

Adverse event. An incident in which the protection of the respondent may have been violated. Adverse events include a physical or psychological injury to a participant in a research study. Adverse events also include situations in which the protocol is not followed, which are called breaches in protocol. See *Chapter 10* for more information.

Analysis weight. A weight used in statistical computations that adjusts for sampling design, nonparticipation, and omissions from the sampling frame. For a participating mother in PRAMS, it is the number of women like her whom she represents in the population as a whole. See *Chapter 6* and *Appendix B* for a discussion of analysis weights

Analytic data set. SAS data set sent to state that contains that state's data for one calendar year of sampling. The data set includes all questionnaire and birth certificate variables and selected operations variables. See *Chapter 6* for more information.

BCENTRY.DAT file. The Sample Contact File or BCENTRY.DAT file is created by vital records each month and is used to transfer contact information from birth certificate records into PRAMS software systems. See *Chapter 6* and *Appendix P* for more information.

Biased estimator. A point estimate whose average, over many repeated samples, does *not* equal the value of the population parameter of interest.

Computer Assisted Telephone Interviewing (CATI). CATI is a method by which the interviewer is able to administer the questionnaire and enter data into an electronic database while the interview is being conducted. CATI eliminates the need for telephone data to be recorded twice, once on paper and then later into the data entry system. See *Chapter 6* for more information regarding the PIDS CATI system.

Cognitive interviewing techniques. Techniques that assess respondents' understanding and interpretation of questions, and the thinking process used to formulate responses. See *Chapter 5* and *Appendix C* for more information.

COMMENT Data. This information consists of an comments that were written on the questionnaire or that were expressed during a telephone interview. Comments are keyed in verbatim into the PIDS system provided by CDC. See *Chapter 6* for more information regarding the COMMENT data.

Confidence level. A range of possible values for the population parameter, usually constructed so that it has a specified probability of including the population parameter.

CONTACT.DAT file. The new name of the BCENTRY.DAT file in the PIDS software system, implemented in 2012.

Core questionnaire. The part of the PRAMS questionnaire that is the same for all states. Data from the core questionnaire are used for comparisons of maternal behaviors among states. See *Chapter 5* for more information regarding Questionnaire development and design.

CPONDER. This is a public use version of PONDER (The PRAMS On-line Data for Epidemiologic Research) which includes selected indicators from the PRAMS Surveillance reports. See *Chapter 6* for more information regarding CPONDER.

Descriptive analysis. The presentation, summarization, and comparison of data that describe the topic(s) of interest. See *Chapter 7* for information regarding different types of analyses.

Domain. A subset of the population that has one or more characteristics in common (e.g., all women who smoked during pregnancy).

Epidemiologic surveillance. The ongoing and systematic collection, analysis, and interpretation of health data in the process of describing and monitoring a health event or behaviors associated with a health event or condition

Exclusions. A list of reasons women will be excluded from the sampling frame. Examples include out-of-state residents, infants of multiple gestation (>3), and adopted infants. See *Chapter 4* for more information.

Federal Wide Assurance (FWA). An assurance that an institution engaged in human subjects research that is conducted or supported by any agency of the U.S. Department of Health and Human Services (HHS) is compliant with the HHS regulations (45 CFR 46.103) for the protection of human subjects.

File linkage. Matching related records from different files based on common identifiers. The PRAMS identification number permits linkage of the birth certificate, operations, and questionnaire files. Files are linked at CDC to form analytic data sets. States may link files for operational or analytic purposes. See *Chapter 6* for more information.

Goal. The ultimate result one strives to attain. For example, to improve the health of mothers and infants. See *Chapter 2* for assistance in developing your state specific goals.

Human Subjects Training. A series of events led the Institutional Review Board (IRB) at the Centers for Disease Control and Prevention (CDC) to recommend that PRAMS develop a training for all staff. PRAMS Human Subjects Protections Training consists of 4 modules, to be performed on a quarterly basis for all new staff (on-site/off-site, contractors/staff). The purpose of the training is to ensure that all PRAMS staff are knowledgeable about human subjects protections and understand the implications of breaches in protocol. Refresher trainings should be conducted at least once per year, and all modules should be repeated in the case of a breach in protocol. See *Chapter 3*,

10 and the *Human Subjects Training Manual* for more information regarding Human Subjects.

Implementation Manual. The Implementation Manual provides written documentation for training state PRAMS staff in the use of PRAMS software for conducting data collection, PIDS. The manual is the source of information that CDC will use to train new states. Additionally, existing states may use this manual for training new staff to use the PRAMS software for collecting data

Inferential analysis. Investigation and testing of relationships between variables of interest which allow conclusions to be made about a more general group or topic. For example, the inference of PRAMS findings to all women who have newborn infants. See *Chapter 7* for more information.

