From Proteins to Populations: How Do We Integrate Biomedical Informatics across Kansas University?

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Disclaimer

- **Warning**: this talk draws extensively from the work of esteemed informaticians and should not be seen as the novel thought of the presenter.

- Any proposals are based on a preliminary three month assessment and are designed to promote discussion.

- The presenter does not have any conflicts of interest regarding the information presented.
Why the Neanderthals Became Extinct

I don't know. It seemed easier when we just went hunting.

Yes, but Og assures me that this will improve our efficiency and keep us ahead of those Cro-Magnons in the valley.
Outline

- Perspectives on biomedical informatics
- NIH objectives regarding translational research?
- Strawman for KU and filling medical informatics gaps
- Discussion:
  - What is the vision for bioinformatics in Kansas?
  - What are the strongest stories and linkages we can tell or relationships we can build across campuses?
  - What projects should we pursue to make contributions to informatics as a discipline versus providing clinical translational research support?
Background: Charles Friedman

- The Fundamental Theorem of Biomedical Informatics:
  - A person working with an information resource is better than that same person unassisted.

  $$(\text{Brain} + \text{Computer}) \geq \text{Brain}$$

- NOT!!
Background: Randolph Miller

- **ON THE NEED FOR DECISION SUPPORT:**

  1. Life is short, the art long, opportunity fleeting, *experience treacherous*, *judgment difficult*. Hippocrates. *Aphorisms*, ~460-400 BC

- **ALSO ON THE NEED FOR DECISION SUPPORT:**


- **ON THE NEED TO EVALUATE DECISION SUPPORT SYSTEMS:**

  (also interpreted as avoidance of medical informatics vaporware)

  3. The proof of the pudding is in the eating. Miguel de Cervantes. *Don Quixote*, 1605
Background: William Stead
The Individual Expert

Evidence

Patient Record

Clinician

Synthesis & Decision

William Stead: http://courses.mbl.edu/mi/2009/presentations_fall/SteadV1.ppt
The demise of expert-based practice is inevitable.

- Proteomics and other effector molecules
- Functional Genetics: Gene expression profiles
- Structural Genetics: e.g. SNPs, haplotypes
- Decisions by Clinical Phenotype

William Stead: http://courses.mbl.edu/mi/2009/presentations_fall/SteadV1.ppt
Background: Edward Shortliffe

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Basic Research

Biomedical Informatics Methods, Techniques, and Theories

Imaging Informatics
Clinical Informatics
Public Health Informatics

Bioinformatics

Molecular and Cellular Processes
Tissues and Organs
Individuals (Patients)
Populations And Society

Background: Edward Shortliffe
Biomedical Informatics Research Areas

- Biomedical Knowledge
- Biomedical Data
- Knowledge Base
- Inferencing System
- Data Base

Knowledge Acquisition

Biomedical Research Planning & Data Analysis

- Machine learning
- Text interpretation
- Knowledge engineering

Real-time acquisition
- Imaging
- Speech/language/text
- Specialized input devices

Model Development
- Information Retrieval
- Diagnosis
- Treatment Planning
- Human Interface
- Teaching
- Image Generation

Background: Dan Masys
NIH Goal to Reduce Barriers to Research

Administrative bottlenecks
Poor integration of translational resources
Delay in the completion of clinical studies
Difficulties in human subject recruitment
Little investment in methodologic research
Insufficient bi-directional information flow
Increasingly complex resources needed
Inadequate models of human disease
Reduced financial margins
Difficulty recruiting, training, mentoring scientists
“It is the responsibility of those of us involved in today’s biomedical research enterprise to translate the remarkable scientific innovations we are witnessing into health gains for the nation.”
CTSA Objectives:
The purpose of this initiative is to assist institutions to forge a uniquely transformative, novel, and integrative academic home for Clinical and Translational Science that has the consolidated resources to:

1) captivate, advance, and nurture a cadre of well-trained multi- and inter-disciplinary investigators and research teams;

2) create an incubator for innovative research tools and information technologies; and

3) synergize multi-disciplinary and inter-disciplinary clinical and translational research and researchers to catalyze the application of new knowledge and techniques to clinical practice at the front lines of patient care.
Reengineering Clinical Research

- Interdisciplinary Research
  - Innovator Award
- Bench
  - Building Blocks and Pathways
  - Molecular Libraries
  - Bioinformatics
  - Computational Biology
  - Nanomedicine
- Bedside
  - Translational Research Initiatives
- Practice
  - Integrated Research Networks
  - Clinical Research Informatics
  - NIH Clinical Research Associates
  - Clinical outcomes
  - Harmonization
  - Training

Dan Masys: http://courses.mbl.edu/mi/2009/presentations_fall/masys.ppt
Role of Informatics in Clinical and Translational Research

