

PCORnet: A Commitment to Patient Privacy and Data Security

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The public can benefit greatly from research that harnesses electronic health record data generated through real-world clinical experiences to address critical questions for improving health and health care. PCORnet, the National Patient-Centered Clinical Research Network, is a novel coalition of networks led by patients, health systems, researchers, and clinicians. PCORnet is funded by the Patient-Centered Outcomes Research Institute (PCORI) to realize the goal of improving the health of Americans through faster clinical research that is directly relevant to patients and those who care for them.

Patients are at the center of PCORnet, helping select the research questions that are studied, and playing key roles in how the network operates. Patient involvement is also vital for developing approaches to protect data privacy and ensure data security.

Because health information holds such promise, it is crucial that PCORnet identify and implement appropriate privacy and confidentiality protections to guide its research. The principles listed below are guiding PCORnet's development of policies for assuring the privacy, security, and confidentiality of health data and ensuring that the data are used appropriately. PCORnet's [Data Privacy Task Force](#) has been charged with policy development, based on these principles.

Guiding Principles

- 1) PCORnet believes that protection of privacy, data confidentiality, and security is essential to the existence and success of healthcare data research networks.
- 2) Patients, patient advocates, and the public are actively engaged with PCORnet at a national level and locally within each participating network, shaping policies and procedures related to data use and patient privacy for their network.
- 3) Decisions to participate in specific PCORnet research projects will always be made at the network level (that is, by the individual CDRN or PPRNⁱ).
- 4) Each individual PCORnet network is committed to protecting patient privacy and adhering to all local policies regarding the use of healthcare data.
- 5) PCORnet member networks are committed to sharing best practices for protection of patient data.
- 6) All research practices in PCORnet comply with current national and local regulatory and oversight provisions.
- 7) PCORnet will communicate clearly with patients, clinicians and all other stakeholders about how their data are used in clinical research, and will seek input and consent by patients and other key stakeholders according to policies developed at the network level.
- 8) The PCORnet Common Data Model (CDM) is based on the Mini-Sentinel Common Data Model (MSCDM; www.mini-sentinel.org) and has been informed by other distributed initiatives such as the HMO Research Network, the Vaccine Safety Datalink, various AHRQ Distributed Research Network projects, and the ONC Standards & Interoperability Framework Query Health Initiative. The PCORnet CDM is positioned within healthcare standard terminologies (including ICD, SNOMED, CPT, HCPCS, and LOINC) to enable interoperability with and responsiveness to evolving data standards.

PCORnet is building a dynamic and engaged alliance with partnerships involving many different stakeholders, including patients, families, communities, clinicians, and health system leaders. These partnerships will ensure that PCORnet provides the greatest possible benefit and is capable of conducting research on a wide array of topics and health conditions. PCORnet will support many different kinds of research studies, and PCORnet policies will reflect the diverse capabilities of our network.

To support PCORnet’s mission to conduct research that is truly patient-centered, we will solicit, welcome, and use public input in developing these policies.

¹ CDRN = Clinical Data Research Network; PPRN = Patient-Powered Research Network