UC-ReX:
Federated Multi-Site Clinical Data Repositories for Population Studies

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A Collaborative Network for:
UC San Diego, UC Davis, UCSF, UC Irvine, UCLA
The Vision

“Enable researchers and quality improvement specialists to query clinical data from all UC Health campuses for research or quality improvement purposes under a common cross-institutional IRB approval process”

UC-ReX proposal, 2010
UC HEALTH

- 5 Academic Medical Centers
- 10 Hospitals
- 144,000 admissions / year
- 3.9 million out-patient visits / year
- 290,000 emergency room visits /year
- 50% of all transplants in California
- 25% of extensive burn care in California
- ~20% of all care delivered in California
- 18 health professional schools
The Value Proposition

• Supporting collaborative research across the University of California Health System
  – Large scale
  – Rare diseases

• Quality Metrics and Comparative Effectiveness
  – Support pay-for-performance/value-based purchasing
  – Characterize best practices in healthcare delivery across the 5 institutions.
  – Support health services research

• Only a handful of healthcare organizations are in a position to aggregate the same number of records, but
  – UC represents the broad and populous diversity of the state of California
  – We have excellent collaboration across our institutions and they all report to UC Health Sciences leadership
UC ReX: University of California Research Exchange
Governance Structure

UC Office of the President Funding for Cross-UC Data Sharing
$5 million/5 years (July 2011-2016) plus local support

UC BRAID
(Biomedical Research, Acceleration, Innovation and Development)
- PI from each UC CTSA
- Budgetary oversight
- Review quarterly status reports
- Roadmap oversight

UC ReX Steering
- 1 voting + 1 non-voting member from each UC
- UC CIO support
- Simple majority
- Rotating annual chair
- Program manager

Working Groups
- Technical Implementation (Lisa Dahm, UCI)
- Data Harmonization (Davera Gabriel, UCD)
- User Support (Lattice Armstead, Mini Kahlon, UCSF)
- Technology Strategy (Lisa Dahm, UCI)
- Data Quality (Doug Bell, UCLA)

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The UC-ReX Federated Repository

UC BRAID

Researcher wants
Kawasaki Disease or
Congestive Heart Failure

UCI (Epic)
UCSF (Epic)
UCD (Epic)
UCLA (Epic)
UCSD (Epic)

Extraction Transformation Load
(Even with same vendor, EHR are configured differently)

UCSF (DW)
UCD (DW)
UC Irvine (DW)
UCLA (DW)
UCSD (DW)

Semantic Integration for Cohort Discovery

Request for data D

Return data D

UC ReX
University of California Research eXchange
Network Development Stages

- Cross-institutional Cohort Discovery
- Preparatory for Research
- Data Explorer tools
- Patient-Level Data Extraction (structured items)
- Research and Quality Improvement Projects*, Registries and Other DBs
- Patient-Level Data Extraction (complex items, connection to bio bank data, genomic medicine)
- Research and QI Projects, interventions through Electronic Health Record

Year 1

Years 2-3

Years 4-5

New! CENA (PPRN)/pSCANNER (CDRN)
Data Explorer: Operational October 2013

SHRINE

Navigate Terms
- SHRINE Ontology
  - Demographics
    - Age
    - Ethnicity
    - Gender
    - Language
    - Marital Status
    - Race
    - Religion
  - ICD-9-CM
    - Diseases and Injuries
      - Certain conditions originating in the perinatal period (760-779)
      - Complications of pregnancy, childbirth, and the puerperium (630-679)
      - Congenital anomalies (740-759)
      - Diseases of the blood and blood-forming organs (280-289)

Find Terms

Query Tool
- Query Name: BreastCancer-35-44 y@15:40:43
  - Group 1
    - Dates
    - Occurs > 0
    - Exclude
    - Malignant neoplasm of female
    - 35-44 years old
    - one or more of these
    - AND
  - Group 2
    - Dates
    - Occurs > 0
    - Exclude
    - one or more of these
    - AND
  - Group 3
    - Dates
    - Occurs > 0
    - Exclude
    - drag a term to here

Previous Queries
- BreastCancer-35-44 y@15:40:43 [5-31-2013] [ldahm]
- Malign-35-44 y@20:04:32 [6-28-2013] [ldahm]
- BreastCancer35-44 y@18:31:11 [5-28-2013] [ldahm]
- BreastCancer-35-44 y@5-24-13 [5-23-2013] [ldahm]
- Age 65 y-Male@19:43:53 [4-17-2013] [ldahm]
- Age 65 y-Male@18:33:51 [4-17-2013] [ldahm]
- Nonspecific(ab@20:29:51 [4-3-2013] [ldahm]
- 18-34-Femal-Diabe@17:46:39 [3-11-2013] [ldahm]

Query Status
- Finished Query: "BreastCancer-35-44 y@15:40:43"
  - UCI SHRINE - 340 patients
  - UCSF SHRINE - 449 patients
  - UCLA SHRINE - 1530 patients
  - UCD SHRINE - 254 patients
  - UCSD SHRINE - 386 patients

UNIVERSITY OF CALIFORNIA
Office of the President

UCReX
University of California Research eXchange

UCBRAID
UC Rex System Status

- UC Davis
  - 1.9M patients in CDW, full EMR (in and out-patient)
- UC Irvine
  - 1.4M patients in CDW, full EMR (in and out-patient)
- UC San Diego
  - 2.1M patients in CDW, full EMR (in and out-patient)
- UC San Francisco
  - 2.9M patients in IDR, full EMR (in and out-patient)
- UC Los Angeles
  - 4.0M patients in CDW, full EMR (in and out-patient)

