HST.921 / HST.922 Information Technology in the Health Care System of the Future, Spring 2009
Harvard-MIT Division of Health Sciences and Technology
Course Directors: Dr. Steven Locke, Dr. Bryan Bergeron, Dr. Daniel Sands, and Ms. Mirena Bagur

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Rise of the Data Tiger

Will Asia Assume Global Leadership in Health Informatics

Keith B. Strier, JD

Principal, Health Science & Government Practice, Deloitte LLP
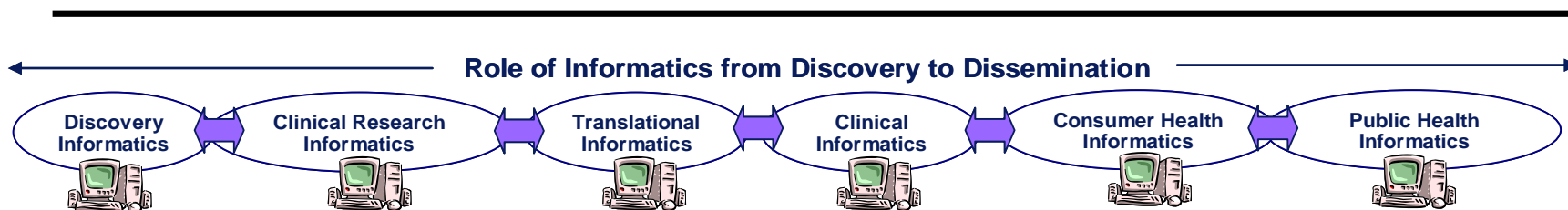
Co-Leader, Health Informatics, Deloitte LLP

Senior Fellow, Deloitte Center for Health Solutions

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Audit.Tax.Consulting.Financial Advisory.

Definitions

__Health informatics__ is an emerging __discipline__ that focuses on the systematic __management and evaluation of patient-level information__ - how it is captured, retrieved, and applied as well as the tools and methods used - to support decision-making along the continuum from discovery to dissemination.

Role of Informatics from Discovery to Dissemination

Discovery Informatics	Clinical Research Informatics	Translational Informatics	Clinical Informatics	Consumer Health Informatics	Public Health Informatics

Discovery Informatics is concerned with the application of informatics theory and methods to drug discovery infrastructures, the integration of scientific applications, the design of drug discovery databases, and the setup of drug discovery datamarts.

Clinical Research Informatics is concerned with the application of informatics to design, conduct and improve clinical research and disseminate the knowledge gained from three kinds of research: patient-focused, epidemiologic and outcomes or health services research.

