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Validated Survey Measures Best Practice Brief

Guidance for developing surveys in research studies.

Overview

Surveys are one of the most important data collection tools in research. Survey data can be collected through a variety of research strategies and methods.[1] Validated survey measures are questions given to research study participants that have been tested and demonstrated to produce accurate (valid) and reliable results. [2] An integral part of validated survey measures are common data elements (CDEs). A CDE is a precisely defined question paired with a set of standardized responses to be used systematically across different sites, studies, and/or clinical trials to ensure consistent data collection and quality.[3] The National Institutes of Health (NIH) has endorsed the use of CDEs and has created the NIH CDE Repository which contains a collection of CDEs that meet federal data collection standards (see *Table 1*). The use of Common Data Elements (CDEs) can facilitate cross study comparisons, data aggregation and meta-analyses, simplify training and operations, improve overall efficiency, promote interoperability between different systems, and improve the quality of data collection. CDEs, especially when they conform to accepted standards, are identified by research communities from variable sets currently in use or are newly developed to address a designated data need.

NIH-Endorsed CDEs

Resource	Description	Translations
PROMIS	Patient Reported Outcomes Measurement Information System (PROMIS) is a database of person-centered measures that evaluates and monitors physical, mental, and social health in adults and children. The PROMIS Health Measures Language Instrument is an in-language health measures categorized by CDE, respondent age, health domain, and language.	Available in 80+ languages
PhenX	PhenX (consensus measures for Phenotypes and eXposures) Toolkit is a web-based catalog of recommended measurement protocols of phenotypes and exposures suitable for inclusion in genomic, clinical, and translational research studies with human participants.	English
NIH Toolbox	NIH Toolbox is a multidimensional set of brief measures assessing cognitive, emotional, motor and sensory function from ages 3 to 85 years.	English, Spanish, Hebrew, Arabic, French, Italian
caDSR	cancer Data Standards Registry and Repository (caDSR) is a repository comprised of reusable metadata, tools and resources for developing and implementing common data elements (CDEs), information models, and case-report forms (CRFs)	English, Spanish
NDAR	National Database for Autism Research is a data repository that aims to accelerate research through data sharing, data harmonization, and the reporting of research results	English
FITBIR	The Federal Interagency Traumatic Brain Injury Research (FITBIR) Informatics System was developed to share data across the entire Traumatic Brain Injury research field	English
dbGAP	The database of Genotypes and Phenotypes (dbGaP) was developed to archive and distribute the data and study results related to the interaction of genotype and phenotype in Humans	English

Table 1. Examples of NIH Common Data Elements Resources. Click the name of the resource to learn more.

Types of Surveys

1) *Exploratory*: This survey type is used to explore and understand a topic or issue without pre-determined hypotheses for testing or expected responses. Exploratory surveys are thus usually qualitative surveys utilizing open-ended questions to probe respondents' perceptions on a topic or issue.

2) *Explanatory*: In contrast to exploratory surveys, explanatory surveys are used to test hypothesized relationships between respondent characteristics and other variables of interest. Explanatory surveys are usually quantitative (e.g., use inferential statistics to quantify relationships between respondent characteristics and specific outcomes) or mixed methods, incorporating a variety of question types.

3) *Descriptive*: Descriptive surveys seek to describe the perception of, interactions with, and behaviors around respondents' association with the topic or issue of interest. Descriptive surveys are usually quantitative, using descriptive statistics to describe associations between variables.

Considerations for Survey Design

In addition to ensuring that the type of survey used in a study is appropriate for the research question(s), researchers must also be mindful of the following when designing a survey:

- *Sampling bias*: Sampling bias occurs when individuals included in the sample are not representative of the population that the research aims to study.
    - Appropriate recruitment strategies are key to reducing sampling bias, as recruitment defines the sample. In addition to clearly defining the population of interest, researchers should consider obtaining a large and random sample and utilizing diverse participant recruitment strategies in order to recruit a representative sample of their population of interest.
- *Coverage bias*: Coverage bias is when there is an unknown or zero chance of individuals from the population of interest being included in the sample.
    - Multimode surveys (e.g., using both online and paper surveys) can reduce coverage error and should be considered in survey research design.
- *Non-response error*: Non-response error is a lack of response from participants.
    - Non-response can be random or biased. In the latter case, researchers should consider why certain individuals are not responding.
        - For instance, if surveys are administered in a language that is not the primary language of the population of interest, then fewer individuals from that population may respond.
        - If a survey is too long or fatiguing, respondents may not take or complete the survey.
    - Researchers should consider user-friendly survey design and implementation of follow-up procedures for non-responders to reduce non-response error.

