



University of California Research eXchange (UC-ReX) The First Year in Production

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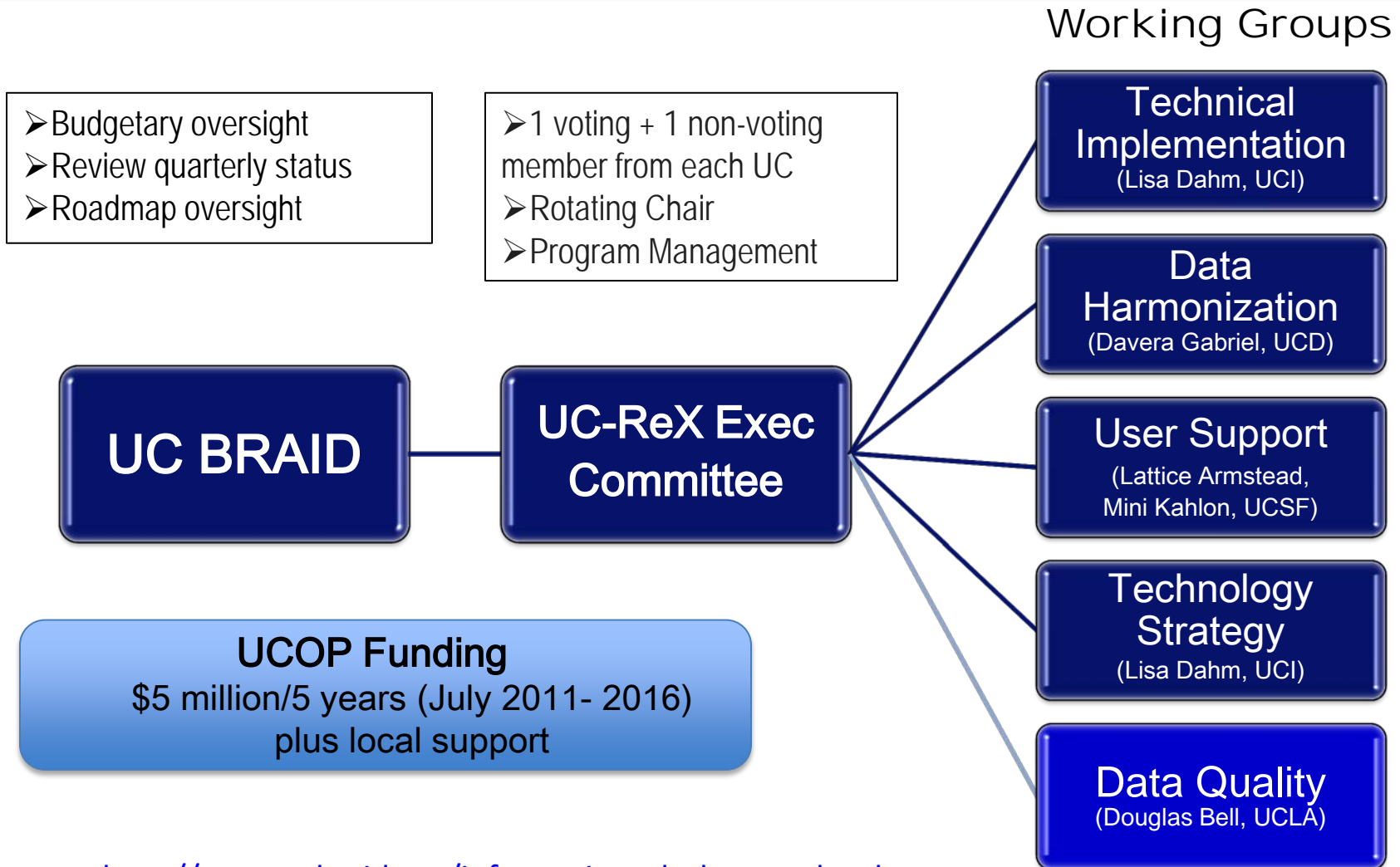
The Vision: UC ReX

*“Enable researchers and quality improvement specialists to **query clinical data from all UC Health campuses** for research or quality improvement purposes”*

