xDR - A Clinical Enterprise Data Repository that Supports Research

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Summary

The xDR (Enterprise Data Repository) is a large scale data warehouse system containing data derived from multiple clinical systems including the CareConnect EHR, Radiology, Pathology, Pharmacy, Outpatient Billing, Hospital Billing, Managed Care, and Clinical Labs. In addition to supporting operations and clinical quality management functions of the UCLA Health System, the xDR serves as a data source for multiple research purposes, including analyses of the UCLA patient population in preparation for research, identification of patient cohorts for potential recruitment, generation of secondary data sets for hypothesis testing, correlative studies, retrospective analysis, comparative effectiveness research, and patient centered outcomes research.

Project Description

The xDR provides a platform and infrastructure to provision clinical data for enterprise management and for research. The CTSI Biomedical Informatics Program (BIP) has developed a compliant, scalable, and sustainable process to extract xDR data for research studies. Any release of patient-level data must be approved Compliance. The process begins with BIP reviewing IRB applications and recommending changes prior to submitting the request to Compliance. While the changes are in process of being approved by the IRB, BIP will complete the Compliance data request form on the behalf of the researchers then have them sign the form and get the signature of their department director or chief administrative officer. Once the IRB has been approved and signatures are in place, all documentation is submitted to Compliance. Upon Compliance approval, the xDR data request is then added to the work queue. After the data is delivered, BIP submits the list of patients to the Health Information Management team for HIPAA disclosure tracking. A summary of the requests received and completed is displayed below.

From July 2013 through April 2014, 30 research data requests have been received, 12 have been delivered, 7 are currently in progress, 2 are awaiting approval from Compliance, and 9 are still being reviewing by the IRB. In January 2014, the first research project to receive an automated feed from xDR into REDCap was completed. REDCap is an open source data management tool developed at Vanderbilt University and is widely used at academic medical centers. 3 other projects will be leveraging this capability.
Along with providing data for individual studies, xDR feeds data to i2b2, UC ReX, and LADR. These are self-service web applications for researchers to quickly determine the number of patients that meet certain demographic and clinical characteristics. These data strengthen grants, help researchers complete NIH planned enrollment tables, facilitate the generation of new hypotheses, and identify potential cohorts for recruitment into clinical trials.

UCLA is a member of two SHRINE networks: University of California Research eXchange (UC ReX), funded by the University of California Office of the President, and Los Angeles Data Resource (LADR). The UC ReX network federates i2b2 queries between the five University of California medical centers (UCLA, UCSF, UCD, UCI, UCSD), all of which are members of the Clinical and Translational Science Award (CTSA) program of the National Institutes of Health. The LADR network federates i2b2 queries among Los Angeles-area medical centers beginning with UCLA and Cedars-Sinai Medical Center. Along with the two SHRINE networks, UCLA also has its local i2b2 instance. UCLA researchers have the ability to query the de-identified records of 15 million patients between these three applications.

The vision of UC ReX is to enhance the competitiveness and impact of clinical research at the University of California by enabling multi-campus projects and to support identification of best practices among UC Health Systems. Below is a chart of the number of UC ReX queries per month ran by UCLA researchers with an upwards linear trend line. Currently, 101 UCLA researchers have access to run UC ReX queries.

The vision of LADR is to link data from a majority of health care providers in the Los Angeles region to provide a nearly complete picture of each patient’s care and outcomes. The initial service is cohort discovery, allowing investigators to conduct interactive searches on demographics, diagnoses, and procedures across the participating medical centers. Two additional services, that will heavily leverage xDR, will then be created that enable different uses of the specified cohorts: cohort recruitment for prospective clinical research studies (LADR-CR) and the provision of cross-institutional limited data sets for retrospective comparative effectiveness studies (LADR-CE). Future partners prepared to join LADR include the University of Southern California, Children’s Hospital Los Angeles, and City of Hope.
Technology Infrastructure

The CareConnect EHR system’s data is transferred nightly into Clarity, an Oracle 11g database. Legacy data is extracted from Microsoft SQL Server 2012 databases. The data is then extracted into the Research Staging Oracle 11g database, transformed into the i2b2 data model, and then loaded into the i2b2 data mart with SAP Data Services.

i2b2 (Informatics for Integrating Biology and the Bedside) is a scalable informatics framework that enables clinical researchers to use existing clinical data for discovery research. i2b2 is a Java-based application deployed on jBoss and an Oracle 11g database. [https://www.i2b2.org/index.html](https://www.i2b2.org/index.html)

SHRINE (Shared Health Research Information Network) is a platform for enabling clinical researchers to solve the problem of identifying sufficient numbers of patients to include in their studies by querying across distributed hospital electronic medical record systems. SHRINE is also a Java-based application, but is deployed on Tomcat. [https://open.med.harvard.edu/wiki/display/SHRINE/Welcome+to+SHRINE](https://open.med.harvard.edu/wiki/display/SHRINE/Welcome+to+SHRINE)

REDCap (Research Electronic Data Capture) is a secure web application designed exclusively to support data capture for research studies. All web-based information transmission is encrypted. REDCap was developed specifically around HIPAA security guidelines. REDCap is a PHP application with a MySQL database. [http://project-redcap.org/](http://project-redcap.org/)
**Timeframe of Implementation**

August 2012  Begin xDR Implementation  
November 2012  1st UC ReX Distributed Query  
March 2013  CareConnect EHR Go-Live  
March 2013  Pilot UC ReX Users  
September 2013  1st Research Data Request Delivered  
October 2013  UC ReX Launch  
January 2014  1st Data Feed from xDR to REDCap  
February 2014  1st LADR Distributed Query  
May 2014  LADR Launch  
June 2014  i2b2 Scheduled Launch

**Relevant URLs**

http://www.ctsi.ucla.edu/research/pages/xDR

http://www.ctsi.ucla.edu/research/pages/ucrex

http://www.ctsi.ucla.edu/research/pages/LADR

https://ucrex.ctsi.ucla.edu (Internal Only)

https://ladr.ctsi.ucla.edu (Internal Only)

https://i2b2.ctsi.ucla.edu (Internal Only)

**Objective Customer Satisfaction Data**

The CTSI tracks all xDR Research Data Extracts and surveys researchers on their satisfaction with the service they received. Thus far 2 responses have been received for xDR requests and UC ReX support:

**xDR:**

- How satisfied are you with the quality of services provided by BIP? **Satisfied**
- How satisfied are you with the time it took to complete the service request? **Somewhat satisfied**
- How likely are you to recommend the BIP resource to your department or colleagues? **Somewhat likely**

**UC ReX:**

- How satisfied are you with the quality of services provided by BIP? **Extremely Satisfied**
- How satisfied are you with the time it took to complete the service request? **Extremely Satisfied**
- How likely are you to recommend the BIP resource to your department or colleagues? **Extremely likely**