



COVID-19 Assessment Recommendations for SBE Supplement Grantees

To facilitate data harmonization and integration among investigators receiving awards for supplement and revision applications to support data collection via [NIH COVID-19 Notices](#), the NIH is providing additional guidance to investigators on item and measure selection, as per [NOT-OD-20-118](#), to enhance comparability across investments intended to support health research on COVID-19. The guidance is not intended to require comprehensive use of all listed items, but instead encourage use of existing items in domains investigators intend to include in their proposed data collections to facilitate data linkages to the sources of these items or questionnaires and to promote the ability for supplement grantees to link data among each other. All investigators, however, are expected to collect a minimal set of sociodemographic variables including age, gender identity, race/ethnicity, educational attainment, and home physical address and/or zip code (for linkages to geolocation datasets).

For non-COVID-19 specific items and measures, supplement grantees should refer to the PhenX toolkit to assess domains such as:

- Demographics: <https://www.phenxtoolkit.org/domains/view/10000>
- Psychosocial: <https://www.phenxtoolkit.org/domains/view/180000>
- Mental Health: <https://www.phenxtoolkit.org/collections/view/1>
- Substance Abuse: <https://www.phenxtoolkit.org/collections/view/2>
- Social Environments: <https://www.phenxtoolkit.org/domains/view/210000>
- Social Determinants of Health: <https://www.phenxtoolkit.org/sub-collections/view/28>

For COVID-19 specific measures, the NIH created the COVID-19 Survey and Clinical Assessment Repositories in [DR2](#) and [PhenX](#) to facilitate data integration by using items and item modules from surveys already developed and/or fielded. The surveys in these repositories were developed rapidly in response to the pandemic. Therefore, there is limited information regarding the development, testing, and validation of these item modules. In the absence of such information for determining a “consensus” set of items or measures that supplement grantees should adopt, the NIH is recommending that supplement grantees select COVID-19 specific items for domains relevant to their research from surveys being conducted in large and diverse samples, preferable those also translated into Spanish.

For **adult general population samples**, investigators are strongly encouraged to draw COVID-19 specific items from the following surveys, in priority order below:

1. [US Census Household Pulse Questionnaire](#). This survey was developed by multiple federal statistical agencies to assess employment status, consumer spending, food security, housing, education disruptions, and basic dimensions of health in a nationally representative sample. Investigators interested in these domains should draw items first from this survey.
2. [Center for Economic and Social Research Understanding America Survey](#) (CESR-UAS). This nationally representative panel survey asks respondents about the impact of the coronavirus (COVID-19) pandemic on their lives. It assesses some domains already covered above by the Census questionnaire (e.g., employment impacts) but complements the Census focus by assessing domains such as COVID-19 symptoms, perceptions of the pandemic, consumer behavior, lifestyle, education, family, health status, health insurance, social networks and subjective well-being impacts.

3. [RAND American Life Panel](#). This survey is being administered to a nationally representative internet panel. The survey includes COVID-19 specific item modules assessing daily impacts, attitudes, sources of information about COVID-19, and financial and employment impacts. Domains not assessed by either of the two surveys above can be drawn from this survey to provide linkage to another nationally representative sample.
4. [NIH All of Us program COPE survey](#) is being administered in a large and diverse cohort, albeit not nationally representative. The All of Us survey includes COVID-19 specific item modules assessing social distancing, symptoms, testing, treatment, and impact on daily life that may be relevant and not available from one of the three surveys listed above.
5. [Johns Hopkins University COVID-19 Community Response Survey](#). These survey modules were developed by the JHU Bloomberg School of Public Health. The goal of this toolkit is to provide a set of standardized quantitative and qualitative assessments to harmonize data collection efforts and facilitate comparisons of the impact of the novel coronavirus (COVID-19) and promote collaborations across research efforts. This toolkit provides a comprehensive set of items that should address any remaining domains of interest not assessed by the four above. Use in large, diverse, and nationally representative samples is not known; therefore, it is recommended as a source for items when those from known and well-characterized samples are not adequate to assess all of the domains of interest.

For **child and adolescent samples**, supplement grantees should draw COVID-19 specific items from the [NIH Environmental Influences of Child Health Outcomes \(ECHO\) COVID-19 Questionnaires](#). These surveys items were developed by the ECHO team and include questionnaires for pregnant women and caregivers, children ages 0 to 12 years old (via parent report), and adolescents ages 13 years and older (via self-report). The purpose of these questionnaires is to assess the impact of being infected with and living during the time of the COVID-19 outbreak.

If a supplement proposes assessing child or adolescent COVID-19 specific domains that are not assessed by the ECHO survey, then supplement grantees should consider, in the order below, additional domains from the following list of surveys in the order below.

1. [Adolescent Brain and Cognitive Development \(ABCD\)](#). The ABCD COVID-19 Impact survey was created to be administered to the participants of the NIH-sponsored Adolescent Brain and Cognitive Development (ABCD) longitudinal study of 11,880 diverse community youth enrolled at age 9-10 in 2016-2018. These measures were developed by a workgroup consisting of ABCD investigators with expertise in adolescent development, mental health, sleep, physical activity, substance use, and disaster response, and the electronic surveys underwent preliminary testing via expert review and pilot testing with adults and children.
2. [NIMH CRISIS Survey](#). The CRISIS Survey is designed to enable researchers and care providers to examine the extent and impact of life changes induced by the COVID-19 epidemic on the mental health and behavior of individuals and families across diverse international settings. To facilitate multicultural perspectives, translations in a broad range of languages are available.
3. [COVID-19 and Perinatal Experiences \(COPE\)](#). This survey focuses particularly on prenatal and perinatal women and may include relevant domains specific to new and expectant mothers.

For **healthcare worker** samples, the [HERO project survey](#) assessing the use of PPE and experiences of distress relevant to being a front-line covid-19 worker. The [University of Iowa COVID-19 Evaluation of Risk in Emergency Departments survey](#) also should be considered if the HERO project survey does not

cover all relevant domains of the supplement grantee or if the focus on the supplement study is on emergency departments.

Supplement grantees are encouraged to discuss decisions regarding the selection of survey and patient-reported outcome measures in their studies with program staff, and to coordinate their selections with other COVID-19 supplement grantees addressing similar research questions.