

The background features a large, faint watermark of the University of California seal, which includes the text "THE UNIVERSITY OF CALIFORNIA" and the year "1868".

# **UC-Research eXchange (UC-ReX): A Federated Multi-Site Clinical Data Repository**

The UC-ReX Project

UC Davis, UC Irvine, UC Los Angeles, UC San Francisco, UC San Diego



# 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

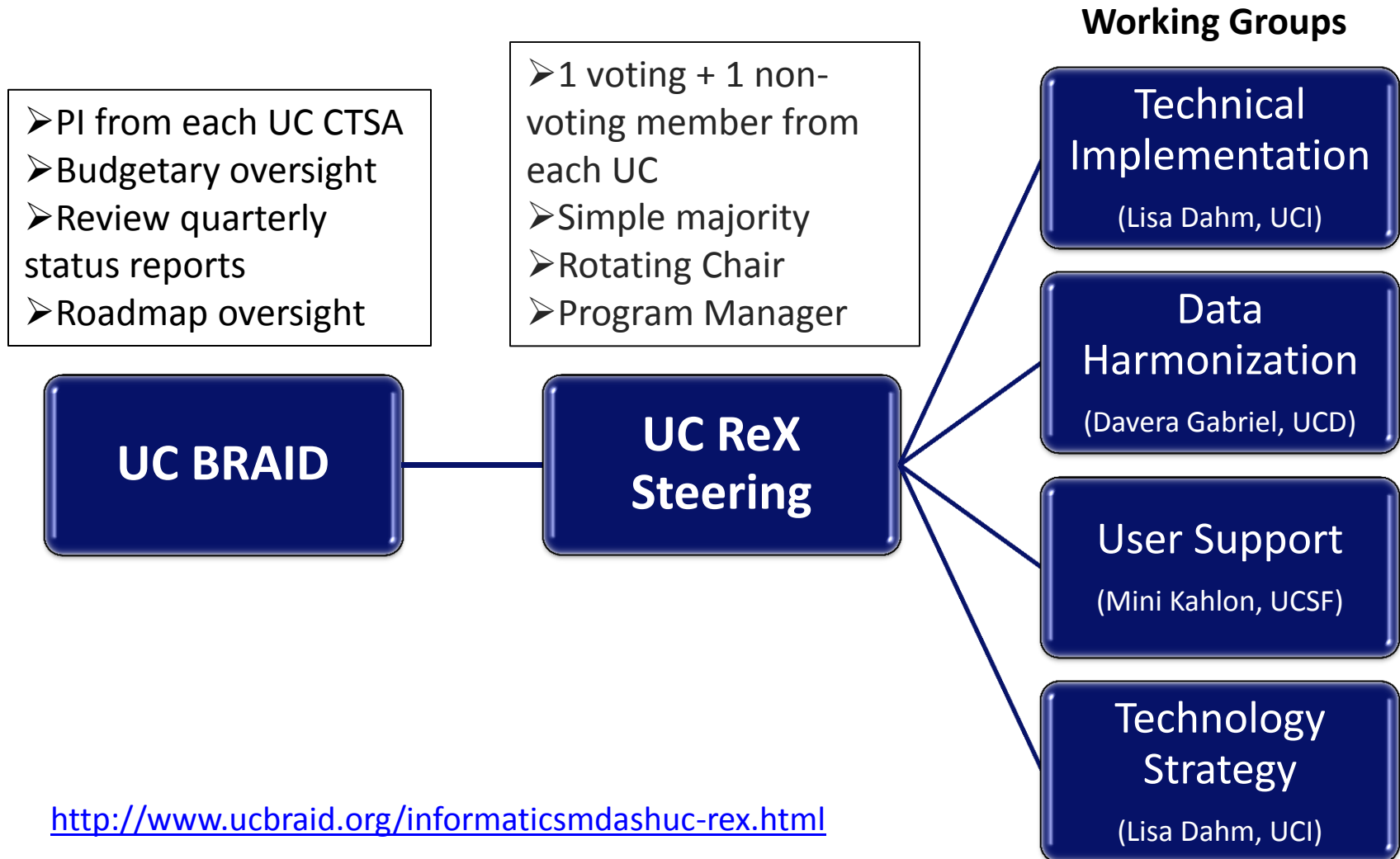


# UCReX Goals

- UC Office of the President Funding for Cross-UC Data Sharing
  - \$5 million/5 years (July 2011- 2016) Plus local support
- **Year 1 Goal:** Enable cohort discovery, i.e., allow researchers to use a graphical user interface to query five institutions on demographics, diagnoses, and procedures.
- **Year 2 Goal:** UCReX Data Explorer Enterprise Go Live, move from innovation to sustainability
- **Year 3 Goal:** Develop and implement a cross-UC Honest Broker Process



