

Sources of Measures for Use in Health Disparities Research

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This document is one of two that provides resources for locating measures of health and health-related concepts, often in Spanish.

- *Sources of Measures for Use in Health Disparities Research*: sources with descriptions and hyperlinks.
- *Measures Compilations and Reviews*: sources that include reviews of the conceptual and psychometric properties of the measures.

Examples of the types of measures that can be found on these websites are:

- Health and health-related quality of life (perceived health, physical functioning, sleep, fatigue, health distress, depression, anxiety, perceived stress)
- Disability and functioning (functional status, geriatric syndromes, hearing loss, vision loss)
- Social determinants of health (social support, food insecurity, English proficiency, resilience, physical environment)
- Lifestyle and disease self-management (diet, physical activity, tobacco use, stress management, self-efficacy)
- Sources of health information and knowledge (cancer risk and knowledge)
- Quality of health care (interpersonal processes of care, decision making, health literacy, trust in physicians, satisfaction with care)
- Healthcare utilization (screening tests, outpatient visits, mental health visits, hospital and emergency department)
- End-of-life care (advance care planning, quality of life at the end of life)

We have organized the list by type of source, and within each one, some examples. The list thus illustrates numerous ways of finding measures. Some websites include measures that are appropriate for minority aging and health disparities research. Each source offers one or more of the following: critical review of several measures of a concept, psychometric information, actual instruments, and scoring instructions. The categories include:

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| • Organizations and research centers | • Searchable databases |
| • Government agencies | • Systematic reviews of measures |
| • National and state surveys | • Universities and individual researchers |
| • Large research studies | • General web-based sources |

Organizations and Research Centers

Several organizations and research centers have expertise in measurement development and have created websites for accessing measures.

The RAND Health Care program specializes in developing and testing measures for use in health and healthcare research. Measures of health-related quality of life include measures relevant to epilepsy and epilepsy surgery, kidney disease, refractive error, asthma, and visual function. Other measures include aging and health (vulnerable elders); homelessness; HIV patient experiences; mental health; quality of care, including patient satisfaction with care; health-related quality of life including disease-specific quality of life (epilepsy, kidney disease); social support; sleep problems; and end-of-life care. Medical Outcomes Study (MOS) measures of functioning and well-being are included. All measures are public documents, available without charge. Some surveys are available in languages other than English. The website includes questionnaires, scoring, and publications relevant to each measure.

[The Self-Management Resource Center \(SMRC\)](#) provides a variety of measures in English and Spanish of health status (e.g., pain, fatigue, shortness of breath, health distress), self-efficacy (chronic disease self-efficacy, diabetes self-efficacy), self-management behaviors (exercise, stress management), and health care (communication with physicians, health care utilization). The website includes each measure, scoring rules, and psychometric characteristics. Measures of diabetes self-management also are available on the website.

[UCSF CTSL Accelerate: Research Resources](#) includes a section “Validated measures for research with vulnerable and special populations” which provides a compendia of measures in several domains, with hyperlinks. The instruments on this site are designed for primary data collection and were selected for applicability to “special populations,” i.e., groups under-represented in patient-oriented research.

- *Social factors*, e.g., educational attainment, food insecurity, health insurance, socioeconomic status, income, assets, limited English proficiency, race/ethnicity.
- *Health care experience*, e.g., caregiving burden, discrimination in health care, end-of-life decision making, health literacy, shared decision-making preferences, trust in physicians.
- *Disability*, e.g., dementia screening, functional status, geriatric syndromes, hearing loss, vision loss.
- *Other domains*, e.g., adverse childhood events, sexual trauma, tobacco use, depression, post-traumatic stress, stress, allostatic load.

[HealthMeasures](#) is the official information and distribution center for PROMIS®, Neuro-QoL, NIH Toolbox, and ASCQ-Me®, which were developed and evaluated with National Institutes of Health (NIH) funding.

