

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

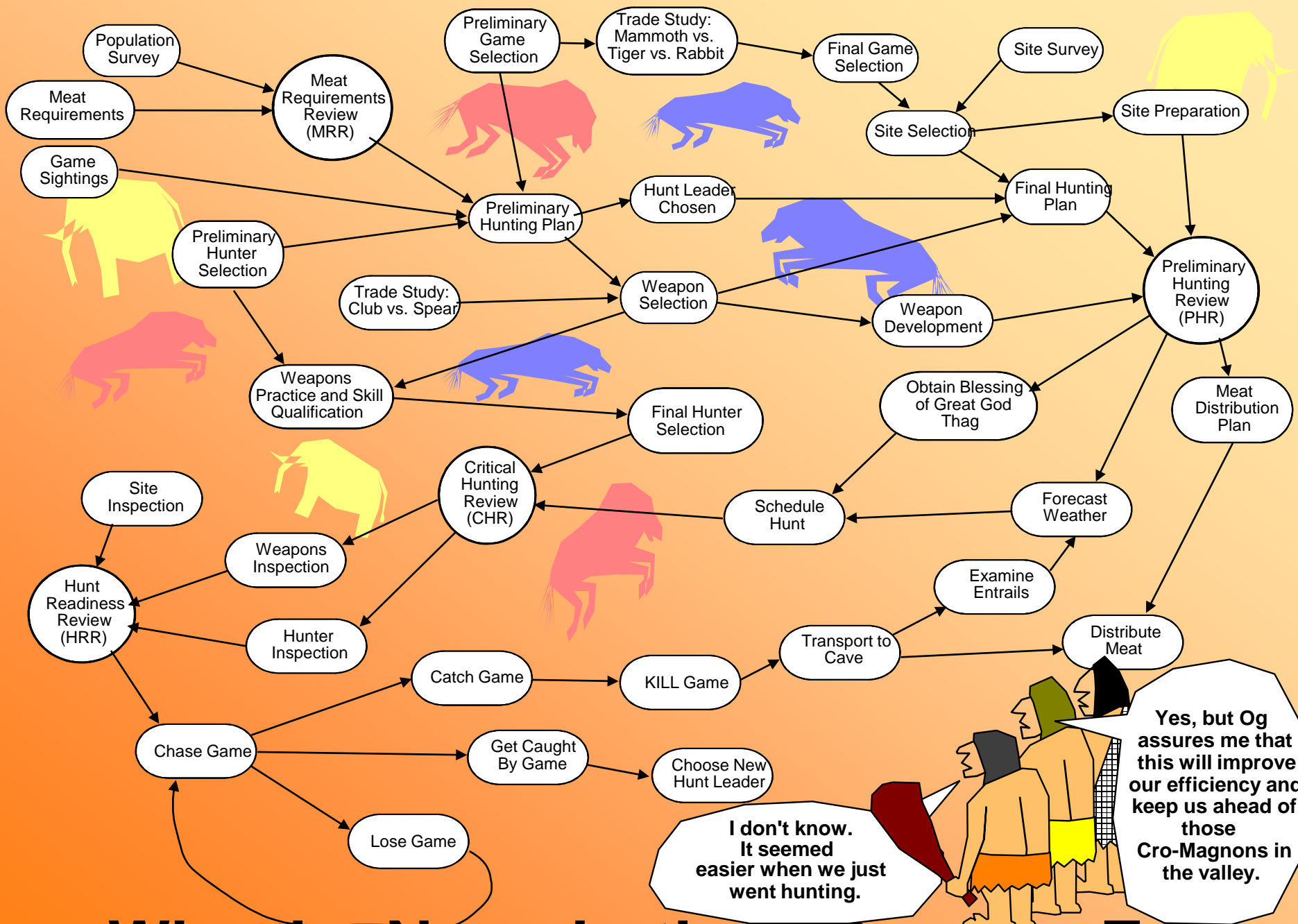
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K-INBRE Seminar May 11, 2010

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

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

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

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?



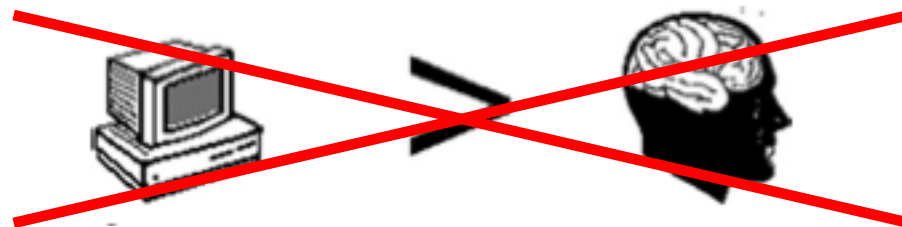
Background: Charles Friedman

- ▶ The Fundamental Theorem of Biomedical Informatics:

- ▶ A person working with an information resource is better than that same person unassisted.



