Resource Guide on Study Participant Characteristics and Settings

The participant characteristics display is an initial version. We encourage those interested in providing feedback to send suggestions to <u>preventionservices@abtassoc.com</u>.

The Prevention Services Clearinghouse records and displays information about study settings and participant characteristics for all studies that receive a moderate or high rating on design and execution, when reported in study documents. This Resource Guide describes how the information included in the Study Participant Characteristics tables on the website is collected and organized. For more information on how the Clearinghouse establishes design and execution ratings, please see the <u>Handbook of Standards and Procedures</u>.

The characteristics included in the Study Participant Characteristics tables on the website are shown in Table 1. For each characteristic, Clearinghouse reviewers record available information based on what study authors report and how they describe the characteristic. For example, consider three studies with moderate design and execution ratings. The first study includes a table of participant characteristics reporting "Women: 23%" and "Men: 77%". The Clearinghouse will record and display both characteristics, that is: "23% Women" and "77% Men." The second study only reports in the text that "23% of study participants were female". The Clearinghouse will record and display "23% Female" for this study. Only the characteristics for which affirmative information is provided are recorded, even if the total does not add up to 100 percent of the study sample. The third study does not report on the gender of participants. The Clearinghouse will display "—" for this study to indicate that information on gender was not reported in the study.

The Clearinghouse displays participant characteristics separately for adults and children/youth when both are present in a study. In most cases, adults are defined as individuals ages 18 and over and children/youth are defined as individuals under the age of 18. However, there are several exceptions. The children/youth category may include individuals ages 18 and over when the sample is at least 50% under the age of 18 or when the study also includes the parents or caregivers of the participating youth. This allows the Clearinghouse to display the characteristics of both the youth (even if some are 18 or older) and their parents or caregivers. Additionally, if study participants under the age of 18 are themselves parents or caregivers, they will be displayed as adults to allow for the characteristics of the children/youth in their care to also be displayed.

The sample on which participant characteristics is reported varies across studies. For example, some studies may report the characteristics of the sample at randomization or enrollment, whereas others may report the characteristics of the participants included in study analyses. Some studies may report characteristics for each study condition (e.g., separately for the intervention group and for the comparison group); others may report on the combined sample. The Clearinghouse records the information that is available, regardless of the sample. If participant characteristics are reported for more than one sample in a study, the Clearinghouse will select a single sample for the display, preferencing the sample included in study analyses (the "analytic sample") over the sample at study entry. This reflects the intent to mirror as closely as possible the characteristics of individuals contributing to reported study findings. If there are multiple analytic samples in a study, the Clearinghouse will display the one with the largest sample size). The Clearinghouse also prefers information on the combined sample, when available (i.e., the intervention and comparison groups combined versus only the intervention condition), but the Clearinghouse will display the characteristics of the intervention condition (or the comparison condition) if that is the only information available in a study. For studies with more than one intervention versus comparison group pair that receives a moderate or high rating, participant characteristics are displayed separately. The Clearinghouse does not request information about participant characteristics from study authors unless such information is needed to establish a design and execution rating (e.g., when demographic characteristics are required for baseline equivalence).

Characteristic	Description	How the Data are Collected and Reported	Examples
Study Location	The geographic location where the study was conducted.	The Clearinghouse generally displays the smallest geographic unit provided by study authors.	Philadelphia, PA, USA United Kingdom Southwestern Tribal Reservation Communities
Study Year	The calendar year when a study began.	The Clearinghouse displays the four-digit calendar year that a study began, such as when participants were assigned to study conditions or enrolled in a program or service.	2022
Age or Grade- Level	The age or grade- level of participants.	The Clearinghouse displays the age, age range, grade-level, and/or grade range of adult and/or children/youth participants as reported by study authors.	Average age: 24 years Grade range: 3 rd -4 th grades Age categories: 15% under age 5; 85% age 5-12
Race, Ethnicity, Nationality	The racial, ethnic, or national identities of participants in the study.	The Clearinghouse displays the distribution of participants' racial and/or ethnic identities and/or participants' nationalities, as reported by the study authors.	 82% Sweden 11% Other Country 6% European 39% Mixed ethnicity (predominately Latino/White) 28% Latino 15% African American 9% White 7% Asian 3% Other Ethnicity
Gender	The gender identity of participants.	The Clearinghouse displays the distribution of participants' gender identities, as reported by study authors.	100% Female 40% Boys 58% Girls 2% Non-binary
Populations of Interest	Selected populations of interest.	For children, those who are involved with the child welfare system, experiencing homelessness or ran away from home, victims of sexual abuse, sexual or juvenile	All children diagnosed with posttraumatic stress disorder associated with maltreatment

