UC-Research eXchange (UC-ReX): Connecting Data Across our Clinical Data Warehouses

UC-Wide Biomedical Research Acceleration Initiative Retreat

9/23/11
SHRINE

At a glance

Key Features
- Request aggregate numbers of patients seen at participating hospitals who meet criteria of interest
- Useful for:
  - Characterizing potential clinical trial cohorts
  - Generating new research hypotheses
  - Conducting research requiring large sample sizes (e.g., population health studies)

Available to
- Eligible clinical investigators at participating institutions

What is SHRINE?

The Shared Health Research Information Network (SHRINE) helps researchers overcome one of the greatest problems in population-based research: compiling large groups of well-
• Research project funded by the NHGRI
• Private institutions
• 5 diseases ONLY
  – Long QT
  – Cataract
  – Dementia
  – PAD
  – DM
• 8 year project
• 4 year budget is 25 million
• Pediatric RFA up
Status of Clinical Data Warehouses (CDW) and EMR systems

- UC Davis
  - 2M patients in CDW, full EMR (in- and out-patient)
- UC Irvine
  - 1.5M patients in CDW, full EMR (in- and partial out-patient)
- UC SD
  - 2M patients in CDW, full EMR (in- and out-patient)
- UC SF
  - 2.7M patients in IDR, EMR under implementation
- UC LA
  - > 2M, CDW under construction, EMR under implementation
Planned Evolution of Data Sharing

UC-ReX is funded for Cross-institutional work, each campus is responsible for their own Data Warehouse Development

$5M over 5 years
Querying Across Institutions

Researcher wants AATD and COPD data

Extraction Transformation Load
(even with same vendor the EMRs are configured differently)

Semantic Integration for Cohort Discovery

Request for data D

Return data D
Year 0

**Proof-of-Concept** of Cross-Institutional Cohort Discovery

UC Davis Researcher

UC Davis

Reference Ontology

UCSF

Research Project
Limited number of diseases
Not 24/7 production system
Year 1

*Real* Cross-Institutional Cohort Discovery

- UC Davis
- UC Irvine
- UC San Diego
- UCSF
- UCLA
Discussion

• IRB Workgroup
  – Unified IRB or federated?
    • Federated requires uniform guidelines
  – Protocol for count queries across campus approved by early Spring’ 12

• Contracts Workgroup
  – Need contract with vendor signed now
Clinical Data at UC

UC is investing > $500,000,000 to collect patient data through EMRs

1% of this to enable data sharing initiatives for research and quality improvement