PCORnet

Leveraging the data dividend for evidence generation

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PCORnet’s Mission

• 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 partnerships with patients and health systems.

• Harness data and research findings to facilitate health system learning and improvement.

• And in the process, transform the culture of clinical research from one directed by researchers to one driven by the needs of patients and those who care for them.
PCORnet Health Systems Partners

PCORnet’s Clinical Data Research Networks (CDRNs)

- The Chicago Community Trust (CAPriCORN)
- The Children’s Hospital of Philadelphia (PEDSnet)
- Harvard University (SCILHS)
- Kaiser Foundation Research Institute (PORTAL)
- Louisiana Public Health Institute (REACHnet)
- Mayo Clinic (LHSNet)
- Oregon Community Health Information Network (ADVANCE)
- University of California, San Diego (pSCANNER)
- University of Florida (OneFLorida)
- University of Kansas Medical Center (GPC)
- University of Pittsburgh (PaTH)
- Vanderbilt University (Mid-South CDRN)
- Weill Medical College of Cornell University (NYC-CDRN)
PCORnet Health System Participants

130 health systems across the country
Over 60 data marts
Data on over 70 million patients
PCORnet Common Data Model v3.0

**DEMORPHIC**
- PATID
- BIRTH_DATE
- BIRTH_TIME
- SEX
- HISPANIC
- RACE
- BIOMARKER_FLAG

**VITAL**
- VITALID
- PATID
- ENCYCLOPEDIA (optional)
- MEASURE_DATE
- MEASURE_TIME
- VITAL_SOURCE
- HT
- WT
- DIASTOLIC
- SYSTOLIC
- ORIGINAL_BMI
- BP_POSITION
- SMOKING
- TOBACCO
- TOBACCO_TYPE

**ENROLLMENT**
- PATID
- ENR_START_DATE
- ENR_END_DATE
- CHART
- ENR_BASIS

**DISPENSING**
- PATID
- PATIENT_NAME
- PRESCRIBINGID
- DISPENSE_DATE
- NDC
- DISPENSE_SUP
- DISPENSE_AMT

**CONDITION**
- CONDITIONID
- PATID
- ENCYCLOPEDIA (optional)
- REPORT_DATE
- RESOLVE_DATE
- ONSET_DATE
- CONDITION_STATUS
- CONDITION_TYPE
- CONDITION_SOURCE

**DEATH**
- PATID
- DEATH_DATE
- DEATH_DATE_IEM
- DEATH_SOURCE
- DEATH_CONFIDENCE

**PRO_CME**
- PRO_CME_ID
- PATID
- ENCYCLOPEDIA (optional)
- PRO_ITEM
- PRO_LOINC
- PRO_DATE
- PRO_TIME
- PRO_RESPONSE
- PROCEDURE
- PRO_CAT

**DIAGNOSIS**
- DIAGNOSISID
- PATID
- ENCYCLOPEDIA (optional)
- ENC_TYPE (replicated)
- ADMIT_DATE (replicated)
- PROVIDER (replicated)
- DX
- DX_TYPE
- DX_SOURCE

**PROCEDURES**
- PROCEDURE_ID
- PATID
- ENCYCLOPEDIA (optional)
- RX_PROVIDER
- RX_ORDER_DATE
- RX_ORDER_TIME
- RX_START_DATE
- RX_END_DATE
- RX_QUANTITY
- RX_FREQUENCY
- RX_BASIS

**LAB_RESULT_CM**
- LABRESULTID
- PATID
- ENCYCLOPEDIA (optional)
- LAB_NAME
- SPECIMEN_SOURCE
- LAB_LOINC
- STAT
- RESULT_LOC
- LAB_RESULT_CM
- LAB_RESULT_CM_TYPE

**PREScribing**
- PRESCRIBINGID
- PATID
- ENCYCLOPEDIA (optional)
- RX_PROVIDER
- RX_ORDER_DATE
- RX_ORDER_TIME
- RX_START_DATE
- RX_END_DATE
- RX_QUANTITY
- RX_FREQUENCY
- RX_BASIS

**HARVEST**
- NETWORK
- NETWORK_NAME
- DATAMART
- DATAMART_NAME
- PATIENT_NAME

**Process-related data**
- REFERRAL_DATE
- REFERRAL_DATE
- REFERRAL_DATE
- REFERRAL_DATE
- REFERRAL_DATE
- REFERRAL_DATE
- REFERRAL_DATE

Data captured within multiple contexts: healthcare delivery, registry activity, or directly from patients.
Challenge: getting “complete” data

(what’s wrong with this picture?)

Data in Claims

Data in Ambulatory EHRs

Data in inpatient EHRs

Patient Reported Outcomes

Genomic data

Bio-specimens

Death data

Social determinants of health

Prescriptions paid out of pocket
“For a data infrastructure to be sustainable, there must be a business case for everyone who needs to participate: for patients, clinicians, and health systems leaders as well as for researchers and research funders”

Basit Chaudry
IBM Research
July 2, 2012
PCORnet Sustainability Plan –
3 Primary Sources of Support

NIH/PCORI/Others

Industry

Health Systems

Sustainability
PCORI – IOM meeting held on June 20, 2014

29 health systems leaders (majority from PCORnet health systems – Vanderbilt, Baylor, UPMC, NYU, Kaiser-Permanente)

Health systems leaders not especially interested in either embedded clinical trials or large observational studies

But very excited by prospect of closer ties with PCORnet researchers and data; a focus on measuring system performance and on opportunities for iterative data analyses and rapid-cycle learning
PCORI provides support to PCORnet CDRN sites to engage health systems leaders to jointly identify and prioritize a set of data-driven research activities of high interest to systems and/or clinicians within the systems. This is organized and supported by PCORnet’s Health Systems’ Interaction Collaborative Group.

PCORI invites submission of proposals of high priority to health systems for up to five one-year (rapid cycle) studies. These studies will be awarded through a limited PFA.
• Need for data availability at the point of care
• Delivery system leaders helping to shape research priorities
• Early relationship-building between research and operations
• Shared leadership accountability
• Dissemination and implementation plans essential
• Critical need to involve plans and link systems data with claims data.
• The same data should be used for clinical care, measurement, and reporting
• Incentives for improving front-line data collection may include the opportunity for clinicians to participate in research activities
• Need for electronic health records to record core social determinants, patient preferences, and key behavior patterns
• Training needs for future researchers within system settings
Wrap-up

- Health systems leaders – both delivery systems and plans - must be actively involved if learning is to happen
- The case for research as a useful management tool remains to be made – though interest is mounting
- Improved performance assessment holds promise if it can be made useful and credible
- There is a need for training researchers versed in the language and perspectives of the C-suite
- There is a need to involve clinicians in the use of data if they are to support the use of the EMR and notion of the learning health system.