Table 1. Characteristics Collected and Displayed by the Clearinghouse

Characteristic	Description	How the Data are Collected and Reported	Examples
		offenders, identify as having a disability*, or identify as Lesbian, Gay, Bisexual, Transgender, Queer or Questioning, Intersex, and more (LGBTQI+). For adults, those who are parents/caregivers, pregnant, involved with the child welfare system, have experienced intimate partner violence or perpetrated intimate partner violence, are single parents, are people experiencing homelessness, identify as having a disability*, or identify as Lesbian, Gay, Bisexual, Transgender, Queer or Questioning, Intersex, and more (LGBTQI+).	 (36%), sexual abuse (21%) road accident (15%), witnessing unnatural death (12%), other types of trauma (6%) 100% Single parents
Household Socioeconomic Status	The household income, employment rate, or poverty rate of study participants.	The Clearinghouse displays household income, employment rate, or poverty rate of study participants using the metric reported by the study authors. For studies conducted outside the United States, only employment rate is displayed (if available).	42% Under \$10,000 per year 33% \$10,000 to less than \$20,000 per year 13% \$20,000 to less than \$30,000 per year 11% \$30,000 or more per year 15% employed

*Note. There is no publicly available comprehensive list of disabilities or standard definition for disability. The Centers for Disease Control and Prevention (CDC), the World Health Organization (WHO), and the Americans with Disabilities Act (ADA) all consider disabilities stemming from an interaction between a physical or mental state with the environment and the impact of this interaction on functioning.

The WHO encourages consideration of three dimensions: (1) impairment in a person's body structure or function, or mental functioning; (2) activity limitation; and (3) participation restrictions in daily activities. Disabilities may be "hidden," that is, not immediately observable. The CDC similarly considers how an impairment can result in activity limitations or participation restrictions (or both).

The ADA definition includes physical or mental impairments that substantially limit one or more major life activities, having a history or record of physical or mental impairments, or being perceived by others as having physical or mental impairments. The ADA defines physical or mental impairments as:

• Any physiological disorder or condition, cosmetic disfigurement, or anatomical loss affecting one or more body systems, such as: neurological, musculoskeletal, special sense organs, respiratory (including speech organs), cardiovascular, reproductive, digestive, genitourinary, immune, circulatory, hemic, lymphatic, skin, and endocrine; or

• Any mental or psychological disorder such as intellectual disability, organic brain syndrome, emotional or mental illness, and specific learning disability.

The Prevention Services Clearinghouse is intentionally broad in its current definition of disabilities that may be included in the Study Participant Characteristics tables on the website. It is common for studies reviewed by the Clearinghouse to include information about potentially disabling conditions experienced by the participants, but it is much less common for studies to label such conditions as disabilities. For example, a study of a substance use treatment intervention may report on the number of participants with *diagnoses* of substance use disorder. A second study of the same intervention may report on the number of the beginning of the study from a diagnostic test. A third study of the same intervention may report on the frequency of substance use in the month prior to seeking treatment. The Prevention Services Clearinghouse may report any of these characteristics; it is not required that studies refer to potentially disabling conditions as disabilities or report on official diagnoses of disabilities.

Studies may report on a wide range of disabilities. For the initial version of the participant characteristics, the Clearinghouse focused on reporting disabilities that are a focus of the intervention, an eligibility requirement for the intervention, an eligibility requirement for the intervention, an eligibility requirement for the study, are a part of the study's research questions, or are otherwise indicated as being of specific interest in the study. This means that the Clearinghouse may not report every potentially disabling condition listed in the study in the Study Participant Characteristics tables at this time. The Clearinghouse is currently seeking consultation from experts, including those with lived experience, and input from the public to enhance and improve the display.

Sources

Americans with Disabilities Act: Introduction to the Americans with Disabilities Act | ADA.gov Centers for Disease Control and Prevention: Disability and Health Overview | CDC World Health Organization: Disability (who.int)