- ▶ **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:

2. Men are men; the best sometimes forget. Shakespeare. *Othello*, 1604-5

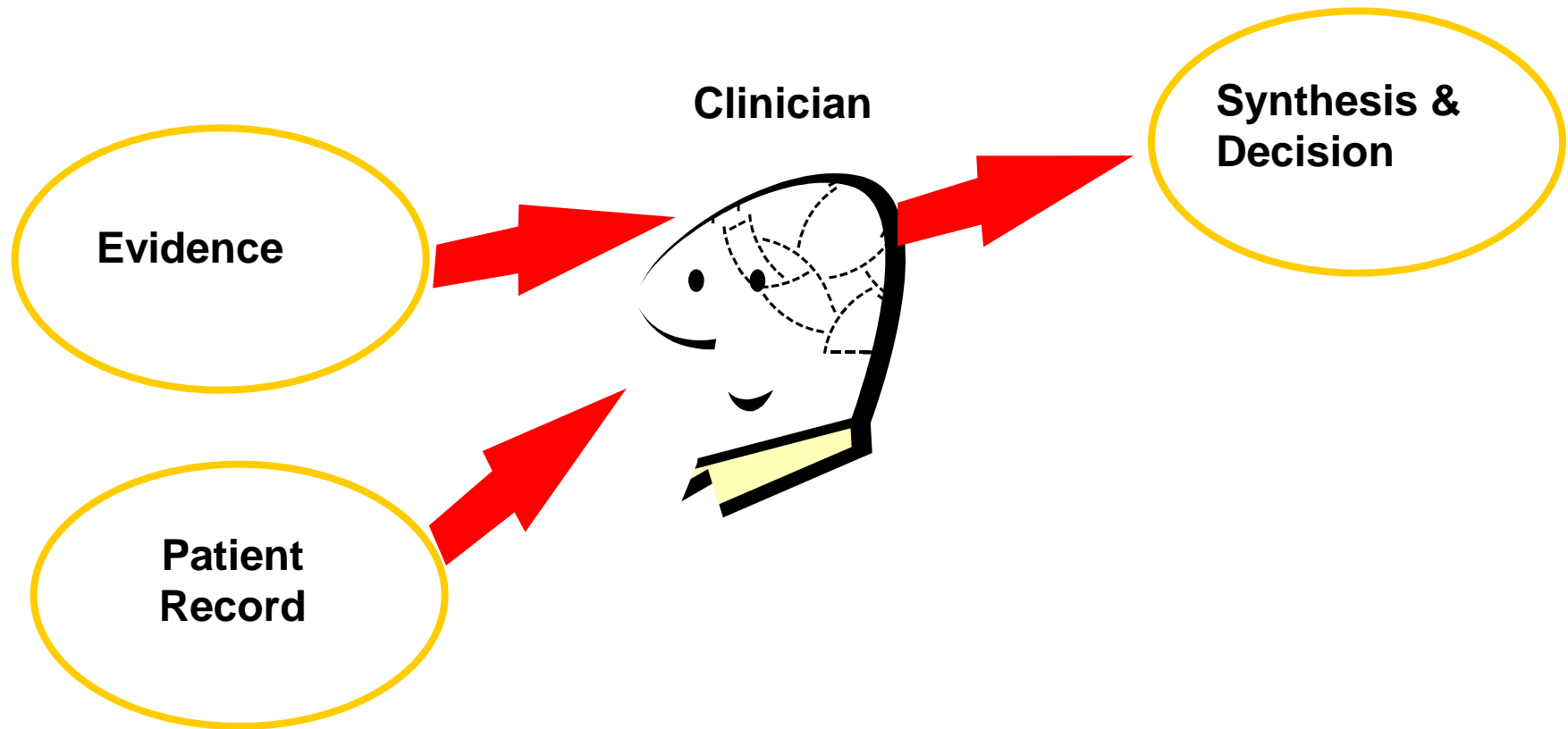
▶ ON THE NEED TO EVALUATE DECISION SUPPORT SYSTEMS:
(also interpreted as avoidance of medical informatics vaporware)

