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

Russ Waitman, PhD
Director of Medical Informatics,
Associate Professor, Department of Biostatistics
Director, Frontiers Biomedical Informatics
Assistant Vice Chancellor, Enterprise Analytics
University of Kansas Medical Center
Kansas City, Kansas

This project is supported in part by NIH grant UL1TR000001.
Overview

• How we currently engage users
• Demonstration
  – General use
  – Timelines
  – UHC
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 July 10.
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. Klashill
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

HERON Research Data Repository

Russ Waitman (rwaitman) [logout]
1. [ ] KUMC Faculty?
2. [ ] Human subjects training is complete and current?
3. [ ] Signed system access agreement?
Problems? Questions? Ideas?
Gripes/Praise
Tools
CRIS
RETRIm

KU Medical Center
The University of Kansas

i2b2 Query and Analysis Tool
Start Query Tool
Training Materials
HERON Access
Investigator Requests

HERON Sponsorship Request
HERON Data Usage Request

Search KUMC web site [keyword name]
myKUMC Email ANGEL Directory Library

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
i2b2 : **AND** in Frontiers Research Registry

Dragging 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
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).
Moving to FusionIO storage memory platform (August 2011) improved performance, but after upgrading to i2b2 1.6, query times increased significantly.

**Herong, an Integrated Data Repository, is Hard: Need Technical Expertise to Surmount Challenges**

**Hardware/Software:** SUSE Linux Enterprise Server 11 (x86_64), Oracle 10g, 70G of RAM, 12 CPUs, Fusion-IO 1.28 TB IoDrive Duo storage tier.
• 850 million facts
• 1.9 million patients but...
  – Most are just 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.
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 (NAACCR 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 new 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)
- Procedure charges (CPT)
- Outpatient Billing diagnoses (ICD9)
- Specimen collected
- Tumor Staging and Grade
- Diagnosis and Treatment
- Survival and Progression
- Death per Social Security Administration
- MSDRG
- Technical Charge Diagnoses ICD9
- Service line, AHRQ quality measures
- Triple Negative Breast Cancer Registry

Status as of July 15, 2012

http://informatics.kumc.edu/work/wiki/HeronProjectTimeline#March2012Planning
- contains current plan for next several monthly releases
Idealized HERON Cancer Center Research Workflow

1. See what we have
2. Define a cohort
3. Conduct Analysis
4. Resulting Plot

Cancer Survival: Obese (BMI > 30) Diabetic Breast