Informed consent. The process of providing potential study participants with information about the study and seeking their consent to participate. In PRAMS, information regarding the purpose and confidentiality of the project is stated in the cover letter and is part of an interviewer's introductory comments. Informed consent is implied when the respondent returns the questionnaire or answers an interviewer-administered questionnaire. There is no written informed consent form included with the PRAMS questionnaire. See *Chapter 5, 10* and *Appendix I* for more information regarding Informed consent.

Item nonresponse. Failure to answer a particular question on the questionnaire.

Objective. A measurable result that one strives to achieve as part of reaching one's goal. For example, to establish a surveillance system that systematically collects information from a defined sample of new mothers. See *Chapter 2* for assistance in developing your state specific objectives.

Operational Data. The files that contain information summarizing the attempts and results of mail and telephone contact. There are three operations files: operations, mail details, and telephone details. The operations file becomes part of the analysis data set. The mail and telephone detail files are independent files that can be used to evaluate operations. See *Chapter 6* for more information.

Participation incentive. A gift enclosed with the questionnaire when it is presented to the mother through the mail. See *Chapter 5* for more information regarding the use of incentives.

Participation reward. A gift given to a respondent after a completed questionnaire is received. See *Chapter 5* for more information regarding the use of rewards.

PONDER. The PRAMS On-line Data for Epidemiologic Research (PONDER) is a menu-driven, web-based query system which is located on the limited access internal PRAMS website. See *Chapter 6* for more information regarding PONDER.

Population. The group that one wants to learn about and expects the sample to represent (e.g., all pregnancies that resulted in a live birth among women who lived and delivered in Maine in 1989).

The PRAMS Working Group. The PRAMS Working Group will appear as an acknowledgment on all journal articles or presentations related to PRAMS, and the individual members of the Working Group will be identified. The group includes one individual, identified by name, from each PRAMS state. See Chapter 8 for more information regarding The PRAMS Working Group.

PRAMStat. PRAMS online query system available to the public via the CDC DRH website. The system provides data tables on over 200 indicators, and became available in the spring of 2015, replacing both the PONDER & CPONDER systems.

PRAMTrac. A software tracking program developed by CDC to assist state-level personnel in day-to-day operational activities related to PRAMS. The use of PRAMTrac ended with the implementation of the PIDS Software System in 2012.

PIDS System. PRAMS Integrated Data Collection System (PIDS) project consists of the creation of software which encompasses Customer Relationship Management [CRM] solution integrated with Data Collection solution. PIDS replaces the previous PRAMS software systems, QDS, PRAMTrac, WebCATI, Comment, PASS, PRAMS Receiver, WinBatch, and SDN.” See *Chapter 6* for more information regarding the PIDS System.

Proportion. The part of a population that exhibits an attribute of interest (i.e., the share of all mothers who smoke during pregnancy). A proportion is always between 0 and 1, but is often multiplied by 100 so it can be represented as a percentage.

Proportional sampling. A sampling scheme where each member of the population has the same probability of being selected. Because of different sampling fractions across strata, PRAMS is *not* a proportional sample.

Questionnaire Development System (QDS). A software system used to record mothers’ responses from mail questionnaires. CDC PRAMS began using QDS for survey data collection starting with 2000 birth data. The use of QDS ended with the development of the PIDS Software System in 2012. For a comprehensive description and detailed information please see *Chapter 6*.

Questionnaire files. These files contain information from the completed questionnaires. The information is entered using data entry programs provided by CDC. See *Chapter 6* for more information.

RTI International. A company that CDC contracted with for the development of a standard Web-CATI system (in 2004) and to provide ongoing data management support (in 2005 -2009) and software support (2009 -2011). RTI software support ended with the implementation of the PIDS System in 2012.

Sample. A subset of the population selected to represent the population. See *Chapter 4* and *Chapter 6* for detailed information regarding all sampling topics.

Sample Birth Certificate Variable file. This file contains selected information from the infant's birth certificate. The sample birth certificate file has one record for each mother in the PRAMS sample. These data are used to assess response bias, verify demographic and other data, and analyze relationships between maternal behaviors, birth weight, and gestational age. See *Chapter 6* for information regarding this data file.

Sampling fraction. A ratio of the number of mothers sampled to the number of mothers eligible to be sampled. See *Chapter 4* for more information regarding Sampling.

Sampling fraction evaluation. Verifies that the stated sampling fractions are actually those that were applied for each stratum.

