Advancing Clinical and Translational Research with HERON at the University of Kansas Medical Center

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Overview

• Overview

• Demonstration
  – General use
  – University HealthSystems Consortium
  – Orders and Medications
Biomedical Informatics Can Help Your Research

- We have tools and expertise to manage data and convert it into information
  - **REDCap** and **CRIS** – enter and manage data
  - **HERON** – **fish for data** from the hospital/clinic
  - **Biweekly** Frontiers Clinical Informatics **Clinics**
    - Tuesday 4-5 pm in 1028 Dykes Library.
    - Next session November 27.
You’re that fisherman: wanting to land data to answer your research hypothesis

Bennett Spring Trout Park, Lebanon Missouri
http://mdc.mo.gov/regions/southwest/bennett-spring
The Fish: Diagnoses, Demographics, Observations, Treatments
Why so many fish? Medical Informatics

**Current Goal:** Build Hatchery, Manage the Fishery
Second Goal: If you need help fishing, hire a guide from Medical Informatics

Photo Credit: HuntFishGuide.com
http://www.flickr.com/photos/huntfishguide/5883317106/
Prepare and Analyze data with Biostatistics

Photo Credit: S. Klathill
http://www.flickr.com/photos/sklathill/505464990/
Our shared goal: a tasty publication

Photo Credit: Steve Velo
http://www.flickr.com/photos/juniorvelo/259888572/
Nightmare: looks like a nice river, but can’t catch fish

- I’ll just enter everything in Excel....
- What if I lose or accidentally sort my spreadsheet?
- How to I let students only review de-identified data?
- Prevent the wrong people (statistician/student) from entering/changing data?
- Hospital/Clinic is making me use this Electronic Medical Record and I get nothing in return...

Little White Salmon River, Washington State, last Summer in July
I want to go fishing, not fill a fish tank (REDCap)
Use HERON: a managed fishery

Bonneville Hatchery: Trout, Salmon, Sturgeon, Columbia River, Oregon
Aim #2: Create a data “fishing” platform: HERON, https://heron.kumc.edu

- **Get a License:** Develop business agreements, policies, data use agreements and oversight.

- **Get a Fishing Rod and Bass Boat:** Implement open source NIH funded (i.e. i2b2 https://www.i2b2.org/) initiatives for accessing data.

- **Know what your catching:** Transform data into information using the NLM UMLS Metathesaurus as our vocabulary source.

- **Stock Different Tasty Fish:** link clinical data sources to enhance their research utility.
HERON: Getting a Fishing License

- Fill out System Access Agreements to sponsor students/staff
- Fill out Data Use Agreement to request data export
- **No Limit!!!** IRB Protocol Not Required to view or pull de-identified data
- Must be on campus or use VPN
- Check [http://informatics.kumc.edu/work/blog](http://informatics.kumc.edu/work/blog) for latest status

Single sign-on using your email username
Real-time check for current human subjects training
The i2b2 “Fishing Rod”: build Diabetes cohort

Types of “fish” in folders

Drag concepts from upper left into panels on the right
Drag over the second condition
When you add a numeric concept, i2b2 asks if you want to set a constraint.
i2b2 Result: 497 patients in Cohort

Run the Query
Query took 4 seconds
497 patient in cohort
### I2b2: Explore Cohort, Visualize Timelines

#### Timeline

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<th>Specify Data</th>
<th>View Results</th>
<th>Plugin Help</th>
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**FRONTIERS**

THE HEARTLAND INSTITUTE FOR CLINICAL AND TRANSLATIONAL RESEARCH

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*Note: The above text is a screenshot of a software interface showing patient data and timelines.*
The dream: landing the big one

http://www.oregon.com/columbia_gorge_attractions/bonneville_hatchery

Catch the data for JAMA, NEJM publication
Without getting bit
NIH Clinical Translational Science Awards are somewhat an anti-grant

- Provide a **portal for investigators to access** clinical and translational research **resources**, track usage and outcomes, and provide informatics consultative services.
- Create a **platform**, HERON (Healthcare Enterprise Repository for Ontological Narration), **to integrate clinical and biomedical data** for translational research.
- 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).
- **Leverage** an active, engaged statewide **telemedicine** and Health Information Exchange (**HIE**) effort to enable community based translational research (addressing T2 translational research).
HERON: Current Contents

- ~850 million facts
- 1.9 million patients but...
  - Most are old administrative registrations
Richness of Phenotype is the Goal.
Example: Frontiers Participant Registry

Frontiers Participant Data Richness Today

*All Frontiers Participants have Diagnosis and Procedure Data.

Patients with Medications Data

Patients with Laboratory Results

July 2012
Engagement and Review

- Dedicated Coordinator. Informatics Clinics held biweekly and one-to-one trainings and consultations offered.
- Integrating HERON’s use into other research workflows:
  - Finding patients for prospective trials: combining the Frontiers Participant Registry with the EMR data to find willing participants that meet study criteria.
  - Searching for samples: Biospecimen Repository combined with EMR to find tissues that meet research criteria.
- Auditing small queries
Supporting National Cancer Institute Cancer Center Designation

Incorporate Clinical, Administrative, Research Datasources

- Inpatient and outpatient electronic medical records (Epic)
- Professional Services Billing and Scheduling (GE IDX)
- KUCC Biospecimen Shared Resource Samples Database
- Hospital (KUH) Tumor Registry (NAACR format)
- Social Security Death Master File (NIST format)
- Technical Charges from hospital and clinics (UHC validated format)
- Research Data Capture (REDCap)
- Clinical Research Information System (Velos)

HERON’s current contents with Cancer Center centric data in green

- Demographics (master patient index)
- Race/Ethnicity
- Laboratory Results
- Nursing observations/vital signs
- Clinical Diagnoses (ICD9)
- Medications (dispensed, ordered, home meds, administered)
- Physician Orders
- Procedure charges (CPT)
- Outpatient Billing diagnoses (ICD9)
- Inpatient visit/provider service
- Specimen collected
- Tumor Staging and Grade
- Diagnosis and Treatment
- Survival and Progression
- Site Specific Factors (e.g. ER positive)
- Death per Social Security Administration
- MDSRG, APDRG, LOS, Readmissions
- Technical Charge Diagnoses ICD9
- Service line, AHRQ quality and JCAHO core measures
- Triple Negative Breast Cancer Registry initial pilot completed

Status as of September 19, 2012

http://informatics.kumc.edu/work/wiki/HeronProjectTimeline#Sep2012Planning
- Contains current plan for next several monthly releases

http://informatics.kumc.edu/work/blog
- Always has an article describing our last release’s contents and features.
Idealized HERON Research Workflow