup>27</sup> Job Insecurity,<sup>28</sup> and Wealth.<sup>30,31</sup> The integration of these protocols into the COVID-19 Research Collections emphasizes the importance of health disparities, especially SDoH, in COVID-19 research.

## **Discussion**

The process described in this report for defining and identifying the important research constructs that influence disparities in health and health care, and agreeing on a core set of common data collection protocols for use in primary data collection, are major steps to advance the science of minority health and health disparities. NIMHD, with collaboration from several NIH Institutes and Centers, launched this initiative to leverage the power of data science and to encourage the research community to measure critical data collected from questionnaires or

derived from secondary data in the same way. Use of common data elements for SDoH will provide the foundation to inform the field for years to come.

A PhenX WG of experts from diverse disciplines identified a set of SDoH measurement protocols for the PhenX Toolkit. These well-established, broadly accepted measures of SDoH are suitable for a variety of population groups, diseases, and conditions. Because these protocols have been recommended by SDoH experts, researchers in any field can use them with confidence. SDoH measures are relevant to a variety of study types and designs—including clinical, translational, and public health.

The well-established protocols of SDoH in the PhenX Toolkit enhance the ability to compare and contrast SDoH findings when used in multiple studies. The ability to do so will help elucidate the impact of SDoH on biological and behavioral mechanisms, phenotypes, exposures, and health outcomes; help identify effective interventions; and promote collaborative research through data sharing and cross-study analysis.

The PhenX Toolkit website provides investigators with search and browse functions to identify protocols of interest. The search functionality allows users to find protocols and supplemental information using keywords and filters to narrow results based on life stage, data collection type, and language. The Toolkit provides a Browse Protocols Tree feature, based on PubMed Medical Subject Headings (MeSH) terminology, that clusters conceptually similar protocols. The PhenX Toolkit also offers tools to help investigators integrate protocols in their study designs. PhenX Data Collection Worksheets not only promote consistent data collection but also provide















































**Table 3. Final Protocols for May 2020 PhenX Toolkit Social Determinants of Health****Collections**

Collection	Final Protocols for May 2020 PhenX Toolkit
Core Social Determinants of Health Collection	<ul style="list-style-type: none"> <li>x Access to Health Services</li> <li>x Annual Family Income<sup>a</sup></li> <li>x Biological Sex Assigned at Birth<sup>a</sup></li> <li>x Birthplace<sup>a</sup></li> <li>x Current Address<sup>a</sup></li> <li>x Current Age<sup>a</sup></li> <li>x Current Employment Status<sup>a</sup></li> <li>x Educational Attainment—Individual<sup>a</sup></li> <li>x English Proficiency</li> <li>x Ethnicity and Race<sup>a</sup></li> <li>x Food Insecurity</li> <li>x Gender Identity<sup>a</sup></li> <li>x Health Insurance Coverage<sup>a</sup></li> <li>x Health Literacy</li> <li>x Occupational Prestige</li> <li>x Sexual Orientation<sup>a</sup></li> </ul>
Individual Social Determinants of Health Specialty Collection	<ul style="list-style-type: none"> <li>x Access to Health Services</li> <li>x Access to Health Technology</li> <li>x Discrimination<sup>a</sup></li> </ul>

	<ul style="list-style-type: none"> <li>x Disparate Health Care Quality</li> <li>x English Proficiency</li> <li>x Food Insecurity</li> <li>x Health Literacy</li> <li>x Health Numeracy</li> <li>x Job Insecurity</li> <li>x Occupational Prestige</li> <li>x Spirituality</li> <li>x Wealth</li> </ul>
<p>Structural Social Determinants of Health Specialty Collection</p>	<ul style="list-style-type: none"> <li>x Air Quality Index</li> <li>x Concentrated Poverty</li> <li>x Educational Attainment—Community</li> <li>x Environmental Justice</li> <li>x Food Swamp</li> <li>x Percent Unionized for Non-Agricultural Labor Force</li> <li>x Race/Ethnic Residential Segregation—American Community Survey<sup>a</sup></li> <li>x Race/Ethnic Residential Segregation—Separation (S) Index, Unbiased</li> <li>x Race/Ethnic Residential Segregation—U.S. Census<sup>a</sup></li> <li>x Social Vulnerability</li> </ul>

<sup>a</sup> Indicates measurement protocols that were already in the PhenX Toolkit that were included as part of the SDoH Collections.