Sampling frame. The population of subjects eligible for inclusion in the sample. The PRAMS *conceptual* sampling frame is all mothers who delivered a live-born infant in a specified interval. The recommended *operational* sampling frame is infants who were born alive during a specified interval.

Sampling frame bias. Can occur if ineligible records are included in the sampling frame or eligible records are omitted from the sampling frame.

Sampling Frame Birth Certificate Variable file. This file represents the actual sampling frame. It contains one record for every mother who was available to be sampled at the time the sample was drawn. It is used to evaluate the sample selection and to assess any bias that may have been introduced when drawing the sample. It does not become part of the PRAMS analysis data set. See *Chapter 6* for more information.

Sampling plan. The overall annual sample size, rationale, and stratification plan.

Sampling weight. The reciprocal (or inverse) of the sampling fraction or selection probability for a particular stratum. For example, if the sampling fraction is 1/100 (one out of 100 mothers is sampled), the reciprocal (or *sampling weight*) would be 100.

Science Applications International Corporation (SAIC). A company that CDC contracted with for the development of the PIDS system in 2011, now known as Leidos (as of 2013).

Secure Access Management System (SAMS) provides identity proofing and authentication services. It also provides secure file transfer facilities for sending pass through files and receiving certified data files. These files are secured with an address and password.

Selection bias. Occurs when the sample selected for PRAMS in a particular stratum is not representative of all records in that stratum in the sampling frame.

Selection probability. The likelihood that an individual member of the population will be selected for the sample. It ranges from 0 to 1, with 1 representing 100% chance of being selected.

SharePoint Site. Microsoft **SharePoint** is a browser-based collaboration and document management platform from Microsoft - Wikipedia. It allows groups to set up a centralized, password protected space for document sharing. CDC PRAMS implemented a PRAMS SharePoint site for PRAMS grantees as a means of communication for upcoming events and posting of documents and information. The PRAMS SharePoint site replaced the Inside PRAMS website in the spring of 2015.

Standard error. A measure of the variability of a point estimate in repeated sampling. An estimate with a high standard error is imprecise and results in wide confidence intervals, reflecting variability in the population, inadequate sample size, or both.

Standard questions. Questions developed and tested by CDC that are available for states to choose as state-specific questions. Standard questions may be interspersed with core questions on the same topics or placed at the end of the questionnaire with state-developed questions. Standard questions do not require testing by states before their use and allow multiple states with interests in the same topic to exchange data and compare findings. See *Chapter 5* for more information.

State-developed questions. State-developed questions address topics of particular interest to a state. For example, these questions may assess access to or use of particular intervention programs. State-developed questions follow the core questions at the end of the questionnaire. They are developed by the states in consultation with CDC. See *Chapter 5* for more information.

State-specific questions. Questions the state chooses to add to the PRAMS questionnaire. States have a specified number of pages for questions they choose. These questions can either be chosen from the standard questions or developed by the state. See *Chapter 5* for more information.

State Working Group. The State Working Group (SWG) was established to help with planning activities and/or providing input on a variety of operational and methodological PRAMS issues. Topics include but are not limited to; questionnaire revision, national meeting, training activities, software issues, and other topics as needed. The structure and format of the group consists of a group of representatives from 7 regions with one primary representative and one secondary representative (backup person) identified for each region. The primary representatives and secondary representatives will serve in their respective roles for one year. The 7 regions include: Pacific, West, South Central, Midwest, Southeast, Mid Atlantic and Northeast.

Statistical significance. An estimate of the probability of the observed or greater degree of association between two variables under the null hypothesis. Statistical significance is usually conveyed by the *p* value.

Steering Committee. A state-based committee comprised of participating health department representatives and workers from the broader public and private health community. The Steering Committee advises PRAMS staff on the use, dissemination, application of findings, and in securing resources for program changes based on PRAMS findings. The committee may recommend modifications in current intervention programs, in the development of new intervention programs, or in the allocation or reallocation of resources. See *Chapter 3* for detailed descriptions of possible Steering Committee representatives.

Stratum. A defined sub-population sampled with equal frequency. See *Chapter 4* for more information regarding stratification.

Telephone Interviewer Training Manual The PRAMS Telephone Interviewer Manual has been developed to assist states in achieving consistency and, at the same time, to allow states to tailor specific components of the telephone interviewing process to their needs. Several portions of this manual are derived the CDC PRAMS Model Protocol. See *Chapter 3* more information regarding this manual.

Unit nonresponse (often referred to as nonresponse). Sampled person did not complete any part of a questionnaire.