# Governance Structure





# Steering Committee

- **Davis**
  - Mike Hogarth\*, Mike Minear, Kent Anderson
- **Irvine**
  - Lisa Dahm\*, Jim Murry, Charles Boicey
- **Los Angeles**
  - Doug Bell\*, Mohammad Mabouba
- **San Diego**
  - Lucila Ohno-Machado\*
- **San Francisco**
  - Mini Kahlon\*, Doug Berman
- **UCReX Program Manager**
  - Lattice Armstead

\*voting member



# Working Groups

## Technical Implementation

- Ensure that infrastructure & critical software are deployed & maintained

## Data Harmonization

- Ensure semantic interoperability
- Oversee data quality

## User Support

- Define processes, create SOPs
- Coordinate user training & support
- Design UCRex Website, roll-out pilot

## Technology Strategy

- Specify use cases
- Provide functional gap analysis
- Propose technology roadmap



# UCReX Data Explorer (SHRINE)

SHRINE

Find Patients | Analysis Tools | Message Log | Help | Logout

### Navigate Terms

### Find 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)

### Query Tool

Query Name: BreastCancer-35-44 y@15:40:43

Group 1			Group 2			Group 3		
Dates	Occurs > 0x	Exclude	Dates	Occurs > 0x	Exclude	Dates	Occurs > 0x	Exclude
			Malignant neoplasm of fem	35-44 years old				
one or more of these			AND			one or more of these		
			AND			drag a term to here		

Run Query New Query Print Query 2 Groups New Group

### Previous Queries

- BreastCancer-35-44 y@15:40:43 [5-31-2013] [ldahm]
- Maligna-35-44 y@20:04:32 [5-28-2013] [ldahm]
- BreastCancer35-44 y@18:31:11 [5-28-2013] [ldahm]
- BreastCancer-35-44 y@5-24-13 [5-23-2013] [ldahm]
- >= 65 y-Male@19:43:53 [4-17-2013] [ldahm]
- >= 65 y-Male@18:33:51 [4-17-2013] [ldahm]
- Nonspecific (ab@20:25:51 [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 - 346 patients	FINISHED [3.9 secs]
UCSF SHRINE - 449 patients	FINISHED [6.0 secs]
UCLA SHRINE - 1530 patients	FINISHED [5.0 secs]
UCD SHRINE - 254 patients	FINISHED [5.0 secs]
UCSD SHRINE - 386 patients	FINISHED [5.3 secs]



# UC ReX Data Metrics (Sept 2013)

	<b>PATIENTS</b>	<b>OBSERVATIONS</b>
<b>UCSD</b>	2,156,004	82,610,531
<b>UCI</b>	1,478,806	52,651,819
<b>UCSF</b>	2,974,048	254,976,654
<b>UCD</b>	1,991,319	121,653,668
<b>UCLA</b>	4,098,784	124,954,417
<b>TOTAL</b>	<b>12,698,961</b>	<b>636,847,089</b>





# UCReX - Year 2

- Enterprise Pilot Go Live, March 2013
  - UCReX-SHRINE Data Explorer running across 5 UC academic medical centers: 12 million patients
  - Demographics, Diagnoses, Procedures
  - Developed survey tool to collect facilitated feedback from pilot users (10-15 per site), IRB approved as Trust & Rely through UCLA IRB
  - Developed [ucrex.org](http://ucrex.org) Website to facilitate user access to UCReX Data Explorer
- Full Enterprise Go Live, October 2013
  - Add Lab Results (top 200, LOINC-encoded), Vital Status, Medications (subset)
  - Provision of IRB-approved Data Sets



# Provisioning UC-ReX Data Sets

- Patient Cohort defined using UC-ReX Data Explorer (SHRINE)
- Investigator requests approval for data set using cross UC IRB trust/rely process
- Leverage Honest Broker at each UC to retrieve approved data
- Approved data set is stored and provisioned for access using infrastructure compliant with Data Use Agreement and IRB approval as needed.



