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

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Leader, Biomedical Informatics Program, UCLA CTSI
2014-15 Chair, UC-ReX Executive Committee
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 BRAID
- UC-ReX Exec Committee

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 (Douglas Bell, UCLA)

UCOP Funding
$5 million/5 years (July 2011-2016) plus local support

http://www.ucbraid.org/informaticsmdashuc-rex.html
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

<table>
<thead>
<tr>
<th>Site</th>
<th>Distinct Patients</th>
<th>Total Observations</th>
<th>Demographic Facts</th>
<th>Diagnoses</th>
<th>Procedures</th>
<th>Lab Results</th>
<th>Vital Status</th>
<th>Medications</th>
</tr>
</thead>
<tbody>
<tr>
<td>UCSD</td>
<td>2,289,724</td>
<td>88,908,599</td>
<td>7,523,257</td>
<td>13,822,181</td>
<td>0</td>
<td>54,281,953</td>
<td>2,494</td>
<td>13,278,714</td>
</tr>
<tr>
<td>UCI</td>
<td>1,546,661</td>
<td>48,656,723</td>
<td>12,334,791</td>
<td>12,584,745</td>
<td>857,439</td>
<td>22,876,452</td>
<td>3,296</td>
<td>42,258</td>
</tr>
<tr>
<td>UCSF</td>
<td>1,943,699</td>
<td>108,239,989</td>
<td>12,423,154</td>
<td>6,807,231</td>
<td>334,282</td>
<td>88,615,563</td>
<td>35,423</td>
<td>24,336</td>
</tr>
<tr>
<td>UCLA</td>
<td>4,303,700</td>
<td>189,006,757</td>
<td>30,125,900</td>
<td>30,822,882</td>
<td>1,328,967</td>
<td>113,505,222</td>
<td>43,996</td>
<td>13,179,790</td>
</tr>
<tr>
<td>Total</td>
<td><strong>12,265,187</strong></td>
<td><strong>516,659,002</strong></td>
<td><strong>75,541,889</strong></td>
<td><strong>80,683,708</strong></td>
<td><strong>2,520,688</strong></td>
<td><strong>342,107,662</strong></td>
<td><strong>148,291</strong></td>
<td><strong>26,525,098</strong></td>
</tr>
</tbody>
</table>
Usage

Sum of Researcher Queries by Quarter

* Projected through 12/2014
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**

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

UC ReX is a program of UC Biomedical Research Acceleration, Integration & Development (BRAID) funded by a generous grant from UCOP.
Thank You