pcornet
The National Patient-Centered Clinical Research Network

Building **Trustworthiness** in PCORnet

PCORnet Public Trustworthiness
Important Terms and Acronyms

Acronym	Title	Definition
AHRQ	Agency for Healthcare Research and Quality	AHRQ is a federal agenda that was established to enhance the quality, appropriateness, and effectiveness of health care services and access to care by conducting and supporting research, demonstration projects, and evaluations; developing guidelines; and disseminating information on health care services and delivery systems.
CC	PCORnet Coordinating Center	The PCORnet Coordinating Center (CC) provides technical and logistical support to new and existing CDRNs and PPRNs that comprise PCORnet and supports overall coordination, collaboration, and communication for PCORnet. The CC includes Executive Leadership, Project Management Office (PMO), and Committee leads.
CDC	Centers for Disease Control and Prevention	The leading federal agency for consumer health education; CDC focuses national attention on developing and applying disease control and prevention.
CDE	Common Data Element	Common data elements (CDEs) are standardized data elements that are shared across networks. The data elements in PCORnet's CDM are CDEs. For information about other CDEs, see the NIH CDE Resource Portal.
CDM	Common Data Model	A system that is utilized by multiple data sources and data services to standardize the definition, format, and content of data across participating data partners so that standard applications, tools, and methods can be applied. A CDM defines the relationships between disparate data entities within a particular environment, thus establishing the context within which those entities have meaning.
CDR	Clinical Data Repository	A real-time database that consolidates data from a variety of clinical sources to present a unified view of a single patient. Typical data types which are often found within a CDR include: clinical laboratory test results, patient demographics, pharmacy information, radiology reports and images, pathology reports, hospital admission, discharge and transfer dates, ICD-9/ICD-10 codes, discharge summaries, and progress notes.
CDRN	Clinical Data Research Network	A system-based network (such as hospital or healthcare system) that provides data drawn from everyday clinical encounters in healthcare settings, such as hospitals and outpatient clinics. Together they represent a range of healthcare delivery settings and practice arrangements representing real-world U.S. health care delivery and a wide range of medical conditions. There are 13 CDRN's in Phase II of PCORnet.
CER	Comparative Effective Research	Any research program intended to determine the relative efficacy of alternate approaches to patient evaluation or treatment, in order to develop evidence that supports one approach over

		another in a given patient or context to determine which interventions work best for which patients and which interventions pose the greatest benefits and harms. The core question of comparative effectiveness research is which treatment works best, for whom, and under what circumstances.
Co-I	Co-Investigator	An individual recognized by the PI as someone making a significant contribution to a project. A co-investigator is an individual who the PI relies on to assume responsibilities above those of other personnel and who has dedicated effort to the project.
Co-PI	Co-Principal Investigator	A co-PI shares scientific and administrative leadership responsibilities with the Principal Investigator (see PI).
CTSA	Clinical and Translational Science Awards	The CTSA Program is designed to develop innovative solutions that will improve the efficiency, quality and impact of the process for turning observations in the laboratory, clinic and community into interventions that improve the health of individuals and the public.
DAOs	Disease Advocacy Organizations	Organizations that allow individuals with a shared interest to pool their collective resources and shared knowledge of a medical condition.
EHR	Electronic Health Record	A source of electronic information about an individual's health status and health care. EHRs contain much of the same information that is found in a patient's (paper) medical chart, but the data is digital and can be viewed, transmitted, and/or integrated across settings and between different health care providers (e.g. primary care physicians, specialists). EHRs may contain administrative and billing data, patient information, notes, vital signs, medical histories, diagnoses, medications, immunization records, allergies, radiology images, lab and other test results, and much more.
EMR	Electronic Medical Records	EMR and EHR are often used interchangeably. The EMR are patient records created in hospitals and ambulatory environments, which can serve as a data source for the EHR.
FDA	U.S. Food and Drug Administration	The FDA is responsible for protecting and promoting public health through the regulation and supervision of food safety, tobacco products, dietary supplements, prescription and over-the-counter pharmaceutical drugs (medications), vaccines, biopharmaceuticals, blood transfusions, medical devices, electromagnetic radiation emitting devices (ERED), cosmetics, animal foods & feed and veterinary products.
GINA	Genetic Information Nondiscrimination Act	A federal law that protects individuals from genetic discrimination in health insurance and employment. Genetic discrimination is the misuse of genetic information.
HIPAA	Health Insurance Portability and Accountability Act	A government act to reduce fraud and abuse and protect patient privacy in health care.
HIT	Health Information Technology	The use of computer applications to record, store, protect, retrieve, and transfer clinical, administrative, and financial information electronically within and among various health care settings.
HRSA	Health Resources and	The primary Federal agency for improving access to health care