Translational research is concerned with the application of informatics to 1) enabling discoveries generated in the lab (basic science) to become in-human trials and studies, and 2) enhancing adoption of research findings by clinical practice and the community at large
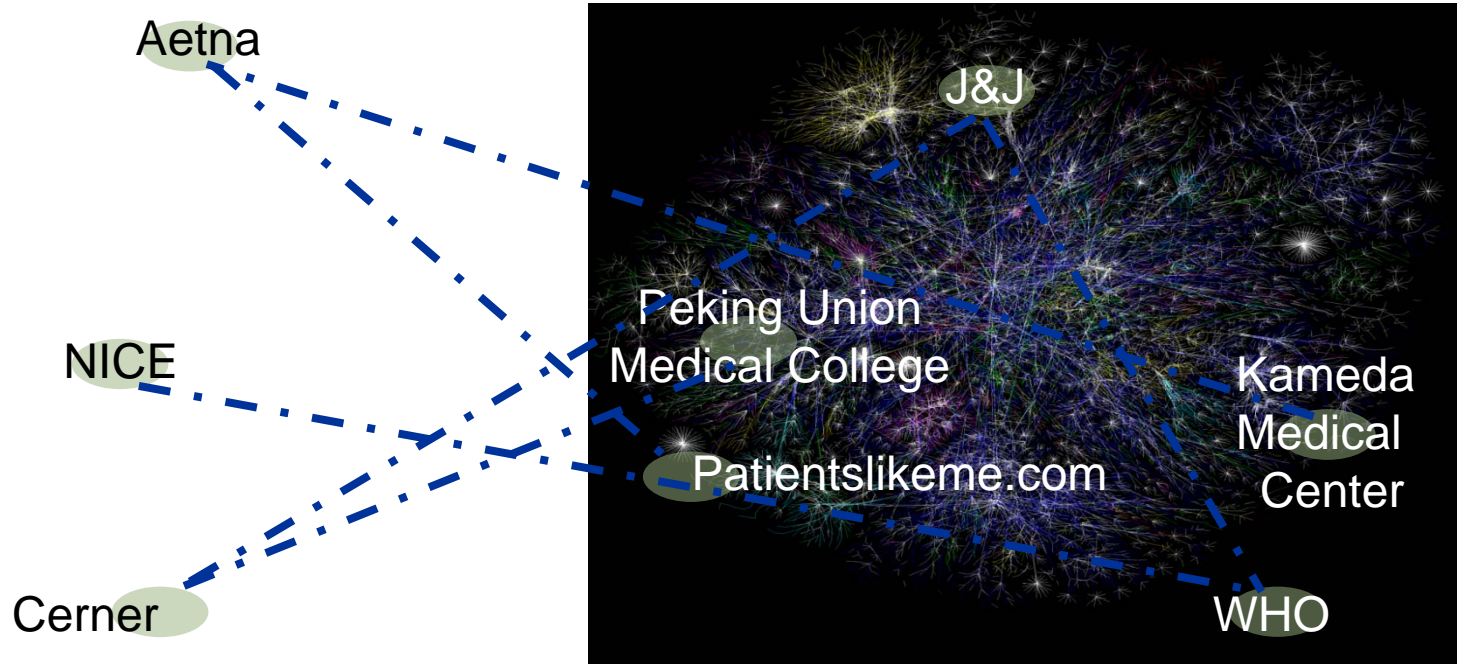
Clinical Informatics is concerned with computer applications that collect, store and analyze medical data to assist in the management and processing of information that support the delivery of clinical care

Consumer health informatics is the branch of medical informatics that analyses consumers' needs for information; studies and implements methods of making information accessible to consumers; and models and integrates consumers' preferences into medical information systems