3. The proof of the pudding is in the eating.
Miguel de Cervantes. *Don Quixote*, 1605

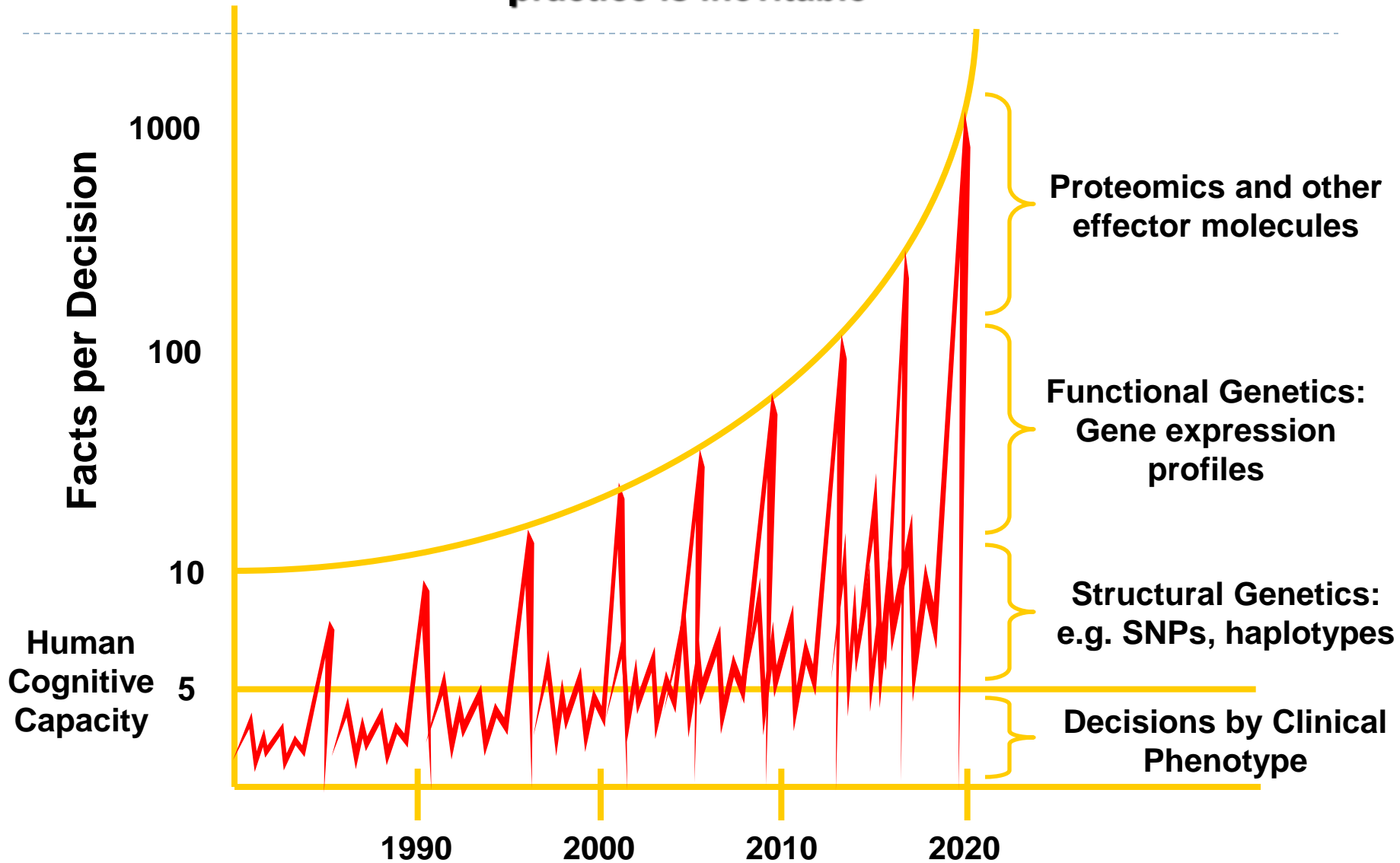


Background: William Stead

The Individual Expert



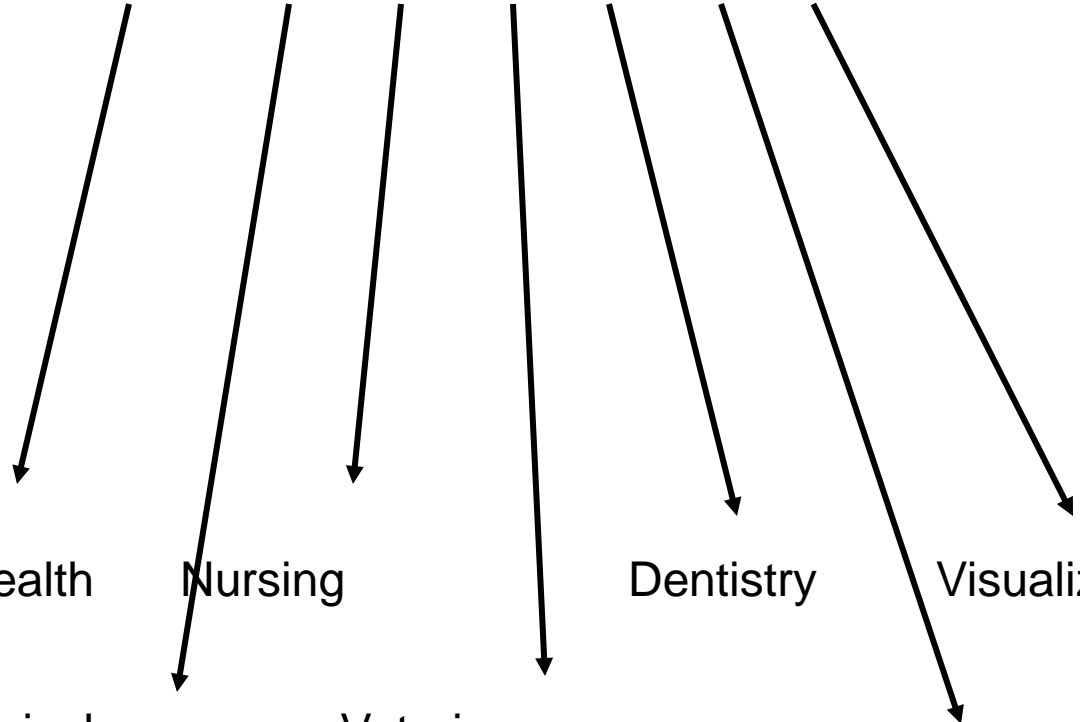
The demise of expert-based practice is inevitable