- [NIH Toolbox®](#) is a comprehensive set of neuro-behavioral measurements that assess cognitive, emotional, sensory, and motor functions. NIH Toolbox® Cognition, Emotion, Motor, and Sensation measures are available through the [NIH Toolbox iPad App](#). The toolbox measures were developed and validated with state-of-the-science methodology to be psychometrically sound. Translations are available in Spanish and other languages.
- [PROMIS®](#) includes over 300 measures of physical, mental, and social health for use with the general population and with individuals living with chronic conditions. PROMIS developed self-report measures for adults for functions, symptoms, behaviors, and feelings. Measures are available in Spanish and many other languages. PROMIS measures are available for free and can be administered in multiple ways.

[MacArthur Research Network on SES and Health](#) aims to further understanding of how socioeconomic status (SES) impacts the health of individuals and communities. Two “notebooks” review measures relevant to this theme:

- The *Social environment* notebook includes socioeconomic status (economic, occupational, educational status), and community/neighborhood (physical environment, social capital, environmental stress, availability of food).
- The *Psychosocial* notebook includes anxiety, coping strategies, discrimination, optimism/pessimism, personal control, psychological stress, purpose in life, self-esteem, social support, subjective social status.

[Michigan Diabetes Research Center](#) provides access to several diabetes survey instruments including the Diabetes Care Profile (DCP), Diabetes History (DMH), Diabetes Knowledge Test (DKT), Diabetes Attitude Scale (DAS-3), Diabetes Empowerment Scale (DES), and Michigan Neuropathy Screening Instrument (MNSI).

[Ottawa Hospital Research Institute \(OHRI\)](#) explores ways to help patients make “tough” decisions about their health care, including multiple options, and benefits/harms that people may value differently. Measures are available regarding decision support needs of people and patients, with a focus on disadvantaged groups and their providers. Measures include, e.g., decisional conflict, decision self-efficacy, and stages of decision-making.

Health Literacy Tool Shed is an online database of health literacy measures. The site contains information about measures, including their psychometric properties, based on a review of the peer-reviewed. This website includes tools (measures, instruments, and items) that measure an individual's literature health literacy and are published in peer-reviewed journals. The published articles describe the measure and its development process, along with the report validation procedures that include at least 100 participants. We did not exclude tools on the basis of accessibility, so some tools may require payment or author permission.¹ The number of available tools to assess an individual's health literacy has increased during the past decade. There are more than 100 tools available on this site.

Government Agencies

Several federal and state government agencies provide information on measures for use in health and health care disparities research.

Centers for Disease Control and Prevention has several measures of literacy, numeracy, and health literacy. This website also has a link to a CAHPS survey that focuses on assessing providers' activities to foster and improve the health literacy of patients. While health literacy depends in part on individuals' skills, it also depends on the complexity of health information and how it is communicated. The primary goal of the CAHPS Item Set for Addressing Health Literacy is to measure, from the patients' perspective, how well health information is communicated to them by health care professionals.

Agency for Healthcare Research and Quality (AHRQ) includes a variety of measures of health care. The premier tool is the Consumer Assessment of Health Plans Survey (CAHPS®) (see below). They also feature measures of other health-related concepts. For example, AHRQ reviews measures of health literacy (the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions) (see [AHRQ Health Literacy tools](#)).

- **The Consumer Assessment of Health Plans Survey (CAHPS®)** refers to “surveys and tools to advance patient-centered care.” CAHPS® comprises numerous measures/surveys that evaluate the interpersonal aspects of healthcare from the patient and consumer point of view. These surveys are used to monitor the quality of care provided by healthcare organizations. CAHPS® surveys are available to assess patient experiences in specific health care settings (e.g., outpatient care, hospital, surgery, mental health care, hospice, home health care, and nursing home), patient reports of providers, enrollee reports of health plans, and patient experiences with condition-specific care.

National Cancer Institute (NCI) provides measurement resources through several divisions and sections.