--UC Research eXchange (UC-ReX) proposal, 2010



Governance Structure





UC-ReX 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

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]

Live in production: October, 2013



Top Accomplishments

- Harmonized and added new data types:
 - Values for top 100 lab tests
 - Medications (All inpatient and outpatient orders)
- Took over technical support from Deloitte
 - Resolved frequent outages
- Enabled UC participation in PCORnet
 - \$7M award for pSCANNER network, led by UCSD
- Formed a cornerstone for NCATS ACT project
 - 5 of 1st 12 sites in a national SHRINE network



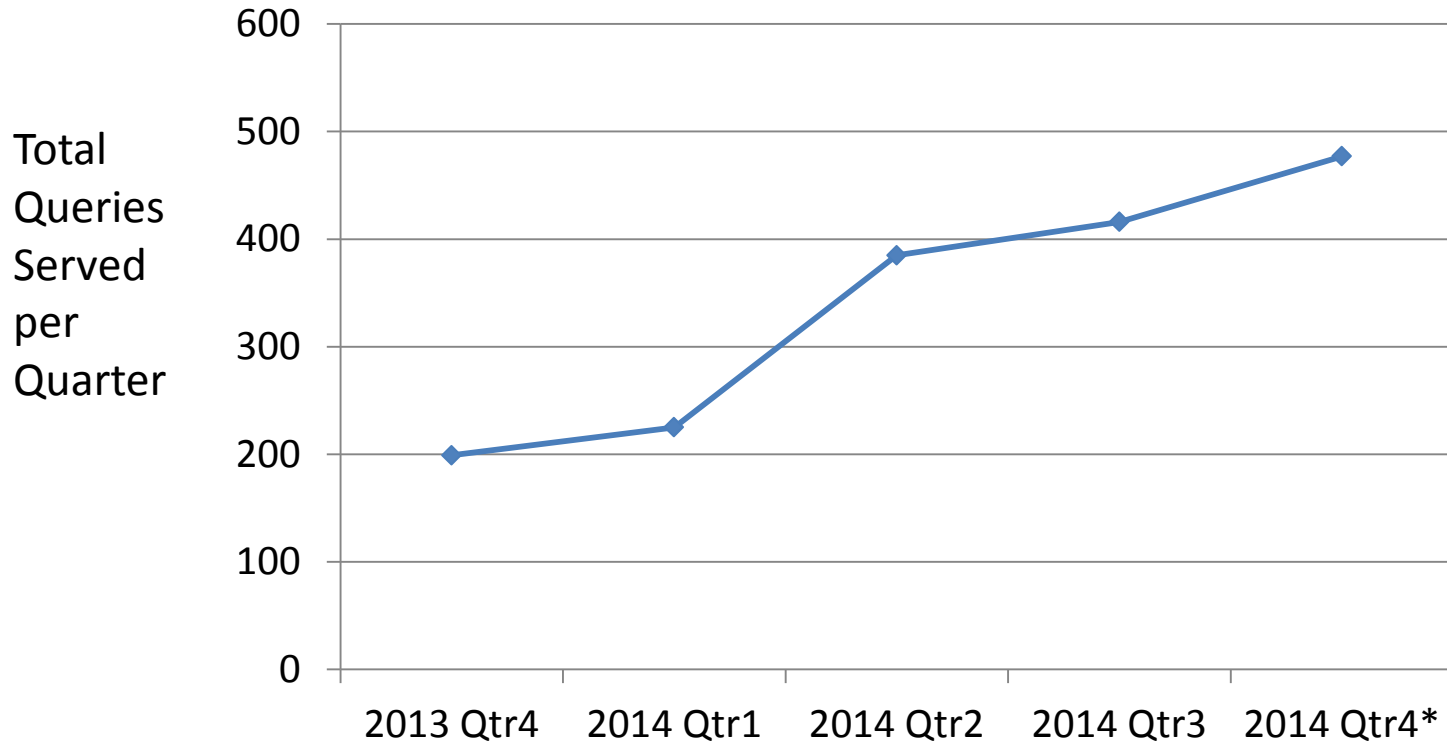
Current Data in Production

Site	Distinct Patients	Total Observations	Demographic Facts	Diagnoses	Procedures	Lab Results	Vital Status	Medications
UCSD	2,289,724	88,908,599	7,523,257	13,822,181	0	54,281,953	2,494	13,278,714
UCI	1,546,661	48,656,723	12,334,791	12,584,745	857,439	22,876,452	3,296	42,258
UCSF	1,943,699	108,239,989	12,423,154	6,807,231	334,282	88,615,563	35,423	24,336
UCD	2,181,403	81,846,934	13,134,787	16,646,669	?	62,828,472	63,082	127,309
UCLA	4,303,700	189,006,757	30,125,900	30,822,882	1,328,967	113,505,222	43,996	13,179,790
Total	12,265,187	516,659,002	75,541,889	80,683,708	2,520,688	342,107,662	148,291	26,525,098