# Challenge: Sustainability

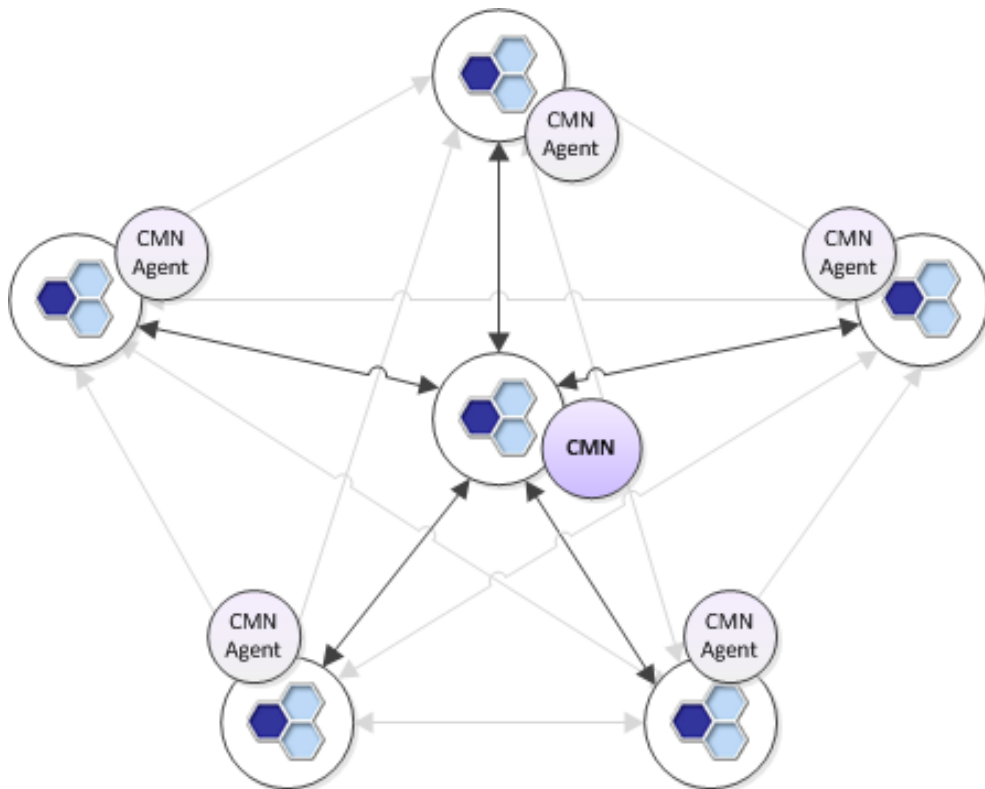
- Partnership with CIOs at each University
- Strong Governance Structure
- Dedicated Program Manager
- Vendor supported system
- Enterprise supported infrastructure



# UCReX Network Topology

**Central Node (located at UCDCMC)**

**Data remain at each UC**



- The Central Management Node (CMN) is a webapp deployed to complement SHRINE – as agent or manager
- Provides a central point for monitoring nodes and gathering information



# SHRINE Management Node (Recombinant)

**Provide a central point that facilitates the running and management of the UCReX SHRINE network**

- Status monitoring
  - Heartbeat status reports
  - Alert users if a node needs attention
  - Access to server log files
- Reviewing query history
  - Gather request data from each individual node
  - An interface to search the combined query history
- Other SHRINE diagnostics
  - Uptime
  - Response time
  - Usage patterns
- Node management
  - Add nodes to network
  - Update SHRINE configuration files remotely
  - Restart SHRINE
- Upgrade agents remotely
  - Check to see if an agent SHRINE is the latest version
  - Download and automatically install new agent
- Upgrade SHRINE
  - Usually a long process for each node
  - A single script could be used to deploy SHRINE across all nodes in the network



# UC ReX Pilot

- 39 Participants
  - Answered a query of interest
  - Structured interview
- Vast majority of participants were positive about experience
- Excited about access to an extended network
- Want more dimensions particularly Procedures Codes
- Want help finding collaborators at sister institutions



# Year 3 Plans

- Upgrade User Interface
  - Implement development network
  - Upgrade to i2b2 version 1.6
- Extend searchable data elements
  - Medications
  - Microbiology Labs
- Develop & implement cross-UC Honest Broker Process
- Determine policy for adding new nodes
- Investigate extension of technology
  - Driven by user-submitted proposals