- Structured observation and record keeping are the essence of science
- Informatics Centric Efforts:
  - Clinical Trial enrollment
  - Clinical Trial software
  - Reuse, integration, and sharing of electronic health data to support translational research
  - Bioinformatics and Biospecimen management
- Methods Applicable to other large infrastructure needs: NCI Cancer Center designation.
- CTSA Informatics cross institutional goals?
CTSA PI Priorities

- National Clinical and Translational Research Capability
  - Clinical Research Management
  - Research Infrastructure
  - Phenotyping-human and pre-clinical models

- Training & Career Development of Clinical/Translational Scientists

- Enhancing Consortium-Wide Collaborations Members
  - Social Networking
  - Inventory of Resources
  - Data sharing

- Enhancing the Health of Our Communities and the Nation
  - Community Engagement
  - Public Health Policy

IKFC Prioritized Projects, Special Interest Groups (SIGs), Projects

- Human Study Database Project group (Sim and Team)
- Data Repositories (Kamerick)
- Standards & Interoperability (Chute)

- Education (Klee, Hersh)

- Collaboration Facilitation (Kahlon)
- Resource Inventory (Becich, Athey & Team)
- Data Sharing (Silverstein, Anderson)

- Nat’l Human Subject Volunteer Registry (Harris)
Building a Vision: Environmental Comparison VU/KU

- **VUMC**: unified leadership across hospitals, clinics, academics
  - Unified informatics: from network jack and server, to library and bioinformatics cores
  - Build/buy mix legacy -> complexity
  - Large consolidated academic home for informatics
  - Data sharing for research a non issue

- **KU/KUMC, Rest of the world**: not so homogenous
  - What can one do with EPIC or Cerner + added informatics?
  - Validated solutions more likely to scale.
  - Data sharing involves multiple organizations
KU Opportunities

- Quality Focused Hospital
  - Without every solution involving informatics
- CTSA goal: Data “Warehouse”
  - Advance research and clinical quality
  - “Green Field” for newer technologies
- State and Region
  - KUMC strong in community outreach research
    - Link our data to external information? (Ex: KHPA Medicaid data)
  - Health Information Exchange “window”
  - KU Lawrence Informatics, Stowers
  - Long term: Cerner
Medical Informatics: Short Term Approach

- Data sharing agreement and data access
  - This is not a one size fits all solution
- Develop terms of agreement and oversight
- Understand current information strategy and timelines of our partner organizations
- Engage research community
- Establish development environment
- Gain experience with KUH/KUPI/KUMC information systems
  - Focus on practical pilot projects
  - Ideally, benefits to clinical quality and research
Data Sharing roles: entities with justifiable (and variable) rights to medical data

First order role definitions:
- Provider, Patient, Payer, “Society”

Second order:
- Providers: primary vs. consultant provider, ancillary support staff
- Patient: self, family, legally authorized reps
- Payer: billing staff and subcontractors, clearinghouses, insurers
- Society: public health agencies, state medical boards, law enforcement agencies

Data Sharing roles: entities with justifiable (and variable) rights to medical data

- Third order:
  - Providers: internal and external QA entities (peer review, JCAHO), sponsors of clinical research
  - Patient: community support groups, personal friends
  - Payers: fraud detection (Medical Information Bureau), business consultants
  - Society: national security, bioterrorism detection

Intermediate CTSA aligned goals

- Build team, evaluate, and choose appropriate informatics products and underlying technologies
- Implement incremental construction of “warehouse” + information strategy
  - Balance retrospective with near real time opportunities
- Clinical data foundation, then link to other resources and provide research opportunity
  - Potential linkages with biospecimens
  - State data for epidemiology research
  - NDNQI nursing quality indicators
Strawman: Recall Shortliffe Model

KU CTSA and Overall Strawman

Academic Homes KU-L
- Center for Bioinformatics
- ITTC EECS Bioinformatics

BioInformatics (K-INBRE coord)
- Cores/Labs
- Public: GenBank

Academic Homes KUMC
- Center for Health Informatics
- Dept. Health Info Mgt (BS)

Medical Informatics
- UKP: clinics
- KUH: hospital
- CRIS: trials

Health Informatics
- Public: SSDI
- State/KHPA: Medicaid+
- State: Exchanges Extension Centers

Organizations/ Data sources

Operational Service Layer

Molecular and Cellular Processes

Tissues and Organs

Individuals (Patients)

Populations And Society
Medical and Health Informatics Vision

- By directly engaging in clinical and health informatics databases, we in turn learn about the delivery of care and the effectiveness of informatics methods as mechanisms for influencing care.

- If we can develop strong relationships with our provider, state, and clinical research organizations, we will provide a rich environment for clinical and informatics research.
  - The hospital and clinic data is our core resource
  - Engagement in state wide data in complementary to our existing research strength in preventative medicine
Share with me your “Vision”

- What is the vision for bioinformatics in Kansas?

- What are the strongest stories and linkages we can tell or relationships we should build across campuses?

- What projects might we pursue to make contributions to informatics as a discipline versus providing clinical translational and other research support?