Public Health Informatics is the systematic application of informatics to public health practice, research, and learning, distinguished from healthcare informatics by emphasizing data about populations rather than that of individuals
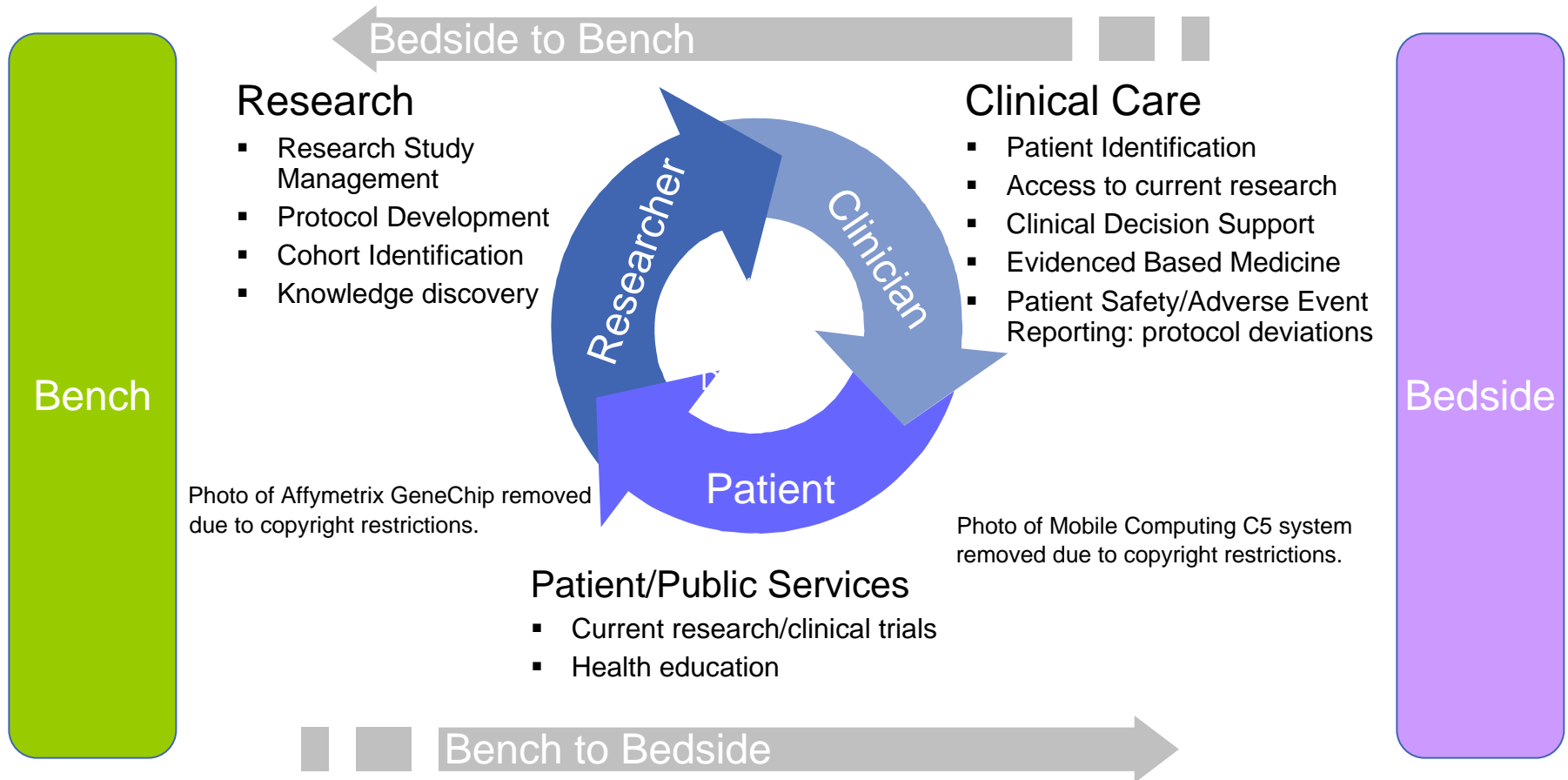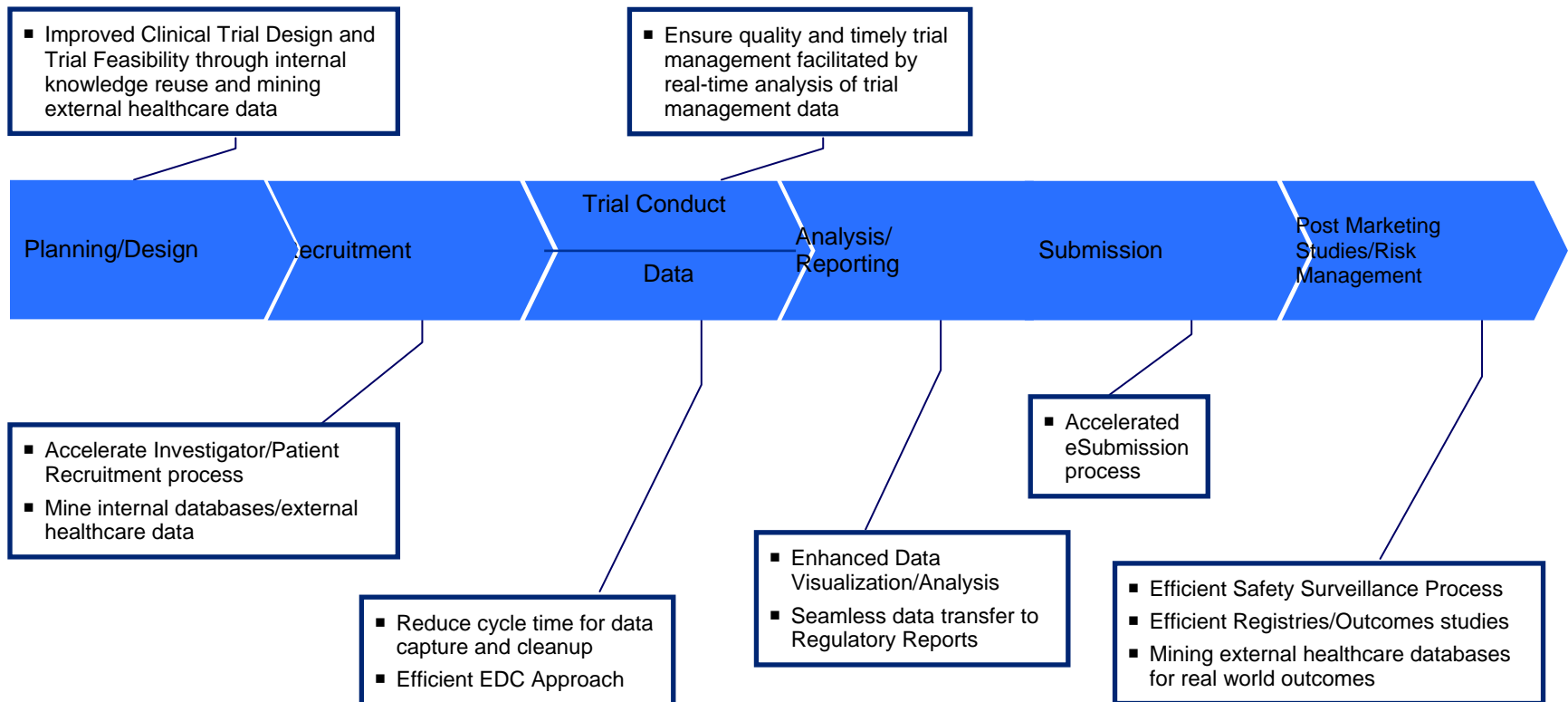
We are all connected

