



October 31, 2022

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1828 L Street NW, Suite 900  
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**Re: Response to RFI on Prioritizing PCORnet Data Infrastructure Enhancements: Social Determinants of Health, Patient Reported Information, and Claims Data**

Dear Dr. Cook:

AcademyHealth welcomes the opportunity to provide input to the Patient-Centered Outcomes Research Institute (PCORI) on the NORC PCORnet data capacity reports and priorities for data infrastructure enhancement. We are the professional home of more than 3,000 health services researchers, policy experts, and practitioners, and we strongly support the production, dissemination, and use of evidence to inform policy and practice. Our membership is highly engaged with PCORI and its work, from informing the creation of the Institute to serving in PCORI's leadership to receiving funding support. AcademyHealth recognizes and applauds PCORI's unique contributions to the development and promulgation of practice- and policy-supporting evidence.

Some notable strengths of PCORnet include its representation of safety net providers, demographic and geographic range, use of the Common Data Model (CDM), and considerable infrastructure for engagement, both with respect to ancillary research and network activities.

**What strategic opportunities for data infrastructure enhancements do you feel are most important to support the use of PCORnet for definitive research that advances PCORI's National Priorities for Health?**

The PCORnet distributed research network model, and its national scope present opportunities for data infrastructure enhancements related to 1) social determinants of health (SDOH), 2) patient-reported outcomes (PROs) and other patient-generated health data (PGHD); and 3) Centers for Medicare & Medicaid Services (CMS) claims data.

Opportunity 1: Expanding Social Determinants of Health Data across PCORnet® Clinical Research Networks

Strengthening PCORnet data infrastructure by increasing SDOH data collection relates to the [Quintuple Aims](#) for healthcare improvement, namely 1) improvement of population health, 2) enhancement of the care experience, 3) reductions of costs, 4) workforce well-being, and 5) advancing health equity. Integration of SDOH data into health system electronic health records (EHRs) or Clinical Research Network (CRN) research data warehouse/DataMart could aid in linking patients with needed services and resources through improving data exchange with community-level supports. These efforts could boost identifying appropriate methods for care management and clinical decision-making, increase health systems interactions with the social sector, improve community-based care coordination and resources, and determine solutions for resource allocation and geospatial needs assessment. Linking geocoding to community-level data can reduce biases inherent in aggregate data, and can facilitate data linkages to nationally representative public data sources and other datasets with plentiful social risk and SDOH data.



Expanding SDOH data across PCORnet CRNs can advance the science of dissemination by facilitating data extraction of SDOH data from clinical notes in EHRs through natural language processing (NLP) algorithms and tools, which PCORnet Network Partners can share with researchers for analyses on the impact of SDOH on health outcomes. These strategic opportunities could inform the evaluation of the breadth of existing inequities, pathways for care interventions, health system integration, cross-sector and multisectoral collaborations, and the standardization of measures to collect SDOH data.

### Opportunity 2: Enhancing Data Infrastructure for Collection and Integration of Patient-Reported Outcomes and other Patient-Generated Health Data across PCORnet Clinical Research Networks

Despite increased interest in prioritizing and scaling patient-centered care, patient-reported outcomes (PRO) data collection is limited. Provider engagement, administrative engagement, payer incentives, and having a provider champion that promotes PRO collection, are some factors associated with enhancing collection rates. Patient-generated health data and PRO are essential for advancing patient-centered care, developing interventions tailored to patients' needs, and evaluating and measuring the efficiency of interventions compared to outcomes. The PCORnet distributed research network model and its national scope presents an excellent opportunity for widespread implementation of PRO/PGHD data collection. Specialists can share facilitators and challenges of data collection, understand the national landscape of PRO/PGHD data, and develop best practices for improving collection rates.

PCORnet is an excellent venue for implementing PRO/PGHD collection and use at the point of care and in the context of a learning health system (LHS), pragmatic research, and real-world evidence. The power of PCORnet is in conforming to a CDM that facilitates large-scale clinical research nationwide. However, patient-centered care and research must be responsive to factors that dictate PRO collection such as quality improvement efforts, health systems priorities, specific policy incentives and initiatives, and patient needs and preferences. The reason to consider this as second to SDOH is related to the expected heterogeneity in specific measures across local settings.

### Opportunity 3: Expanding Access to Medicare and Medicaid Claims Data Across PCORnet® Clinical Research Networks

Medicare and Medicaid claims data could fill gaps in electronic health records (EHR) data collection. There are considerable challenges for expanding access to CMS data, including high costs of purchasing and accessing data, lack of timeliness in obtaining claims data, and DUA restrictions. The primary purpose of claims data is for billing purposes, so data linkage might not capture crucial information meaningful for health outcomes research purposes.

Many ongoing infrastructure activities signal shifts in CMS claims infrastructure. It may be worthwhile for PCORnet to wait before building its infrastructure to interface with a system in transition. In the meantime, it may be more prudent to continue to link on a project basis as health information exchanges (HIEs) and All-Payer Claims Databases (APCDs) gain more traction, and value-based payment (VBP) related quality measures increasingly adopt all-payer denominators (e.g., in MIPS).

### **Do the opportunities identified in the report resonate with your sense of where enhancements to PCORnet resources could make the greatest contribution to national data infrastructure for health research to national data infrastructure for health research?**

Enhancements to PCORnet resources could significantly contribute to research through better social determinants of health data collection and dissemination.

**Are there partnerships with specific organizations you feel will best support PCORI's efforts to implement proposed enhancement opportunities for data infrastructure and conduct research aligned with PCORI's strategic priorities?**

AcademyHealth and our members stand ready to assist PCORI in its work to implement the proposed enhancements for data infrastructure and conduct research aligned with PCORI's strategic priorities. AcademyHealth hosts numerous learning networks that could provide unique expertise for PCORI and PCORnet from researchers, practitioners, policymakers, patients, and other users of data. For example, the State-University Partnership Learning Network (SUPLN) for state-based partnerships between Medicaid policymakers and their resident state or state-related university research teams and can provide technical assistance and partnerships.

**Are there other priorities or areas for consideration related to the report you would like PCORI to consider?**

PCORI could consider additional barriers to collecting and using SDOH data, such as prioritizing the importance of building trust between patients and providers. These relationships should mutually benefit all parties and promote patient and stakeholder agency. Using timely and unbiased data and dissemination of data through culturally appropriate methods could support PCORI's priority of advancing the science of dissemination, implementation, and health communication.

There are numerous PROs available and developing them into EHRs is a substantial undertaking that involves infrastructure investment, staff training, and workflow modifications. The power of PCORnet is in the ability to conform to a CDM that facilitates large-scale clinical research nationwide. However, patient-centered care and research need to be responsive to patient needs and preferences. For example, the needs and preferences of patients in safety net clinics in Oregon may not be the same as those in Geisinger Health System in PA. It would be most effective and resource-efficient if the needs of the patient communities being served drive the decisions about which PROs to include. It would not make sense to stipulate PRO instruments in a top-down fashion.

What could be valuable is for PCORnet to maintain a PRO/PGHD bank, repository, or technical specifications guidelines hub. For example, a "menu" of instruments and technical specifications such that if a system identifies depression screening as a priority investment, the system implements a solution that is interoperable with other systems in PCORnet that have that same shared priority. In this regard, they would be promoting metric/protocol standardization but not at the expense of patient-centered care.

Thank you for the opportunity to discuss PCORnet investments. For further comment, clarification, or inquiry, please email Josh Caplan at [Josh.Caplan@AcademyHealth.org](mailto:Josh.Caplan@AcademyHealth.org).