Russ Waitman, PhD
Director of Medical Informatics,
Department of Biostatistics
Director, Frontiers Biomedical Informatics
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 August 7th (we’re out of town next week).

**Biomedical Informatics Can Help Your Research**
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/
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
i2b2 : **AND** in Frontiers Research Registry

Dragging over the second condition
i2b2: **AND** a high Hemoglobin A1C

When you add a numeric concept, i2b2 asks if you want to set a constraint.
Run the Query
Query took 4 seconds
497 patient in cohort
### I2b2: Explore Cohort, Visualize Timelines

#### Timeline

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**Frontiers**

The Heartland Institute for Clinical and Translational Research
The dream: landing the big one

Catch the data for JAMA, NEJM publication

http://www.oregon.com/columbia_gorge_attractions/bonneville_hatchery
Without getting bit

!! CAUTION!!

TROUT BITE

DO NOT PUT YOUR HANDS
OR FINGERS IN THE WATER
What you need to be aware of: **HIPAA means date shifting**; randomly moving the birthdate and all subsequent events by the same offset (0 to 365 days).

Follow progress: [http://informatics.kumc.edu](http://informatics.kumc.edu)

Monthly releases described on our blog: [http://informatics.kumc.edu/work/blog](http://informatics.kumc.edu/work/blog)
Current Progress on incorporating more sources

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 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

- initial pilot scheduled for release this month

Status as of July 15, 2012

http://informatics.kumc.edu/work/wiki/HeronProjectTimeline#March2012Planning
- contains current plan for next several monthly releases
Demonstration

- Basic functionality of signing up and sponsoring students and staff
  - Systems Access Agreement
  - Data Use Agreement
- Basic query
- Advanced query options (though they may take longer to run and queue)
- Interactive exploration of the data
  - Questions and Answers