Background: Edward Shortliffe

Basic Research

Methods, Techniques, and Theories



Public Health

Nursing

Clinical
Medicine

Veterinary
Medicine

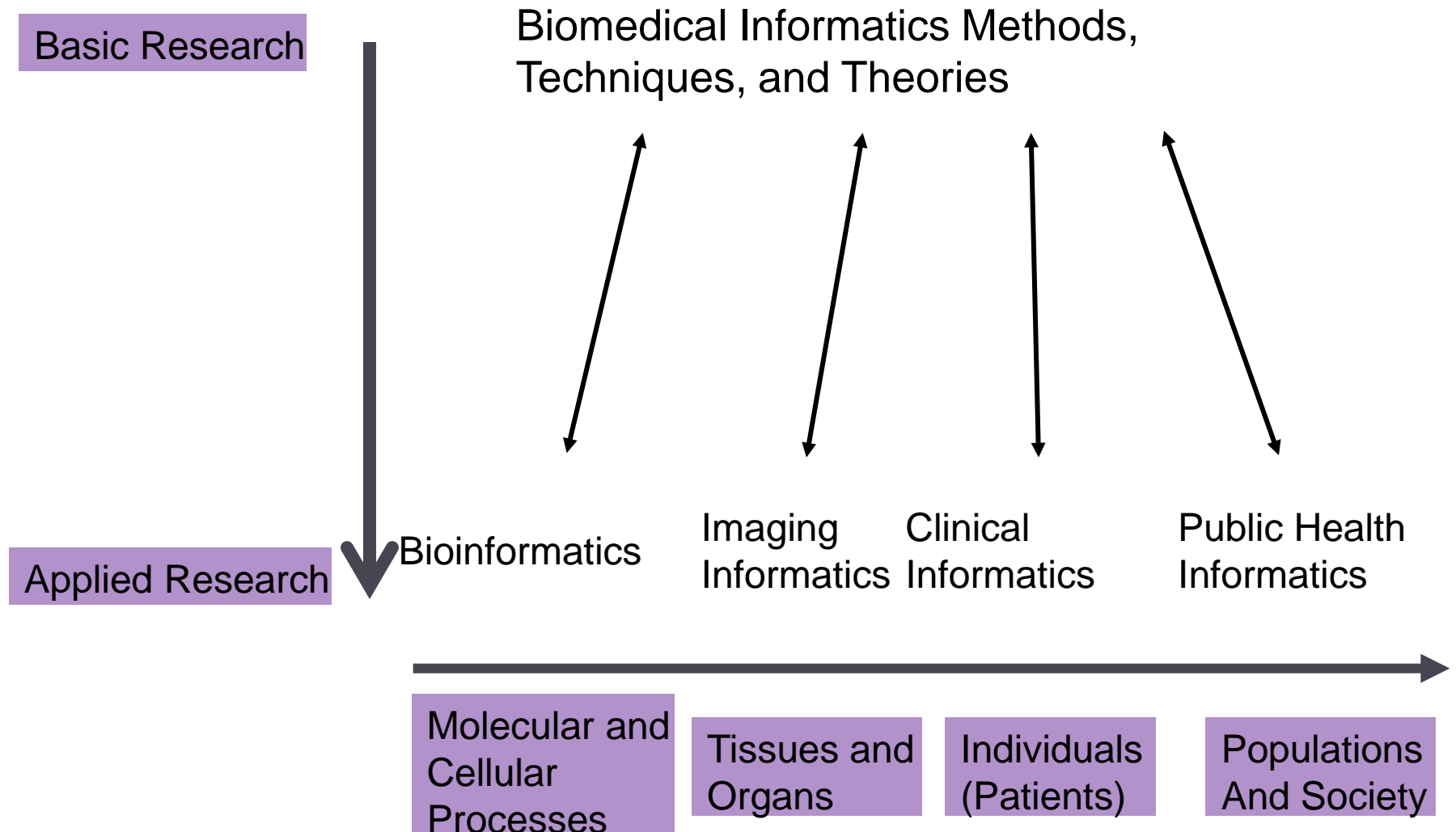
Dentistry

Visualization

Molecular Biology

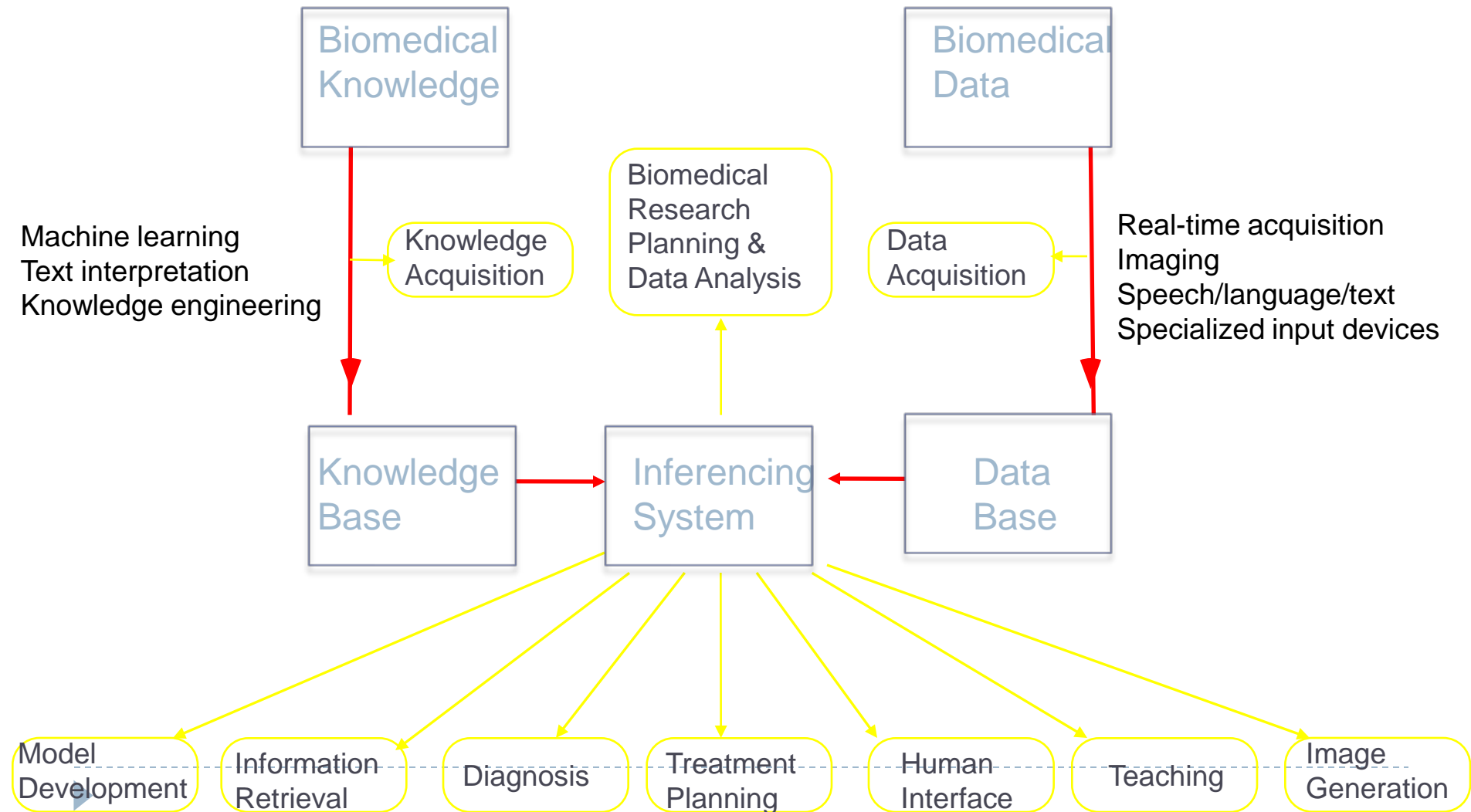
Applied Research

Background: Edward Shortliffe



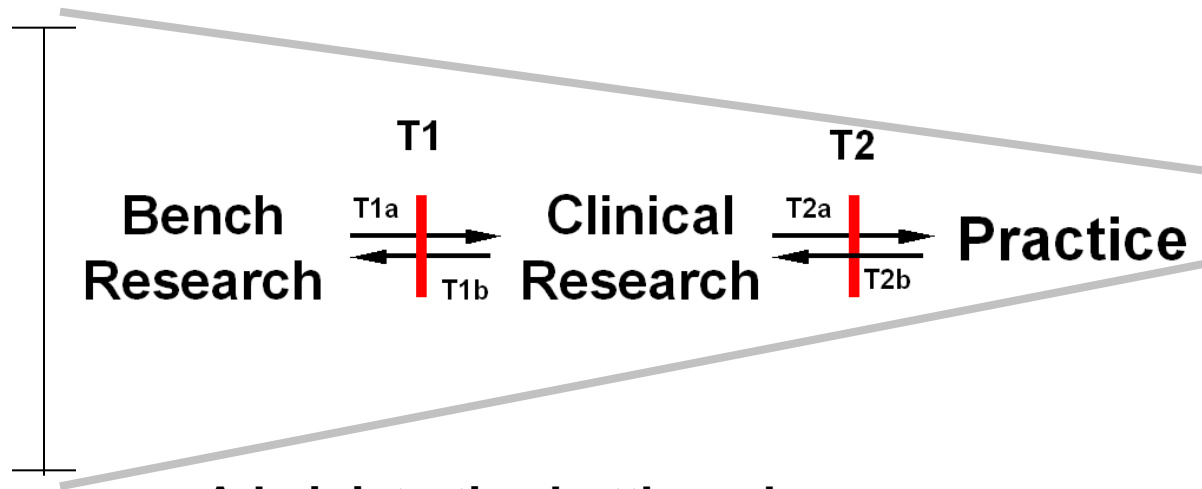
Background: Edward Shortliffe