Usage

Sum of Researcher Queries by Quarter

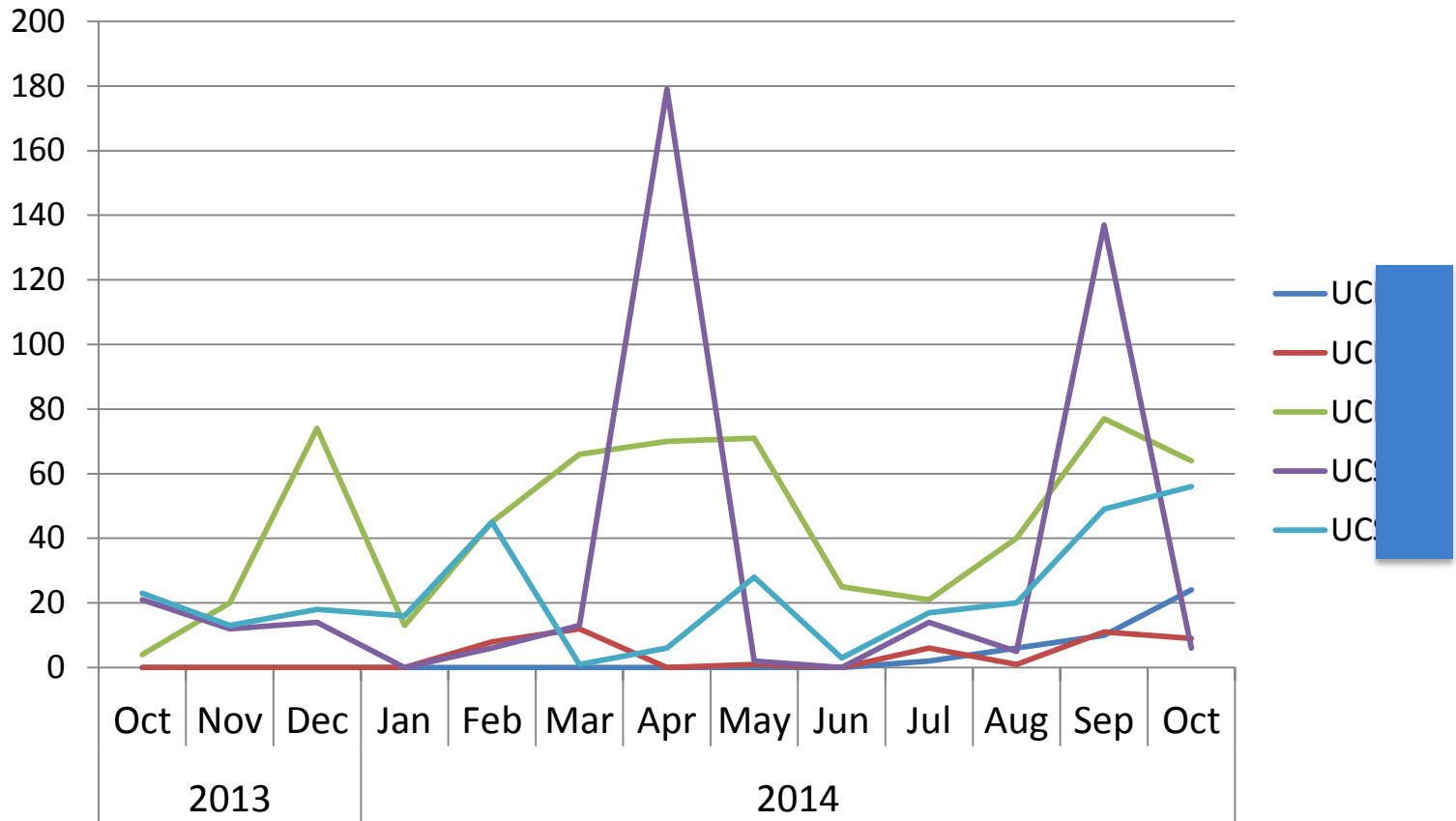


* Projected through 12/2014



Usage By Site

Total
Queries
Served
per Month



N = 116 distinct researchers who've run ≥ 1 query (ReX staff excluded)

By site -- A: 10, B: 7, C: 50, D: 12, E: 37



Proposals Supported

- Requested success stories from users

Title	Agency	Sites	Status	Funding
Integrated Molecular, Cellular, and Imaging Characterization of Screen-Detected Lung Cancer	NCI	UCLA	Pending review	\$3,931,346
COMPARE-UF - Comparing Options for Management: Patient-Centered Results for Uterine Fibroids	PCORI/ AHRQ	UCSF, UCD, UCLA, UCSD, UCI	Funded	One of 8 “sites” in \$20,000,000 overall project
Mapping Immune Responses to CMV in Transplant Recipients	NIH/NIAID	UCLA, UCSF	Pending review	\$10,600,000
Effects of Exercise Training on Cardiac Structure and Function in Prediabetes Using 3D Cardiac MRI Technology	AHA	UCLA	Pending review	\$43,700



Commendations

“I used UC Rex in our grant application for COMPARE-UF to come up with our clinical volume of patients with fibroids and fibroid surgery. We identified 6,200 women with visits for uterine fibroids from June 2012-May 2013 and a large surgical volume, with 720 hysterectomies and 710 myomectomies for women with fibroids.

“UC Rex and UC Rely as well as the financial benefit of contracting within UCs were CRITICAL for us being accepted as a site for COMPARE-UF. No other clinical site has 5 functional sites as we do. I convinced the PI that our UC-wide systems were strong enough to support our group working together as a unit to recruit and enroll for this study.”

-- Vanessa Jacoby, MD, MAS

Department of Obstetrics, Gynecology, and Reproductive Sciences
University of California, San Francisco



