Medical Informatics and HERON Update for KUMC Clinical Chairs

Division of Medical Informatics
Department of Biostatistics

February 24, 2011

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Outline

• Establishing Medical Informatics Division
• CTSA
• HERON – main focus of this talk
• Current Focus
• Subsequent Objectives

Note: you can reference the printed timeline info, which fits better on a text document than Powerpoint
2010 Accomplishments – Medical Informatics

• Software development team and environment established with KUMC Information Resources
  – I2b2 software installed and utilized for small HICTR Participant Registry as early as May

• CTSA section revised and resubmitted after coordination across campuses
  – sets vision

• Established Health Care Enterprise Repository for Ontological Narration (HERON)
Other Related Activities

• Implemented REDCap and REDCap Survey (2011) to support registries and student projects
  – Team STEPPS survey first production usage
  – Provided training and mentoring for Medical School Health of the Public Class

• Met with KUMC-Wichita regarding Health Informatics and various support options (HERON, REDCap).

• Met with KHPA (Medicaid) and participated in development of State HIE plan.
1. Provide a HICTR portal for investigators to access clinical and translational research resources, track usage and outcomes, and provide informatics consultative services.

2. Create a platform, HERON (Healthcare Enterprise Repository for Ontological Narration), to integrate clinical and biomedical data for translational research.

3. Advance medical innovation by linking biological tissues to clinical phenotype and the pharmacokinetic and pharmacodynamic data generated by research cores in phase I and II clinical trials (addressing T1 translational research).

4. Leverage an active, engaged statewide telemedicine and Health Information Exchange (HIE) effort to enable community based translational research (addressing T2 translational research).
Develop business agreements, policies, data use agreements and oversight.

- September 6, 2010 the hospital, clinics and university signed a master data sharing agreement to create the repository. Four Uses:
  - After signing a system access agreement, cohort identification queries and view-only access is allowed but logged and audited
    - **Current Capability being Beta Tested**
  - Requests for de-identified patient data, while not deemed human subjects research, are reviewed.
  - Identified data requests require approval by the Institutional Review Board prior to data request review. Medical informatics will generate the data set for the investigator.
  - Contact information from the HICTR Participant Registry have their study request and contact letters reviewed by the Participant and Clinical Interactions Resources Program
    - **Currently piloted under direction of Dr. Jeff Burns**
HERON: Repository Architecture
Aim 1: Created Portal for Informatics Tools

Welcome to Raven, the Biomedical Informatics Portal at KUMC. Raven's goal is to collect tools for translational research and connect informatics to our customers.

Currently, we provide the following tools:

- **CRIS**: a Comprehensive Research Information System
- **REDCap**: a web-based application to support case report form data capture for research studies
- **HERON**: the HICTR participant registry accessed through i2b2
- **TRAC**: our current development process

Ideas? Problems? Questions? Contact us at heron-admin@kumc.edu. Check Other contact information

If you have a project request, please use our convenient project request form.
Workflow: System Access

Use Case for viewing de-identified HERON Repository with Data Request Oversight Committee (DROC) Auditor review
Author: Russ Waitman
July 12, 2010 v1.0
Workflow & Oversight: Request Data

Use Case for requesting de-identified data from HERON Repository with Data Request Oversight Committee (DROC) review

Author: Russ Waitman
July 13, 2010 v1.1
Electronic Capture of Oversight Process

Sponsor Heron System Usage Users

Title of the General Research Area:

Description of the Preparatory to Research Activities:

A. Network login ID of KUMC employee:

B. Network login ID of non-KUMC employee:

Date of expiration (month/day/year):

For non-KUMC employees, include the position and employer for any students or staff who employed by another institution where there may need to be collaboration regarding conflict of interest or cooperative concerns between that parent institution and KUMC, KU, or UAP.

The individual identified in section A and B above shall be referred to herein after as the Sponsor's "Research Teams Members". They will be required to individually sign a "HERON System Access Agreement" recognizing their responsibilities when using HERON for preparatory to research activities.