Biomedical Informatics Research Areas



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**
-



Clinical and Translational Science Awards A NIH Roadmap Initiative

THE NEW ENGLAND JOURNAL OF MEDICINE

SOUNDING BOARD

Translational and Clinical Science — Time for a New Vision

Elias A. Zerhouni, M.D.

“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.”



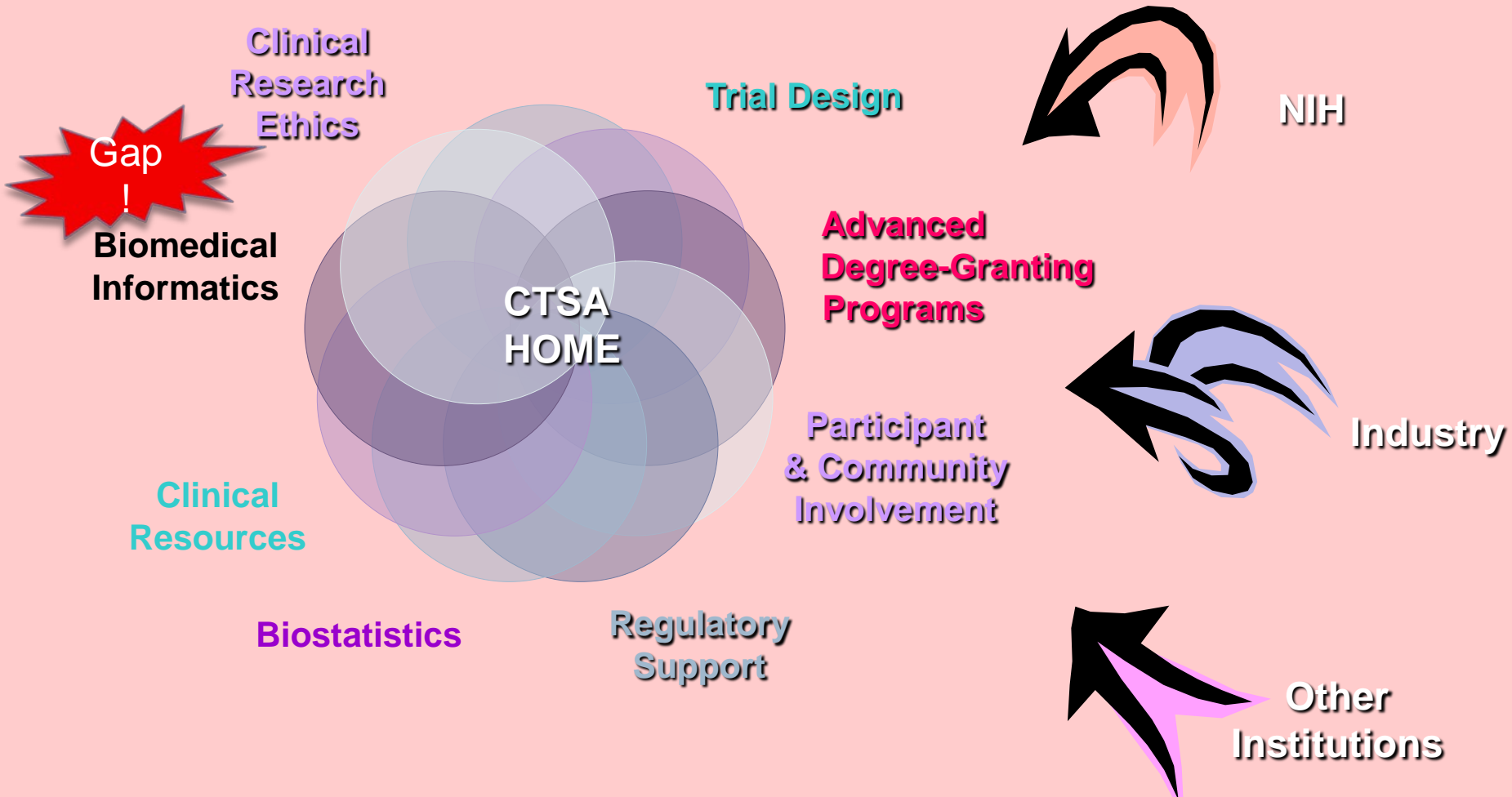
CTSA Objectives:

