

Louisiana Public Health Institute

<https://lphi.org/>

PCORnet® Network Partner in REACHnet since 2013

The purpose of this Site Profile is to provide an overview of the basic research processes at Louisiana Public Health Institute. This profile can help you understand: current PCORnet® Study participation; patient recruitment methods and institutional procedures related to Institutional Review Board and contracting; and data linkages.

Louisiana Public Health Institute serves as the REACHnet Coordinating Center. It is not a health system and does not provide direct patient care. For observational studies and prospective trials, the REACHnet Coordinating Center can serve as a data coordinating center, support patient and stakeholder engagement methods, provide data services for participating REACHnet sites, and facilitate approaches for recruitment, PRO collection, and linkage with claims or other data sources.

PCORnet® Study Leadership (Studies listed below where Louisiana Public Health Institute is the lead site)

Consented Studies (interventional trials & studies with patient-reported data collection)

None

Observational Studies

- Utilizing PCORnet to support transition from pediatric to adult centered care and reduce gaps in recommended care in patients with congenital heart disease

Data Science

None

Engagement (for example, PCORI-funded Science of Engagement projects)

None

PCORnet® Study Participation (Studies listed below where Louisiana Public Health Institute is participating)

Consented Studies (interventional trials & studies with patient-reported data collection)

- Test to Treat

Observational Studies

- Equity in Treatment for Asthma Between Latinos and Whites
- Estimating the Burden of Nonalcoholic Steatohepatitis Using a Multistate Electronic Health Record Data Network
- Understanding the Short- and Long-term Effects of Disasters and other Big Events on the Overdose Crisis

Data Science

None

Engagement (for example, PCORI-funded Science of Engagement projects)

- Achieving Equity: Inclusion of Adults with Congenital Heart Disease (CHD) Living with Neurodevelopmental Disorders (NDDs) in Patient Centered Outcomes Research
- Measuring co-creation during the engagement process in research: A pathway forward

Institutional Procedures

Institutional Review Board (IRB) Arrangements

- May rely on single/central IRB for federally mandated studies only
- May rely on single/central IRB for non-federally mandated studies
- May accept commercial IRB review

Order of Activation

- IRB approval required before contract execution
- Contract execution required before IRB approval
- IRB and contract can be executed in parallel

Administrative Efficiencies

- Will accept PCORnet[®] Master Clinical Research Agreement without redlines for PCORI-funded studies
- Has signed the PCORnet[®] Master Data Sharing Agreement
- Has contracted directly with Industry funders

Linkage with Other Data Sources

Health Plan Claims

- In same or adjacent data mart with common ID
- Established linkage infrastructure and regulatory

Name(s) of Plan(s)

CVS Health, Humana, Louisiana Blue

Other (non-EHR) Data

- Linked in DataMart*
- Established linkage infrastructure and regulatory

Name(s) of Data Source(s)

Louisiana Tumor Registry

*DataMart refers to a specific data source consisting of data collected, captured or otherwise obtained by the health system. Each site's PCORnet DataMart houses data standardized to the PCORnet[®] Common Data Model.

Louisiana Public Health Institute is a Network Partner in PCORnet[®] which has been developed with funding from the Patient-Centered Outcomes Research Institute[®] (PCORI[®]). Louisiana Public Health Institute's participation in PCORnet is funded through a PCORI Award (RI-LPHI-01-PS8). PCORnet[®] is intended to improve the nation's capacity to efficiently conduct patient-centered health research, particularly comparative clinical effectiveness research (CER), by providing a large, highly representative network of health data, research expertise, and patient insights.