PCORnet Common Data Model — Enabling Research Analysis on a National Scale

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The Challenge

How do you ask a research question at hundreds of institutions and get back results you can trust?

Option 1 — Write a description and have everyone create a local implementation to run on their data.

Option 2 — Create an algorithm that can run against a single, common data model.
Why a Common Data Model?

Same data are represented differently at different institutions (e.g., Type of Encounter)

In order to be able to trust results of an analysis, need to have consistent representations.
PCORnet Common Data Model v3.0

- Fundamental basis
  - DEMOGRAPHIC

- Associations with PCORnet clinical trials
  - PCORNET TRIAL

- Process-related data
  - HARVEST

- Data captured from processes associated with healthcare delivery
  - ENROLLMENT
  - DISPENSING
  - DEATH
  - DEATH CAUSE

- Data captured within multiple contexts: healthcare delivery, registry activities, or directly from patients
  - VITAL
  - CONDITION
  - PATIENT-REPORTED OUTCOMES (COMMON MEASURES)

- Data captured from healthcare delivery, direct encounter basis
  - ENCOUNTER
  - DIAGNOSIS
  - PROCEDURES
  - PRESCRIBING
  - LABORATORY RESULTS (COMMON MEASURES)

- 3 versions released between May 30, 2014 & June 1, 2015

- 500+ discrete comments from stakeholders
- Multiple stakeholder sessions to review feedback

- Available at www.pcornet.org/pcornet-common-data-model/
Assessment of Data Quality

Marker: 1
Content:

**STEP 1**
Diagnostic Query (Partner)

**STEP 2**
Data Characterization (Partner)

**STEP 3**
Review of results (CC)

Data refresh (Partner)

Mitigation plan (Partner & CC)

Research

Generation of empirical data characterization report (CC)
PCORnet: the National Patient-Centered Clinical Research Network

- **20** Patient-Powered Research Networks (PPRNs)
- **13** Clinical Data Research Networks (CDRNs)

People’s data available from approximately ~110 Million*

*Based on data from 64 DataMarts as of April 22, 2016
PCORnet and PCORI

About PCORnet

PCORnet, the National Patient-Centered Clinical Research Network, is an innovative initiative of the Patient-Centered Outcomes Research Institute (PCORI). The goal of PCORnet is to improve the nation’s capacity to conduct comparative clinical effectiveness research efficiently by creating a large, highly representative network for conducting clinical outcomes research that directly involves patients in the development and execution of the research. More information is available at www.pcornet.org.

About PCORI

The Patient-Centered Outcomes Research Institute (PCORI) is an independent, nonprofit organization authorized by Congress in 2010. Its mission is to fund research that will provide patients, their caregivers, and clinicians with the evidence-based information needed to make better-informed healthcare decisions. PCORI is committed to continually seeking input from a broad range of stakeholders to guide its work. More information is available at www.pcori.org.