- Some things to consider in user-friendly design include:
    - Appropriate length of survey (not too lengthy)
    - Availability of large print, text-to-speech, and other accessibility options
    - Clean, simple fonts and approachable, uncluttered visual layout
    - Branching logic, whereby certain questions are customized based on previous responses (e.g., cancer screening questions are asked of specific age or gender groups)

- *Measurement error*: Measurement error is the failure of survey questions or survey instruments to accurately "measure" what they intend to measure (e.g., questions that are misleading and poorly reflect the topic at hand, or questions that do not evoke truthful answers).
    - Validation of surveys for the population they aim to study, pretesting questions for clarity of language and appropriateness of answer choices, and utilization of user-friendly and accurate graphics can help to reduce measurement error.
- *Survey Language and Translation*: When working with Limited English Proficient (LEP) populations first check if validated measures are available in the language of your priority population. For each of the measures include where and if the validated measures are available in other languages (see *Table 1*). If the measure has not been translated and validated in your priority language, a multistep process is needed to translate the validated measure into another language.
- *Survey instrument clarity and accessibility:* Consider pre-testing or piloting survey instruments for comprehension, as well as accuracy (including translation accuracy).
    - Researchers should pilot their survey with a group similar to their study participant population.
    - In the pilot, researchers should assess the survey for clear and unbiased language (word choice, phrasing, etc.), clarity, confusion, correct/appropriate type of responses for the question (yes/no, true/false, Likert scale, open text, etc.), survey length and completion time, etc.

Survey Tools and Resources

The following is a list of databases, repositories, and resources to validated health-related survey measures:

Source	Type	Description	Purpose
NIH Common Data Elements (CDEs) Repository	Searchable database/repository	Collection of CDEs, or standardized data elements, that have met NIH criteria for data management.	Facilitates the interoperability of data across different studies.
UCSF Validated Measures for Research with Vulnerable & Special Populations	List of previously validated survey measures	Collection of previously validated survey measures designed for primary data collection. The collection has been curated for applicability to groups deemed by the NIH as "special populations," and survey measures target social factors, healthcare experiences, disability, and other effects on life course. Each survey measure comes in various languages.	Supports primary data collection among groups that the NIH considers "special populations," which facilitates the inclusion of special populations and historically understudied groups in research.
ICPSR Social Science Variables Database	Searchable database/repository	Database containing over 5 million variables structured and tagged according to survey data documentation standards. The variables are drawn from previously published studies and include researchers' coding schemes and/or codebooks.	Searching and comparing variables and how they are measured across major surveys.
American Psychological Association PsycTests	Searchable database/repository	Collection of psychological tests and measures used for social and behavioral science research. Records include reliability, validity, and factor analysis from source documents.	Supports social and behavioral science research.
National Institutes of Health Survey Sources	List of resources	NIH-developed resource on survey retrieval cites major national surveys on health outcomes, expenditure, and epidemiology.	Supports research with national data or scope.
World Health Organization International Classification of Functioning, Disability and Health Database	Searchable database/repository	Database of variables and code classifications for individual function, structure, disability, health, activities, etc. Variables are provided in plain language with an associated/suggested scale of measurement.	Enables standardized classification of health and health-related domains.
Multilingual OpenREDCap Best Practices Brief	Guidance Document	Guidance Document that outlines how to create REDCap surveys that can be administered in a wide variety of languages.	Helps researchers create translated surveys step-by-step in OpenRedCap

Works Cited

1. Ponto, J. (2015.) Understanding and evaluating survey research. *Journal of the Advanced Practitioner in Oncology*, 6(2), 168 – 171.
2. UCSF Clinical & Translational Science Institute. (2018). Validated Measures for Research with Vulnerable and Special Populations. https://consult.ucsf.edu/guidance/special-populations-measures
3. National Library of Medicine. *Common Data Elements (CDEs)*. Common Data Elements: Standardizing Data Collection. https://www.nlm.nih.gov/oet/ed/cde/tutorial/03-100.html
4. Sheehan J, et al. (2016). Improving the value of clinical research through the use of Common Data Elements. Clin Trials; 13(6):671-676. https://pmc.ncbi.nlm.nih.gov/articles/PMC5133155/
5. Lau, F. (2017). Chapter 13 Methods for survey study. In Lau, F. & Kuziemsky, C. (Eds.), *Handbook of eHealth Evaluation: An Evidence-Based Approach* (pp. 227 – 241). University of Victoria.
6. Meade CD, et al. (2023). Transcreation matters: A learner centric participatory approach for adapting cancer prevention messages for Latinos. Patient Education and Counseling Journal, 115 (107888). https://www.sciencedirect.com/science/article/abs/pii/S0738399123002689
7. FIT Research task force (2020). Translation, Localization and Transcreation. Translatørforeningen. http://efaidnbmnnnibpcajpcglclefindmkaj/https://translatorforeningen.dk/wp-content/uploads/2021/01/2021-01-23-FIT-TLT-V2c3.pdf
8. Tsang S, Royse CF, Terkawi AS. Guidelines for developing, translating, and validating a questionnaire in perioperative and pain medicine. Saudi Journal of Anaesthesia; 11(1): S80-S89. doi: 10.4103/sja.SJA_203_17. https://pmc.ncbi.nlm.nih.gov/articles/PMC5463570/#:~:text=Content%20validity%20refers%20to%20the,questionnaire%20is%20designed%20to%20assess.

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