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:

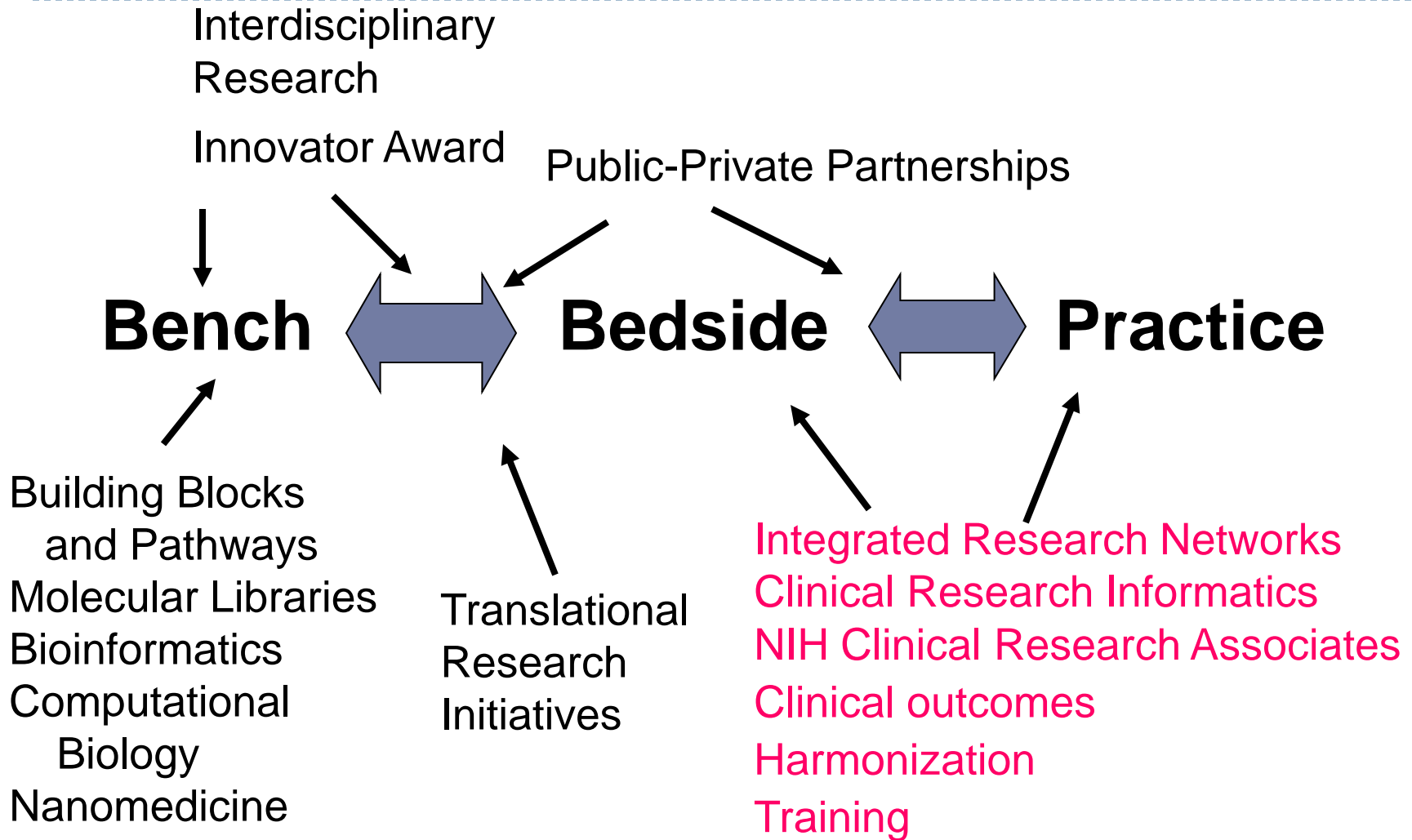
- 1) captivate, advance, and nurture a cadre of well-trained multi- and inter-disciplinary investigators and research teams;
 - 2) create an incubator for innovative research tools and information technologies; and
 - 3) synergize multi-disciplinary and inter-disciplinary clinical and translational research and researchers to catalyze the application of new knowledge and techniques to clinical practice at the front lines of patient care.
-