Aetna

J&J

Peking Union
Medical College

Kameda
Medical
Center

Patientslikeme.com

NICE

Cerner

WHO

And there is no opting out

Translational Medicine/Research is Ground Zero for Health Informatics

Bench

Research

- Research Study Management
- Protocol Development
- Cohort Identification
- Knowledge discovery

Researcher

Clinician

Clinical Care

- Patient Identification
- Access to current research
- Clinical Decision Support
- Evidenced Based Medicine
- Patient Safety/Adverse Event Reporting: protocol deviations

Bedside

Photo of Affymetrix GeneChip removed due to copyright restrictions.

Patient

Photo of Mobile Computing C5 system removed due to copyright restrictions.

Patient/Public Services

- Current research/clinical trials
- Health education

Bench to Bedside

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Life Sciences Companies are Developing Health Informatics Capabilities

Drug Development Lifecycle

- Improved Clinical Trial Design and Trial Feasibility through internal knowledge reuse and mining external healthcare data

- Ensure quality and timely trial management facilitated by real-time analysis of trial management data

Process stages: Planning/Design → Recruitment → Trial Conduct / Data → Analysis/Reporting → Submission → Post Marketing Studies/Risk Management

- Accelerate Investigator/Patient Recruitment process
- Mine internal databases/external healthcare data

- Accelerated eSubmission process

- Reduce cycle time for data capture and cleanup
- Efficient EDC Approach

- Enhanced Data Visualization/Analysis
- Seamless data transfer to Regulatory Reports

- Efficient Safety Surveillance Process
- Efficient Registries/Outcomes studies
- Mining external healthcare databases for real world outcomes

Source: Nigam, J&JDC, 3rd Annual HER & eClinical Technologies Conference

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Health Informatics is Exceptionally Global

Canadian Health Authorities require provincial EHR systems be standardized based to enable data portability

Obama Administration has made Health IT a showcased feature of its economic stimulus package

China has made Health IT a top priority in its national health reform program

Scotland's Translational Medicine Research Collaboration with four universities and Wyeth focuses on personalized medicine

Japan's Kameda Medical Center offers all patients a fully-portable, digital health records

NHS in UK has one of the most ambitious visions for the EHRs - the "National Program for Information Technology (IT)",

National EHR system in place in Taiwan

Malaysia plans to have a Lifetime Health Record (LHR) by 2010

National EHR system in place in New Zealand

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How do we Assess Global Health Informatics Leadership?