- **The NCI Division of Cancer Control & Population Sciences** features “Research Resources and Tools” to find data and resources that support researchers in conducting behavioral research. The site enables exploration of data collection and analysis tools, cancer control publications, and a section dedicated to tobacco cessation resources. Within this Division, there are a variety of measurement resources.
- **Constructs and Measures for Health Behavior** reviews several traditional psychosocial concepts such as perceived control, self-efficacy, social support, and non-traditional concepts such as dispositional optimism, illness representations, optimistic bias, and perceived vulnerability.
- **The Health Information National Trends Survey (HINTS)** examines how Americans use different communication channels to access and use health information, as well as measures cancer knowledge, cancer screening behaviors, risk behaviors, and perception of risk for cancer among Americans.
- **The PhenX Toolkit** is an online catalog of standard measurement protocols for use in biomedical research. PhenX includes 730 measurement protocols covering 25 research domains (e.g., Demographics, Cardiovascular, Diet and Nutrition), while collections provide depth in specific areas (e.g., Substance Abuse and Addiction Research, Mental Health Research). A summary page within this website provides a useful conceptual diagram <https://www.phenxtoolkit.org/about>

[United States Department of Agriculture: Economic Research Service](#) provides resources on measures of food security, including in Spanish and Chinese. Measures include household and adult food security measures, as well as short forms and measures for youth. Also available is the *Guide to Measuring Household Food Security (Revised 2000)* which is “the most authoritative and accessible resource on how to measure household food security. It provides detailed guidance for researchers on how to use the survey module to measure food security and food insecurity. Statistics from surveys that use these methods will be directly comparable to published national statistics.”

National and State Surveys

Regular population surveys are conducted at the state and national level and provide public access to the data and the questionnaires. The surveys include standardized questions on many topics such as chronic medical conditions, health behaviors, risk factors, utilization of health care, and quality of care. Most of these measures are “single items” rather than multi-item scales, thus information on the sources of the measures and the measurement properties is seldom available. These surveys have the advantage of being used in large representative samples. A summary of selected state and national surveys is presented below.

[California Health Interview Survey \(CHIS\)](#) is the nation's largest state health survey and a critical source of data on Californians as well as on the state's various racial and ethnic groups. CHIS samples adults, adolescents and children from all over California. It is available in multiple languages and over-samples minority populations throughout California.

[National Center for Health Statistics \(NCHS\)](#) (part of the Centers for Disease Control and Prevention) is the central body for government-collected health data. NCHS has 2 major types of data systems: systems based on populations, containing data collected through personal interviews or examinations; and systems based on records, containing data collected from vital and medical records. This [link](#) provides a summary of the major NCHS surveys, which are listed below. Surveys included:

- [Behavioral Risk Factor Surveillance Survey \(BRFSS\)](#) is a national survey conducted by the CDC that measures trends in health behaviors in the United States. A table of contents simplifies the task of finding measures of specific concepts. The website includes data, questionnaires, and more from this system of telephone surveys that collects state data about U.S. residents regarding their health-related risk behaviors, chronic health conditions, and use of preventive services.
- [National Health and Nutrition Examination Survey \(NHANES\)](#) is a survey of the health and nutrition of the American population. The survey includes an interview and a medical examination.
- [Hispanic Health and Nutrition Examination Survey \(Hispanic HANES\)](#) is the Hispanic version of the NHANES that sampled 16,000 Mexican Americans, Cuban Americans and Puerto Ricans.
- [National Hospital Care Survey \(NHCS\)](#) provides information on quality of care, access to care, safety and disparities in health care among ambulatory, hospital and long-term care settings.
- [National Health Interview Survey \(NHIS\)](#) is one of the major sources of information on the health of the US population due to its sample size and long-term data collection of many variables, which enables researchers to examine trends over time.

Large Research Studies

Many large-scale, multi-center or longitudinal studies have developed and used measures pertaining to health related topics. Increasingly, these studies are posting their measures for public use.

[Midlife in the United States: A National Longitudinal Study of Health & Well-Being \(MIDUS\)](#). This study began as a study of midlife, but has been continued and now includes older adults. The aim was to investigate the role of behavioral, psychological, and social factors in accounting for age-related variations in health and well-being in a national sample of Americans. MIDUS is a source of measures based on efforts to develop short-form assessments of many psychosocial constructs.

[Longitudinal Studies of Aging \(LSOAs\)](#) is a collaboration between the NCHS and NIA, this study measured factors such as health, physical functioning, living arrangements and health care utilization in cohorts of Americans over 70 years old.

[Health and Retirement Study \(HRS\)](#) provides information on the health, income, insurance, family planning, and retirement of Americans over 50 years old. Questionnaires are available.