NIH CTSAs: Home for Clinical and Translational Science



Reengineering Clinical Research



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

CTSA Strategic Goal Committees

CTSA PI Liaisons

Other Key Function Committees

**IKFC
Prioritization
Process**



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

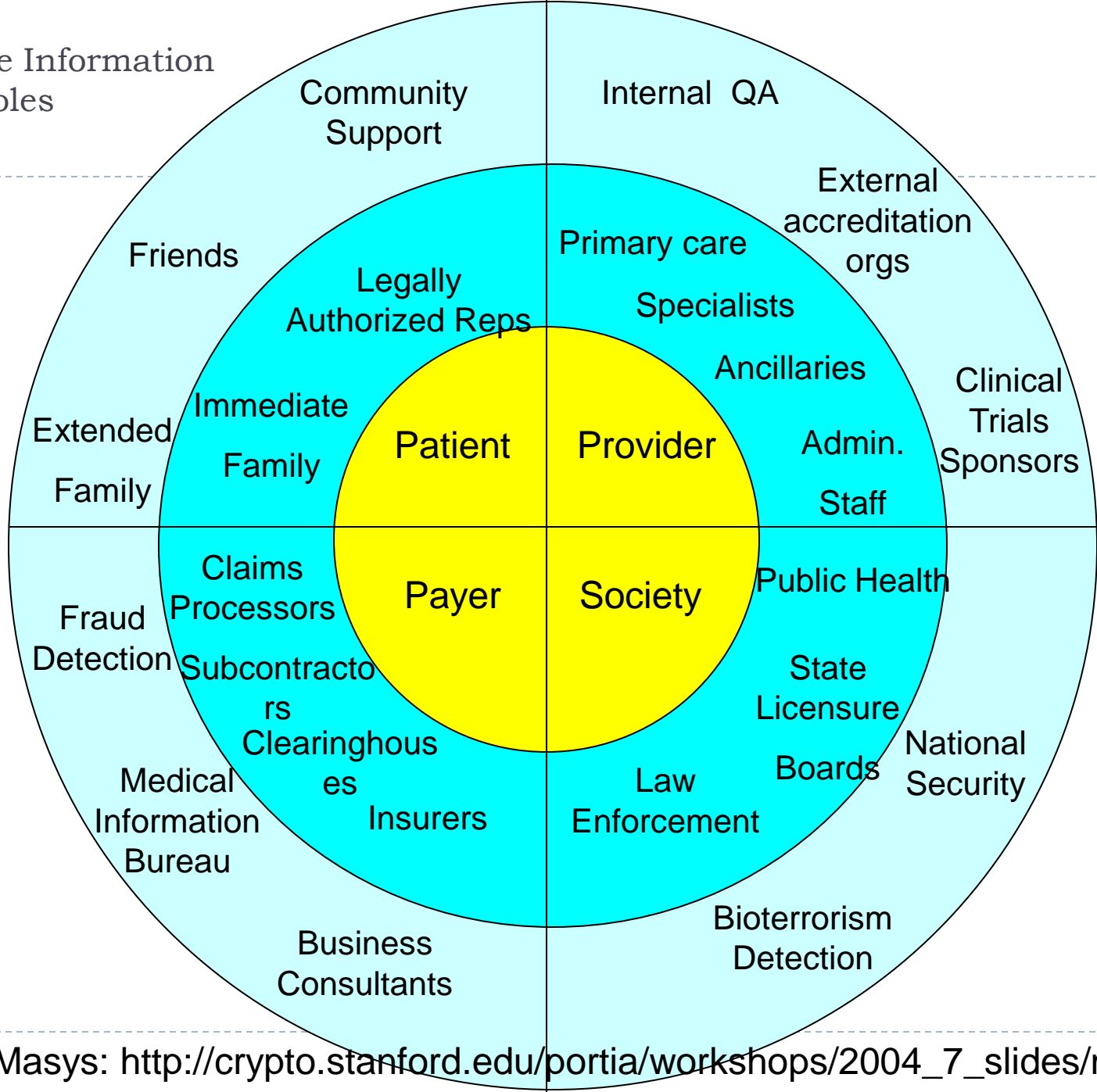
- ▶ **First order role definitions:**
 - ▶ Provider, Patient, Payer, “Society”
- ▶ **Second order:**
 - ▶ Providers: primary vs. consultant provider, ancillary support staff
 - ▶ Patient: self, family, legally authorized reps
 - ▶ Payer: billing staff and subcontractors, clearinghouses, insurers
 - ▶ 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