- Unburdened by the strictures of peer-review or conflict of interest guidelines, I considered what unscientific, purely subjective and anecdotal metrics can be used to benchmark the state of Health Informatics on a regional basis?

- I devised a five-point (im)maturity model:

Academic Informatics Departments

Adoption by Commercial Organizations

Opportunities for the Monetization of Health Data

Regulatory Framework Governing Secondary Use of Health Data

Federal Funding/Policy in Support of HIT

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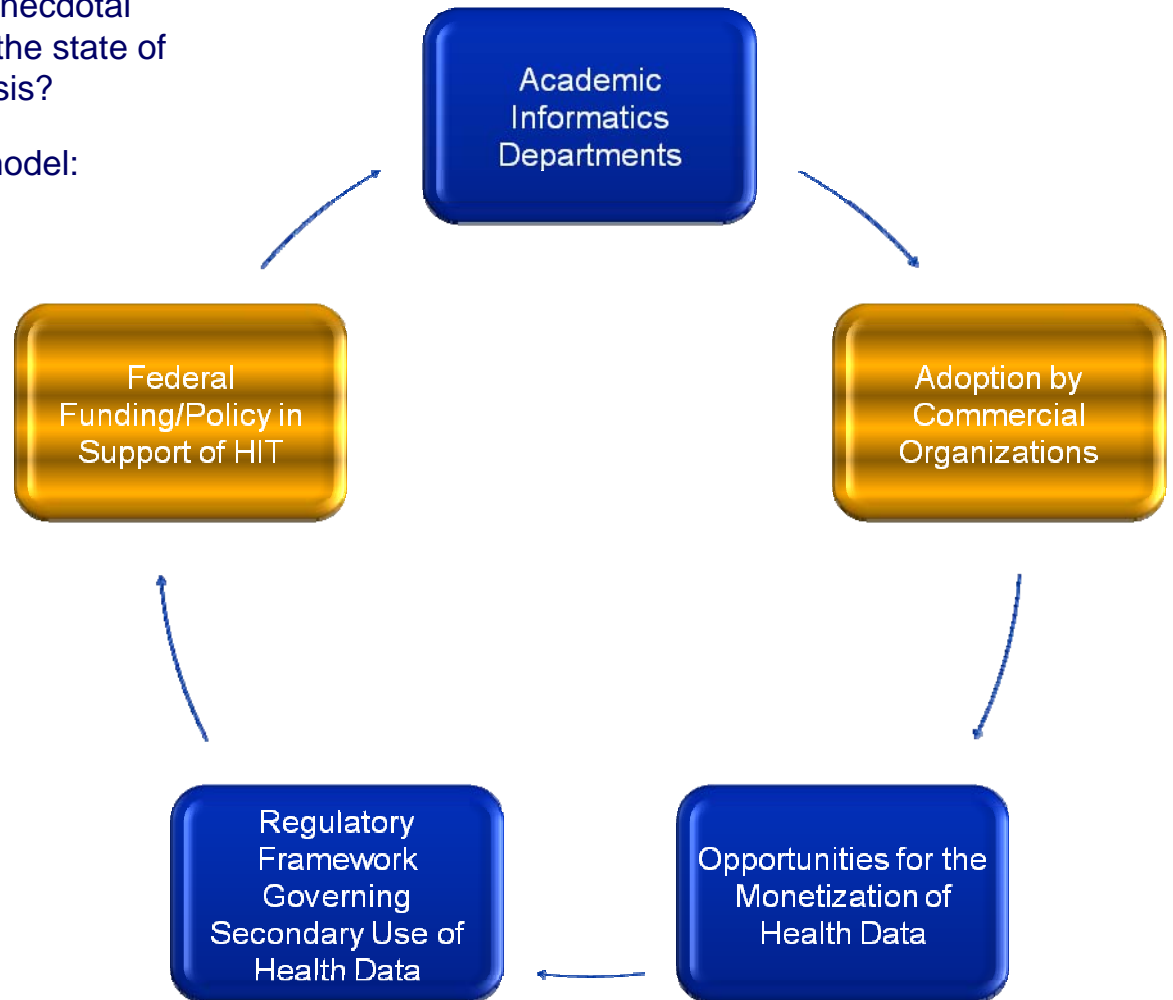
Anecdote: UK Earns High Marks for Federal Support and Regulations Governing Secondary use of Health Data