	Services Administration	services for people who are uninsured, isolated or medically vulnerable.
IT	Information Technology	The application of computers to store, retrieve, transmit and manipulate data, often in the context of a business or other enterprise.
MoU	Memorandum of Understanding	A bilateral or multilateral agreement between two or more parties.
MU	Meaningful Use	A tiered set of objectives related to the American Recovery and Reinvestment Act (ARRA) Medicare and Medicaid EHR incentive programs. Meaningful Use criteria must be met by eligible professionals and hospitals if they are to collect financial rewards for the implementation of qualified, certified EHRs to achieve health and efficiency goals.
NAM	National Academy of Medicine	An independent organization of eminent professionals from diverse fields including health and medicine; the natural, social, and behavioral sciences; and beyond.
NIH	National Institutes of Health	The National Institutes of Health (NIH) is the nation's medical research agency — making important discoveries that improve health and save lives.
PCE	Patient and Consumer Engagement	The process by which patients and consumers become invested in their own health and take control of their care. Patients and consumers are to be treated as key stakeholders when making decisions about their health and health care.
PCO	Patient-Centered Outcome	Patient-centered outcomes (PCOs) are those outcomes that matter to patients and their caregivers. PCOs answer patient-centered questions such as "Given my personal characteristics, conditions and preferences, what should I expect will happen to me?" "What are my options and what are the potential benefits and harms of those options?"; "What can I do to improve the outcomes that are most important to me?"; and "How can clinicians and the care delivery systems they work in help me make the best decisions about my health and healthcare?" PCOs may be objective measures (e.g. cholesterol level) or subjective measures (e.g. health-related quality of life), and include some but not all patient-reported outcomes (PROs).
PCOR	Patient-Centered Outcomes Research	Research that helps people and their caregivers communicate and make informed healthcare decisions, while allowing their voices to be heard in assessing the value of healthcare options. This research answers patient-centered questions.
PCORI	Patient-Centered Outcomes Research Institute	PCORI was authorized by the Patient Protection and Affordable Care Act of 2010 as a nonprofit, nongovernmental organization, with a purpose of helping patients, clinicians, purchasers, and policy makers make more informed health decisions by "advancing the quality and relevance of evidence about how to prevent, diagnose, treat, monitor, and manage diseases, disorders, and other health conditions."
PCORnet	National Patient-	An innovative initiative of the Patient-Centered Outcomes Research

	Centered Clinical Research Network	Institute (PCORI) designed to make it faster, easier, and less costly to conduct clinical research than is now possible by harnessing the power of large amounts of health data and patient partnerships.
PCP	Primary Care Provider	A health care practitioner who sees people that have common medical problems. This person is usually a doctor, but may be a physician assistant or a nurse practitioner.
PhRMA	Pharmaceutical Research and Manufacturers of America	PhRMA represents the country's leading biopharmaceutical researchers and biotechnology companies. PhRMA's mission is to conduct effective advocacy for public policies that encourage discovery of important new medicines for patients by pharmaceutical and biotechnology research companies.
PI	Principal Investigator	Lead scientist(s) for a research project.
PMI	Precision Medicine Initiative	Precision medicine is an emerging approach for disease prevention and treatment that takes into account people's individual variations in genes, environment, and lifestyle. The Precision Medicine Initiative® will generate the scientific evidence needed to move the concept of precision medicine into clinical practice.
PMO	Project Management Office	The PCORnet PMO's core functions include: Program Management, Technical Assistance, Internal Program Evaluation, and Convening. It is responsible for overall coordination, oversight of TFs, development of timelines and assignment of activities, adherence to deliverables, support to PCORnet leadership and networks, and management of the distributed research network.
PPRN	Patient Powered Research Network	An active group of patients, advocacy organizations, and/or clinical research partners who form a network to collect health data, conduct research studies, and provide a common venue for patients and researchers who are focused on moving the research agenda forward and improving decision-making and outcomes for specific medical conditions. Each PPRN is committed to preparing its network to conduct CER. There are 20 PPRN's in Phase II of PCORnet.
PRO	Patient-Reported Outcome	Patient-reported outcomes (PROs) are defined by the Food and Drug Administration as a report of the status of a patient's health condition by the patient without interpretation by a clinician or anyone else. PCORnet also allows caregivers or people who support the patient to provide proxy reports, provided there isn't subjective interpretation of the patient's response leading to modification of data. Reports from non-clinician caregivers are accepted as PROs in instances where patients are incapable of direct communication via self-report (e.g. parent reports for neonatal patients).