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<thead>
<tr>
<th></th>
<th>DISTINCT PATIENTS</th>
<th>PATIENT DATA ELEMENTS</th>
</tr>
</thead>
<tbody>
<tr>
<td>UCD</td>
<td>1,935,972</td>
<td>109,871,655</td>
</tr>
<tr>
<td>UCI</td>
<td>1,426,986</td>
<td>52,651,819</td>
</tr>
<tr>
<td>UCSD</td>
<td>2,156,004</td>
<td>81,610,531</td>
</tr>
<tr>
<td>UCSF</td>
<td>2,974,048</td>
<td>254,976,654</td>
</tr>
<tr>
<td>UCLA</td>
<td>4,028,242</td>
<td>165,220,515</td>
</tr>
<tr>
<td>TOTAL</td>
<td>12,521,252</td>
<td>665,331,174</td>
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Accomplishments and Lessons

**Accomplishments**

- Established representative governance structure and initiated working groups
- Demonstrated collaborative decision making
- Piloted UC ReX Data Explorer virtual clinical data Launched [ucrex.org](http://ucrex.org)
- Loaded demographics, diagnosis, procedures dispositions, 150+ labs, vital status, initial medications
- Developed Harmonization -> Quality -> Validation process
- **Full Enterprise Go Live, October 2013**

**Lessons Learned**

- Real time development requires flexibility
- Different IT and informatics developments in different sites required utilization of common, simple solutions
- Federated model supported expedient delivery and has known limitations
- i2b2 SHRINE function and its role as the initial UC ReX program deliverable requires targeted communication
- Sustainability is required to support ongoing work and plan/develop new capabilities
What does it take?

- EHRs at each site
  - UC’s 5 academic medical centers have spent an estimate of a half billion dollars for healthcare IT.
- Data repositories at each site
- Standardized data (data types, date ranges)
- Common UC-Rex network ontologies and harmonization process
- Ceded IRB process among partner sites (UC “Trust & Rely”)
- Distributed real-time queries
- Unified privacy policy for discovery
  - Nothing returns for patients >89
  - No counts <10
  - No prisoner data
- Unified governance for technology, semantics, process, regulatory, strategy
UC-ReX Executive Committee

- Develops and oversees UC ReX program
  - Operates via a representative, consensus driven governance model
  - Oversees all program management functions and working groups
  - Maintains UC BRAID and UCOP communications and alignment
  - Partners with emerging initiatives
## UC-ReX Functional Work Groups

<table>
<thead>
<tr>
<th>Work Group</th>
<th>Responsibilities</th>
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<tbody>
<tr>
<td><strong>Technical Implementation</strong></td>
<td>• Ensures infrastructure and critical software are deployed and maintained</td>
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<tr>
<td></td>
<td>• ETL, data map development &amp; execution</td>
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<tr>
<td><strong>Data Harmonization</strong></td>
<td>• Establishes data definitions</td>
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<tr>
<td></td>
<td>• Develops mapping approach, coding system utilization</td>
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<td></td>
<td>• Ensures semantic interoperability</td>
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<tr>
<td><strong>User Support</strong></td>
<td>• Defines a single cross-campus user support experience</td>
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<td>• Conducts system evaluations for feature &amp; content development</td>
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<tr>
<td><strong>Technology Strategy</strong></td>
<td>• Specifies use cases</td>
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<td></td>
<td>• Provides functional gap analysis</td>
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<td></td>
<td>• Proposes technology roadmap</td>
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<tr>
<td><strong>Data Quality</strong></td>
<td>• Conducts evaluations of UCReX content</td>
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<td>• Characterizes evaluation findings for consumption by implementation &amp; harmonization groups</td>
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Network Data Alignment Lifecycle

- Data source Requirements
  - UC-REX
  - PCORI grants
  - Investigators
  - Repeatable site assessment plan

- Analysis
  - Data harmonization
  - Project requirements alignment

- Executive Committee
  - Approves analysis
  - Findings & recommendations

- Policy alignment

- Technical alignment
  - Data Quality
  - Curation
    - Data Extract, Transform & Load
    - Mapping to standards
  - Deployment
    - Technical Implementation
Data Provision Process: Delivery

- Currently Secure FTP
- Exploring other modes:
  - PopMedNet
  - iDASH
  - UC Native
CENA PPRN
Community Engaged Network for All

- Genetic Alliance, 10 rare disease advocacy groups, UC Davis, UC San Francisco
- Platform for Engaging Everyone in Research (PEER)
- Use UC-Rex Data Explorer to identify rare diseases cohorts at UCD/UCSF
- Use UC BRAID Trust & Rely system to establish regulatory support for investigator recruitment of patients at UCD/UCSF
- Send “recruit to referral” invitations to patients to CENA platform
pSCANNER CDRN
patient-centered SCAlable National Network for Effectiveness Research
approved for funding by PCORI as part of PCORnet

Members: 5 UCs, National VA (VINCI resource), 3 Federally Qualified Health Systems in LA (USC), RAND
Cohorts: Kawasaki Disease, Congestive Heart Failure, Obesity

Legend:
- Site
- Patient count

TCC: The Children’s Clinic
SFGH: San Francisco General Hospital
OMOP: Observational Medical Outcomes Partnership
VM: Virtual Machine

PREP TO STUDY
OMOP DATASET
SUMMARY
QUERY

UC-REX site
Current State

- Functional and governed network across UC System
- Enabled by CTSAs and UCOP
- Now part of and aligned with 2 PCORI networks
- Exploring models of expansion/alignment

- [www.ucrex.org](http://www.ucrex.org)
- [www.ucbraid.org](http://www.ucbraid.org)
- Email: Lisa Dahm, UC Irvine (ldahm@uci.edu)
Questions?