I, [Your Name], will be responsible for my research team members and hereby agree:

A. To comply with data and federal confidentiality laws, including but not limited to, the Health Insurance Portability and Accountability Act of 1996 (HIPAA) policies, applicable regulations, as amended from time to time, and to comply with HIPAA privacy rules and policies and HIRM system policies and procedures;

B. To reinforce to my research team members that they are prohibited from sharing or disclosing their HERON user ID and password and the Data Set resulting from System User queries with other individuals or entities, except as required by law;

C. That the Data Set(s) resulting from System User queries shall only be viewed by System User within the HERON system environment. No Data Set or data accessed by System User hereunder may be extracted from the HERON system via printing, downloading, screenshots, saving webpages or other method.

D. My research team members will not solicit individual queries to benefit research issues preparatory to research. My research team members will not formulate queries that would be used for competitive advantage or individual advantage of any party other than KUMC, the University of Kansas Hospital Authority, or Pusan University-University Hospital, Inc.

E. That the research to be conducted is in an area of my research team members' scientific expertise;

F. Not to identify, or attempt to identify, data contained in the Data Set(s) by any means, including using participating organizations' clinical systems (Examples: SS, HPC, IDV, KUMC) or other information together with the Data Set(s) (Examples: vital registration records), or to contact any individual whose identity is discovered through the Data Set.

Accept and Submit  Cancel
Current Focus Areas

• HERON Beta and go live
  • Scaling to handle larger ontologies
  • Integrating IDX billing data
  • Validating data with UKP and KUH
  • Engage Research Community
  • Decide on Counting versus Timeline Access

• Pilot projects for Medical Informatics:
  • Nursing Informatics and Flowsheets
  • Pharmacovigilance with KU-Lawrence EECS
Subsequent Objectives

• HERON 1.0
  • Technical: regular updates, richer data
  • Process: Engage researcher community
• Biotissue Repository strategy, plan, integration
• HERON/i2b2 and REDCap integration
  • Blend data entry and data feeds from Epic for registries
• Public Health Informatics
  • Establish linkages with State databases
  • Ex: add social security death index
QUESTIONS?

- Office hours
- Recommend Beta testers
  - Which data most benefits your department?
Implement NIH funded (i.e. i2b2) initiatives for accessing data.
i2b2: Count Cohorts
i2b2: Patient Count in Lower Left
i2b2: Ask for Patient Sets
i2b2: Analyze Demographics Plugin
i2b2: Demographics Plugin Result

Below are the demographic details for the selected patient set. For each demographic category, the values, number of patients, and a histogram are shown.

Patient Set: Migrain-Diagnos@22:11:52 [7-9-2010] [hurthman] [PATIENTSET_303]

Patient Count: 89

Age in Years

<table>
<thead>
<tr>
<th>Age Range</th>
<th>Count</th>
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<tbody>
<tr>
<td>10-20</td>
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<tr>
<td>20-30</td>
<td>7</td>
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<tr>
<td>30-40</td>
<td>17</td>
</tr>
<tr>
<td>40-50</td>
<td>22</td>
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<tr>
<td>50-60</td>
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<tr>
<td>60-70</td>
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<tr>
<td>70-80</td>
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</tr>
<tr>
<td>80-90</td>
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</table>

Sex

<table>
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<tbody>
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<td>F</td>
<td>76</td>
</tr>
<tr>
<td>M</td>
<td>13</td>
</tr>
</tbody>
</table>

Plugins

- Detailed List View
- Category: Detailed List View
- Category: Category
- Category: ALL
- Example: Communicator Tool
- This plugin allows you to interact directly with standard CCM Communicator objects within the web client framework.
- Demographics (1 Patient Set): Simple Counts
- This plugin displays a demographic breakdown of a Patient Set.
i2b2: View Timeline
i2b2: Timeline Results