

Glossary of Terms for the PHDS Implementation Manual

A

Address Correction Service: A service that allows the sender, **on request** using the appropriate ancillary service endorsement, to obtain the addressee's new (forwarding) address (if the addressee filed a change-of-address order with the USPS) or the reason for non-delivery.

Adjusted response rate: A modified response rate that removes from the numerator people who do not fully complete the survey (e.g., answered 80 percent of the items in the survey) and removes from the denominator individuals who were sent the survey but could not complete it because the survey was not delivered to them (due to bad address) or individuals who identified themselves as ineligible to complete the survey (e.g., they do not belong to the health system).

American Academy of Pediatrics (AAP): An organization of 60,000 pediatricians committed to the attainment of optimal physical, mental, and social health and well-being for all infants, children, adolescents, and young adults. The AAP offers everything from general child health information to specific guidelines on pediatric issues.

American Board of Pediatrics (ABP): One of the 24 certifying boards of the American Board of Medical Specialties. ABP certification provides a standard of excellence by which the public can select pediatricians and pediatric subspecialists.

Analysis of variance (ANOVA): A statistical method for analyzing differences.

Analytic variables: In this context, analytic variables are the PHDS survey responses, administrative and utilization data, supplemental items, and descriptive information about the health system. These are described in more detail in Section 5.4.

Anticipatory Guidance and Parental Education (AGPE): Assesses whether a core subset of recommended anticipatory guidance and parental education topics are discussed, and if not, whether the parent wished the topic had been discussed or if he/she already had information about the topic and did not need to discuss it with their child's health care provider. The AGPE section of the PHDS is based on what is recommended for discussion during well-child care in the American Academy of Pediatrics Health Supervision Guidelines and the Maternal and Child Health Bureau's Bright Futures recommendations.

B

Bad address rate: The rate of addresses in your database that are estimated to be incorrect.

Behavioral Risk Factor Surveillance Survey (BRFSS): A state survey of U.S. adults designed to gather information about a wide range of behaviors that affect health. The primary focus of these surveys has been behaviors and conditions linked with the leading causes of death—heart disease, cancer, stroke, diabetes, and injury.

C

CAHMI recommendations: Recommendations from the Child and Adolescent Health Measurement Initiative based on its learning and experiences since 1997.

Care coordination (CC): Services that promote the effective and efficient organization and utilization of resources to ensure access to necessary comprehensive services for children.

Care team: The various caregivers who provide different components of care i.e., the physician (pediatrician, family physician), nurse practitioner, and nurse.

Change concepts: Strategies for improving the quality of care provided.

Child and Adolescent Health Measurement Initiative (CAHMI): CAHMI is a national initiative based out of Oregon Health & Science University in the Department of Pediatrics. Originally housed at FACCT (Foundation for Accountability), CAHMI was established in 1998 to develop and facilitate the implementation of a comprehensive set of consumer-centered quality measurement tools. The CAHMI Web site is www.cahmi.org

Chi-squared (x^2) test: A statistical method for testing differences in proportions.

Coded responses: Responses designated by a code. For example: 1=yes, 2=no.

Cognitive ease: The ease of processing information, applying knowledge, and changing preferences.

Cognitive testing: Testing any self-designed new items added to the survey to make sure the wording is interpreted in the way you intended.

Comparative information: A data display that facilitates comparison by showing quality of scores for different groups of children or by specific characteristics

Comprehensive-care composite or “got all care”: Summarizes the number of children who received all aspects of the recommended care assessed by the PHDS. The “got all care” measure summarizes the quality of care findings across the individual, topic-specific measures of care in the PHDS.

Confidentiality: Ensuring that information is accessible only to those authorized to have access. For the PHDS, confidentiality is the process used to ensure that no personal health information about the child or parent is maintained at the end of the project.

Consumer Assessment of Health Providers and Systems (CAHPS®): A private–public initiative that develops and supports the use of a comprehensive and evolving family of standardized surveys that ask consumers and patients to report on and evaluate their experiences with health care.

CAHPS-CCC (Children with Chronic Conditions): A set of measurements that assesses children with chronic conditions developed by CAHMI. More information about this tool can be found on the CAHMI Web site at www.cahmi.org.

Consumer information framework (CIF): The CIF was developed by CAHMI staff while CAHMI was part of the Foundation for Accountability. The CIF has four components: *messages* to inform consumers and enable their decisions; a *model* to organize information; *measures* that support meaningful and understandable evaluations of performance; and *methods* for scoring and grading performance and presenting results. The CIF model organizes health care quality information into four categories: the basics/staying healthy; getting better; living with illness; and changing needs.

Count variable: A count variable is one which may take on only a countable number of distinct values such as 0, 1, 2, 3, 4, ...

Cross-tabulation: A table of survey results, with several rows and columns of figures.