Healthcare Information Access Roles



Intermediate CTSA aligned goals

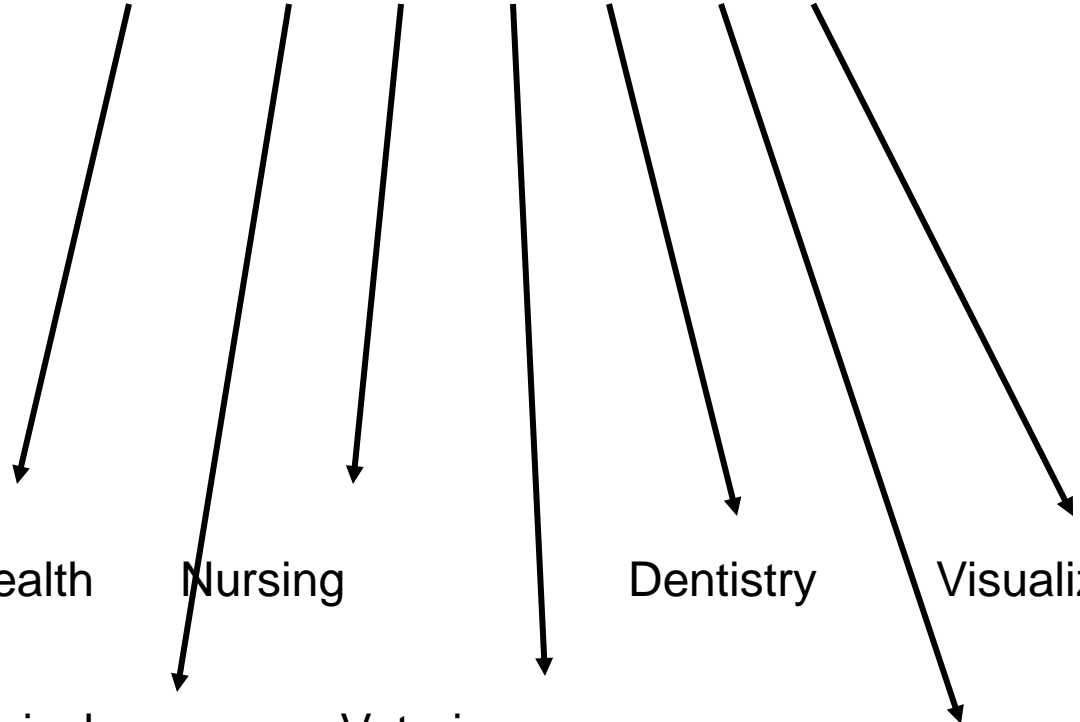
- ▶ Build team, evaluate, and choose appropriate informatics products and underlying technologies
- ▶ Implement incremental construction of “warehouse” + information strategy
 - ▶ Balance retrospective with near real time opportunities
- ▶ Clinical data foundation, then link to other resources and provide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



Strawman: Recall Shortliffe Model

Basic Research

Methods, Techniques, and Theories



Public Health

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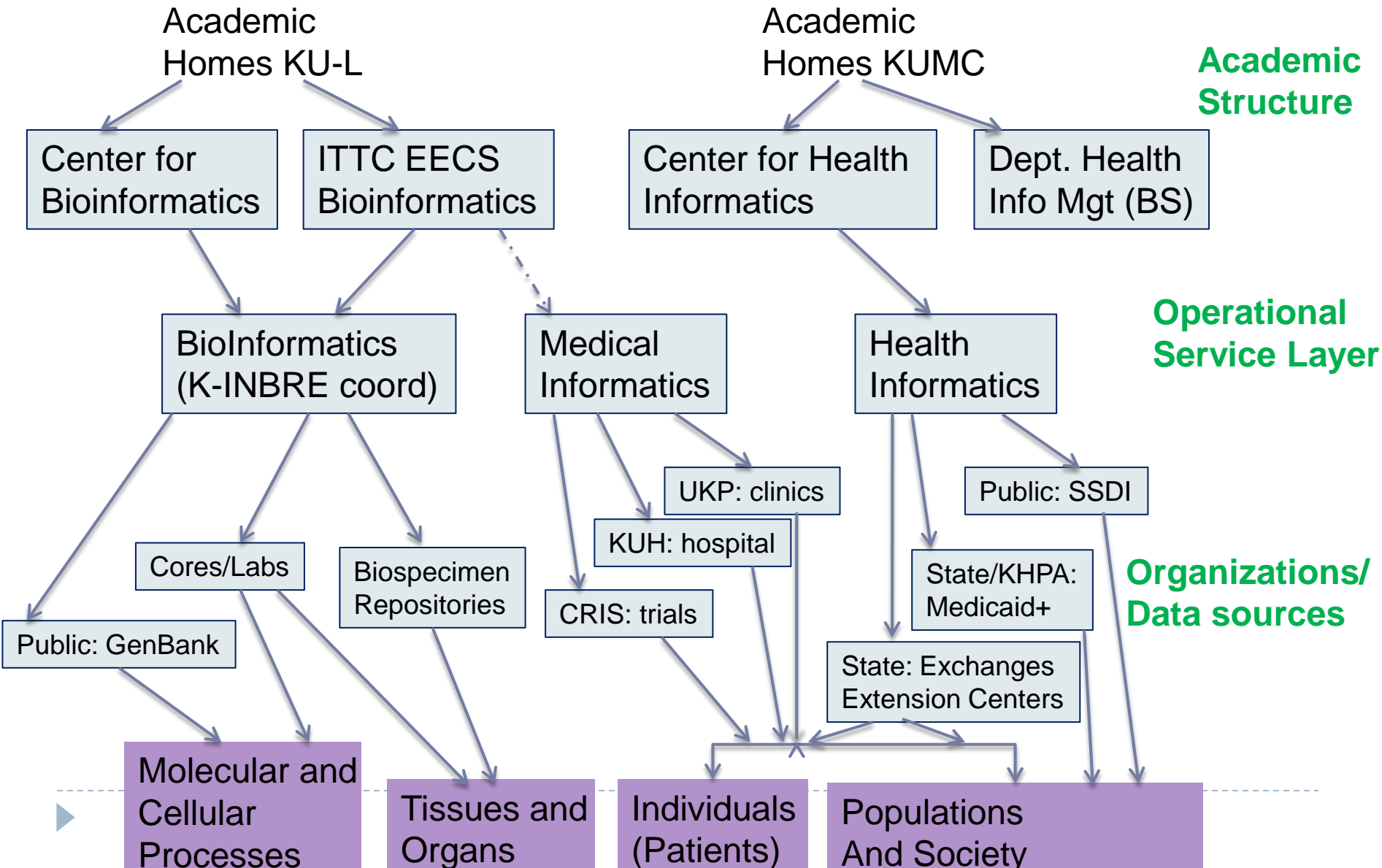
Dentistry

Visualization

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Applied Research

KU CTSA and Overall Strawman



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 is 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?