[Gateway to Global Aging Data](#) is a search engine for population survey data on aging around the world. This comprehensive platform includes 12 international health and retirement surveys from the United States, Mexico, England, Europe, Korea, Indonesia, India, China, Ireland, Japan, and Costa Rica. It allows users to identify survey items by domains across multiple surveys and generate graphs and tables using survey data. This site requires registration to download data files. Registration is free.

Searchable Databases

Several websites have compiled measures of many aspects of health and the determinants of health. They often also provide access to the instruments.

[Measurement Instrument Database for the Social Sciences \(MIDSS\)](#) is a repository for instruments from across the social sciences. It is sponsored by the Irish Social Sciences Platform (ISSP), which is funded under the Programme for Research in Third Level Institutions (Cycle 4), administered by the HEA and co-funded under the European Regional Development Fund (ERDF). If a measure is found in the database, it provides a description, downloadable forms, scoring, psychometrics, and publications.

[Health and Psychosocial Instruments \(HaPI\)](#) is a collection of information on behavioral measurement instruments. The website contains reviews of instruments used in nursing, physical therapy, psychology, and various medical specialties. It also is a source of published studies that have used specific instruments. Produced by Behavioral Measurement Database Services, this bibliographic database is abstracted from hundreds of leading journals covering health and psychosocial sciences. It may require an OVID account.

Systematic Reviews of Measures

We provide a few examples of systematic reviews of measures. To search for such reviews in PubMed, under “title” use search terms “review of” and “measures.”

- Martinez SM, Ainsworth BE, and Elder JP. A review of physical activity measures used among U.S. Latinos: guidelines for developing culturally appropriate measures. *Ann Beh Med*, 2008;36:195-207. PMID: [PMC3885229](#)
- Cosco TD, Kaushal A, Richards M, Kuh D, Stafford M. Resilience measurement in later life: a systematic review and psychometric analysis. *Health Qual Life Outcomes*. 2016 Jan 28;14:16. PMID: [PMC4730639](#)
- Balsamo M, Cataldi F, Carlucci L, Fairfield B. Assessment of anxiety in older adults: a review of self-report measures. *Clin Interv Aging*. 2018 Apr 6;13:573-593. PMID: [PMC5896683](#)

Universities and Individual Researchers

Increasingly, investigators who specialize in measurement as well as some universities provide direct access to measures through their web sites.

[Center for Aging in Diverse Communities \(CADC\), University of California San Francisco](#) is one of several Resource Centers for Minority Aging Research funded by the National Institute on Aging. CADC’s Analysis Core faculty and scholars have developed concept definitions and self-report measurement instruments relevant to the study of health disparities in older adults. Measures and concepts include quality of health care (Interpersonal Processes of Care Survey, Clinician’s Cultural Sensitivity Survey, Patient Satisfaction Survey), physical activity (CHAMPS Physical Activity Questionnaire for Older Adults), social determinants of disparities (Stress of Immigration Survey, social support, resilience, neighborhood factors, perceived discrimination and racism), and socioeconomic characteristics (childhood social and economic circumstances, race/ethnicity). Most surveys are available in non-English languages, primarily Spanish. Resources include the surveys and scoring rules, publications, and the history of development.

[Toolkit of Instruments to Measure End-of-Life Care \(TIME\)](#) provides several instruments used to measure the needs of patients nearing the end of life, their quality of life, and the quality of care these patients receive.

The website provides annotated bibliographies for tools available in specific domains of end-of-life care. One limitation is that the website has not been updated since 2000.

[On-Line Guide to Quality of Life Assessment \(OLGA\)](#) provides information about questionnaires and rating scales for assessing psychosocial effectiveness in clinical studies. OLGA assists clients in selecting the best measures of quality of life and health outcomes for use in clinical trials and economic analyses. This site requires registration and most resources require a fee to access them.

General Web-based Sources

Wikipedia can be used to locate measures of a specific construct, although this is not structured or specific to measures. For example, searching for depression measures results in a wiki page with links to numerous measures of depression. Note that this also yields other links to depression such as “the great depression.”

- [Hamilton Rating Scale for Depression](#) is a multiple-choice questionnaire that clinicians may use to rate the severity of a patient's major depression.
- [Beck Depression Inventory](#) is a 21-question multiple-choice self-report inventory used for measuring the severity of depression.