D

Data dictionary: Contains a description of the variables that will be in a data set and describes the response codes and definitions for each of the variables.

Desired population: The population that represents a group that you want to apply your research to. Populations are often defined in terms of demography, geography, occupation, time, care requirements, diagnosis, or some combination of the above.

Discrete, binomial measure: A discrete, binomial variable is one which may take on only a countable number of distinct values such as 0, 1, 2, 3, 4, ... Discrete, binomial variables are usually (but not necessarily) counts. A discrete variable X is said to follow a binomial distribution with parameters.

E

Early and Periodic Screening, Diagnostic and Treatment (EPSDT): The comprehensive and preventive child health program for individuals in Medicaid under age 21. The program includes periodic screening, vision, dental, and hearing services and was defined by law as part of the Omnibus Budget Reconciliation Act of 1989 (OBRA 89) legislation. EPSDT consists of two mutually supportive operational components: (1) assuring the availability and accessibility of required health care resources; and (2) helping Medicaid recipients and their parents or guardians effectively use these resources. See <http://www.cms.hhs.gov/medicaid/epsdt/>.

Electronic medical records: A computer-based patient medical record.

External quality review: Current federal regulations issued by the Centers for Medicare and Medicaid Services (CMS) obligate states to develop a written strategy for assessing the quality of care for Medicaid beneficiaries in managed care plans. These regulations require states to adopt standardized methods for quality review activities, specify mandatory and optional quality review activities, and provide specific protocols for conducting quality reviews. In return, the regulations give states an enhanced federal match for quality review activities and broaden the types of organizations eligible to conduct reviews. (Definition obtained from http://www.cmwf.org/publications/publications_show.htm?doc_id=278078)

External vendor/team: Partners outside of your team hired to handle the parts of the process of implementing the PHDS that you may not be able to handle internally due to time constraints or lack of expertise.

F

Family-centered care (FCC): A system or philosophy of care that incorporates the family as an integral component of the health care system. The PHDS measure assessing family-centered care focuses on the quality of the communication between the health care provider and the family, as well as the overall experience of care.

Frequencies, or frequency distribution: In a survey, a table showing what number (or percentage) of respondents gave each answer to a question.

Frontline health care providers: Providers who work in clinical settings and provide the health care measured in the PHDS.

G

“Gold standard”: What is achievable or what parents should expect from their child’s health care providers.

H

Health care utilization: How much health care people use. For example: how many visits they have, the kinds of visits they have.

Health Insurance Portability and Accountability Act (HIPAA): The U.S. Congress passed the Health Insurance Portability and Accountability Act (HIPAA) in 1996. Title I of HIPAA protects health insurance coverage for workers and their families when they lose or change their jobs. Title II of HIPAA, the Administrative Simplification (AS) provisions, requires the establishment of national standards for electronic health care transactions and national identifiers for providers, health insurance plans, and employers. The AS provisions also address the security and privacy of health data. The purpose of all these standards is to improve the efficiency and effectiveness of the nation's health care system by encouraging the widespread use of electronic data interchange in health care. (Definition derived from www.hipaacompliance.biz)

Health system characteristics: Specific processes, systems, and resources in the health system that are related to the topics measured in the PHDS.

Health Plan Employer Data and Information Set (HEDIS): A collection of standardized performance measures and their definitions designed to ensure that purchasers and consumers can reliably compare the performance of managed health care plans. The performance measures are related to public health issues such as cancer, heart disease, and asthma and also include

well-child visits. HEDIS is sponsored, supported, and maintained by the National Committee for Quality Assurance. See <http://www.ncqa.org/Programs/HEDIS>.

I

Individual provider variation: The dissimilarity of care that a provider gives to various children and families.

Ineligible cases: Children who do not meet the sampling criteria for age and continuous enrollment.

Institutional review board (IRB): An appropriately constituted group that has been formally designated to review and monitor biomedical and behavioral research involving human subjects. In accordance with Food and Drug Administration (FDA) and HHS regulations, an IRB has the authority to approve, require modifications in (to secure approval), or disapprove research. An IRB performs critical oversight functions for research conducted on human subjects that are *scientific, ethical, and regulatory*.

Interim data sets: Early versions of the data set provided when a specific number of surveys have been received and/or are complete.

Internal team: The team within your office involved in implementing the PHDS survey.

Item-level survey responses: Responses to each question in the survey.

K

Kaiser Permanente Northwest (KPNW): A managed care organization. KPNW covers the Oregon and Washington region for Kaiser Permanente.

M

Maintenance of Certification (MOC): The American Board of Medical Specialties adopted MOC to replace periodic recertification. MOC consists of four components: demonstration of professionalism (part I); commitment to life-long learning (part II); demonstration of cognitive expertise (part III); and evaluation of performance in practice (part IV).