Year 4 Priorities

- Marketing and Communications
 - Revamp ucrex.org web site
 - Enhance self-service online training materials
 - More announcements and training events
 - Goal: 300 users with ≥ 1 query per year
- Data
 - Add BMI, vital signs, mixed race, microbiology
 - Develop and pilot interface with CA death registry
 - Document and correct data quality issues



Year 4 Priorities

- Technology
 - Upgrade i2b2/SHRINE to latest version
 - Implement user feedback survey
 - Evaluate ReX as UC-wide resource for UHC data
- Streamline data provisioning
 - Harmonize IRB & compliance rules for multi-campus data provisioning and patient recruitment
 - Implement UCSD iDASH for hosting and managing data provisioning workflow



Year 4 Priorities

- Expand Network Participation
 - NCATS Accrual to Clinical Trials (ACT) – 7 other CTSA
 - PCORI pSCANNER – 3 VAs, USC, others
 - Children’s hospitals: Rady, Benioff Oakland, CHOC
- If funded by UCOP MRPI proposal
 - Further streamline recruitment infrastructure
 - Provide access to researchers from the other 5 UCs
 - Add genomic data (1st: CLIA-certified allele tests)



Additional Opportunities

- Getting started on ICD-10
- Implementing Shibboleth single sign-on
- Implementing rGate
 - supporting more complex analyses within i2b2
- Assess user needs in more depth
 - Focus groups with different kinds of users
 - Evaluate success in meeting needs
- Develop advanced recruitment services
- Automate data quality monitoring



Challenge: Sustainability

- Relying on CIOs at each University
 - Level of investment varies greatly
- Funding central services
 - Overall program management
 - Technical setup and maintenance
 - User support and training
- Need charge-back mechanism
 - And probably ongoing investment



Thank You