Maternal and Child Health Bureau (MCHB): A bureau of the Health Resources and Services Administration, U.S. Department of Health and Human Services. MCHB provides leadership to both the public and private sectors for the delivery of health care services to all mothers and children.

MCHB Bright Futures: Bright Futures is a national initiative begun by MCHB to promote and improve the health and well-being of children from birth through adolescence. Bright Futures is dedicated to the principle that every child deserves to be healthy and that optimal health involves trusting relationships among the health professional, the child, the family, and the community as partners in health practice.

Mean variable: The mean is the arithmetic average of a data set (the sum of the values divided by number of values). (Definition derived from the BRFSS site <http://www.cdc.gov/brfss>)

Medicaid: The U.S. health insurance program for individuals and families with low incomes and resources. It is jointly funded by the states and federal government, and is managed by the states. Among the groups of people served by Medicaid are eligible low-income parents, children, seniors, and people with disabilities. Medicaid is the largest source of funding for medical and health-related services for people with limited income.

Medical chart: A chronological written account of a patient's examination and treatment that includes the patient's medical history and complaints, the physician's physical findings, the results of diagnostic tests and procedures, and medications and therapeutic procedures.

Medline: Medical Literature Analysis and Retrieval System Online (Medline) is an international literature database of life sciences and biomedical information. It covers the fields of medicine, nursing, pharmacy, dentistry, veterinary medicine, and health care.

Microsystems: Clinical microsystems are the frontline units that provide most health care to most people. They are the places where patients, families, and care teams meet. Microsystems also include support staff, processes, technology and recurring patterns of information, behavior and results. Central to every clinical microsystem is the patient. (Definition derived from <http://www.clinicalmicrosystem.org>)

N

National Academy for State Health Policy (NASHP): An organization that works with states to use health and health care findings to implement changes in state programs and policies. (<http://www.nashp.org>).

National Committee for Quality Assurance (NCQA): A private, not-for-profit organization dedicated to improving health care quality. NCQA generates useful, understandable information about health care quality to help inform consumer and employer choice. It also works to generate information and feedback that helps physicians, health plans, and others to identify opportunities for improvement and make changes that enhance the quality of patient care.

National Health Interview Survey (NHIS): Obtains information about the amount and distribution of illness, its effects in terms of disability and chronic impairments, and the kinds of health services people receive.

National Healthcare Quality Report: A report developed by the Agency for Healthcare Research and Quality (AHRQ) that is the first national comprehensive effort to measure the quality of health care in America. The report includes a broad set of performance measures that can serve as baseline views of the quality of health care. The report presents data on the quality of services for seven clinical conditions, including cancer, diabetes, end-stage renal disease, heart disease, HIV and AIDS, mental health, and respiratory disease. It also includes data on maternal and child health, nursing home and home health care, and patient safety.

National Survey of Children with Special Health Care Needs (NS-CSCHN): A survey sponsored by the Maternal and Child Health Bureau of the Health Resources and Services Administration. The primary goal of the NS-CSHCN is to assess the prevalence and impact of special health care needs among children in all 50 states and the District of Columbia. This survey explores the extent to which children with special health care needs (CSHCN) have medical homes, adequate health insurance, and access to needed services. Other topics include care coordination and satisfaction with care. (Definition derived from cdc.org)

National Survey of Children's Health (NSCH): A survey sponsored by the Maternal and Child Health Bureau of the Health Resources and Services Administration that examines the physical and emotional health of children ages 0–17 years of age. Special emphasis is placed on factors that may relate to the well-being of children, including medical homes, family interactions, parental health, school and after-school experiences, and safe neighborhoods. (Definition derived from cdc.org)

National Survey of Early Childhood Health (NSECH): This survey provides national baseline data on pediatric care (and its impact) from the parent's perspective. Questions focus on the delivery of pediatric care to families with children under 3 years of age and the promotion of young children's health by families in their homes. Parents of more than 2,000 children were interviewed for this survey.

Negative indicator measures: Proportion of children who did not receive recommended care.

O

Office Systems Inventory (OSI): Collects descriptive information about specific office systems related to meeting informational needs and addressing concerns, identifying children at risk, providing strong links to community resources, and promoting optimal parent/child relationships.

Over-sample: A sampling procedure designed to give a demographic or geographic population a larger proportion of representation in the sample than the population's proportion of representation in the overall population. Over-samples are often used to study the attitudes or behavior of groups that make up a small proportion of the total population. For instance, one might over-sample African Americans for a study on discrimination, or people ages 65 and over for a study about Medicare.

P

Parents Evaluation of Developmental Status (PEDS®): The PEDS is a methodology developed by Frances Glascoe, Ph.D., for detecting developmental and behavioral problems in children from birth to 8 years of age. This methodology involves asking parents to complete a 10-item questionnaire, which takes only a few minutes. More information about the PEDS can be found at: <http://www.pedstest.com>

Patient-centered care: Health care where patients are respected, listened to, and partnered with so that their needs and preferences are met. In this context, it applies to the helpfulness of care provided to parents and the effect of care on parental confidence.

Payor: The person to whom a note or bill has been or should be paid. In health care, the payor is typically the insurance company, Medicare, Medicaid, or the individual.

Person-identifiable data: Information that can be linked, directly or indirectly, to individual people. Examples include name, geographical subdivisions, phone numbers, social security number, and health records to name a few.

Practice-level assessment: Examines the quality of the health care by specific health care providers or by the place (e.g., office) where care was received.

Pre-notification letter: A letter sent to each selected child in a strategy to maximize response rates, ensure confidentiality, describe how results will benefit the respondent, and provide instructions on how to complete the survey

Pro-PHDS: The reduced item version of the PHDS that includes three age-specific versions: 3–9.99 months old, 10–18.99 months old, and 19–47.99 months old.

PHDS-PLUS: An additional version of the PHDS for telephone administration.

Provider well-child templates: Standardized forms that can be used by the provider for well-child visits that list topics to cover in the visit.

Psychosocial issues in the family: Asking the parent about their own psychological and social aspects of well-being, including depression, emotional support, changes or stressors in the home, and how parenting is working.

Q

Quality chasm: A term drawn from a report from the Institute of Medicine's Committee on the Quality of Health Care in America, *Crossing the Quality Chasm: A New Health System for the 21st Century*, which urgently calls for fundamental change to close the quality gap. The report authors recommend a redesign of the American health care system, and provide overarching principles for policymakers, health care leaders, clinicians, regulators, purchasers, and others. It offers a set of performance expectations for the 21st century health care system, a set of 10 new rules to guide patient-clinician relationships, a suggested organizing framework to better align incentives inherent in payment and accountability with improvement in quality, and key steps to promote evidence-based practice and strengthen clinical information systems.

Quality measures: Measures that summarize information from between one and 18 individual PHDS items and assess individual components of recommended preventive and developmental care. They are scored on a 0–100 scale, where 0 indicates that recommended care is not received and 100 indicates that all aspects of care were received.

Quality scores: Scores on quality measures.

R

Raw response rate: The number of questionnaires returned divided by the number of children in your starting sample.

Recode: Reassigns the values of existing variables or collapses ranges of existing values into new values.

Reporting audience: The audience that you are reporting survey results to.

Request for Proposals (RFP), or invitation to bid: A proposal made by a commercial organization inviting bids from possible suppliers of a product or service, or by a government or other funding agency inviting bids from possible research bodies.

S

Socio-demographic characteristics: Characteristics of human populations, such as risk for depression, relationship to child, education level, and marital status.

Stakeholder: A person who is (or might be) affected by any action taken by an organization or group. Examples are parents, children, customers, owners, employees, associates, partners, contractors, suppliers, and people that are related or located near by. Any group or individual who can affect or who is affected by achievement of a group's objectives.

Standardized Developmental and Behavioral Screening (SDBS): Screening for developmental and behavioral delays that occurs through the use of a standardized, valid screening tool.

Staying Healthy domain of the Consumer Information Framework: The Consumer Information Framework (CIF) is a customer-centered framework for quality measurement that is based on what consumers conveyed as their health care needs across the lifespan, encompassing the following four domains: Staying Healthy, Getting Better, Living with Illness or Disability,

and Coping with the End of Life. The "Staying Healthy" domain focuses on health care aimed at prevention and early detection of health or developmental problems.

Survey disposition: The current status of the survey in the survey administration process (e.g., whether the survey was completed, and if so, when in the process it was sent back).

T

T-test: Differences in mean scores between two groups.

Threshold measure: A threshold measure is a binomial measure identifying children who did and did not receive a threshold level of quality of care. The thresholds for the PHDS measures were based on consensus obtained from the PHDS advisors about the level of care considered "high quality" for each measure and concurrent validity runs of the threshold measures with other PHDS measures and child/parent outcomes. More information about the threshold measures can be found in the papers listed in Appendix B.

U

Units of analysis: The entities, areas, or groups by which the PHDS findings are analyzed. Each unit has different specifications for sampling.

Utilization data: Data representing the amount of services used prior to the survey.

W

Weekly tracking reports: Reports that describe the survey response rates throughout the administration process and reported on a weekly basis by your vendor.

Weighting methodology: A technique used to assure representation of certain groups in the sample. Data for underrepresented cases are weighted to compensate for their small numbers, making the sample a better representation of the underlying population.

Well-child care: Well-child examinations are intended to assess children's growth and development, recognize problems early on, provide immunizations, educate parents, and provide treatment for existing problems. The American Academy of Pediatrics and the Maternal and Child Health Bureau provide guidelines and a schedule for well-child visits.