Image removed due to copyright restrictions.
Website screenshots from NHS Connecting for Health.
http://www.connectingforhealth.nhs.uk/

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Anecdote: Beijing Ministry of Health supports the development of an EMR for TCM at The People's Hospital Peking University

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Anecdote: US Companies Lead in Commercialization/Monetization of Health Data, Chiefly to Big Pharma

SDI Health
(logo removed due to copyright restrictions)

General Electric
(logo removed due to copyright restrictions)

CONVERGENCE CT

Search   GO

Products & Services

▸ Products & Services Overview

Clinical Data Warehouse

▸ Product Datasheet

▸ Life Sciences Solution

Convergence Global Research Network Overview

Convergence CT (CCT)'s unique and innovative business model links patient data at healthcare institutions with Pharmaceutical and Biotechnology companies' data needs for clinical trial planning and recruitment processes, and research for global markets. With the expansion of the Convergence Global Research Network (CGRN) Convergence CT is working to foster innovation and collaboration between sites that conduct clinical research and manufacturers.

Courtesy of Convergence CT. Used with permission.

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Anecdote: Taiwan Stands out for Pervasiveness of Health Data Capture

National Health Insurance Research Database

After the implementation of the National Health Insurance (NHI) in Taiwan in 1995, the Bureau of National Health Insurance (BNHI) established a national health insurance research database (NHIRD) to host the claim data of patients who are covered by the universal national health care system. These patients count for greater than 96% of the total population in Taiwan. There are greater than 95% of the hospitals contained in this database. Information on all medical treatment undertaken at all medical institutions that contracted with NHI has been recorded in the database since 1996

Data Source Examples	Strengths	Weaknesses
Longitudinal Health Insurance Database (2000 & 2005): The two data sets contain the registration and claim data of randomly sampled patients from 2000 and 2005	• One year of longitudinal information • Clinical information included • Accessibility: De-identified data available for approved research studies • Diagnoses coded in ICD9	• One year time period • Sampling data • Language barrier - diagnoses are coded using ICD9, but narrative text is Chinese
Inpatient expenditures, by admission (DD): Original claim data of inpatients, by admission.	• Longitudinal information • Clinical information included • Data is updated regularly • Accessibility: De-identified data available for approved research studies • Diagnoses coded in ICD9	• Language barrier - diagnoses are coded using ICD9, but narrative text is Chinese

Anecdote: Singapore is Registry Happy

Data Source Examples	Strengths	Weaknesses
Singapore Cancer Registry (SCR) The Singapore Cancer Registry has been in existence for more than 25 years and its accuracy of data for incidence, distribution, changing patterns, etc., is close to 100%	• Complete demographic information • Data accuracy	• Data access: No direct access for external organizations
Singapore Childhood Cancer Registry (SCCR) It was established in 1997. SCCR data is also submitted to SCR	• Data accuracy: Contains all children, aged <=18, diagnosed with haematological or solid malignancies. • SCCR also facilitates multi-institutional clinical trials in the evaluation of treatment efficacy	• Access: Data is strictly confidential and is available to all external institutions solely for research purposes. All data releases are subjected to the approval of the Medical Director of SCCR
Renal Registry It gathers comprehensive data and statistics on kidney disease from dialysis centers and hospitals in Singapore.	• Comprehensive data on a. Glomerulonephritis b. End-Stage Renal Disease c. Transplantation d. Annual dialysis status reports	• Data access: No direct access for external organizations

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Anecdote: China's Health Infrastructure is About to Quadruple

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Xiahuo, Cui, and Lan Tian. "China to spend $124b on healthcare reform."
China Daily, 2009-01-22.
http://www.chinadaily.com.cn/china/2009-01/22/content_7418853.htm.
Accessed 2010-03-02.

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Anecdote: There's at least one company in China trying to commercialize secondary uses of health data

YuxiPacificData

識

HOME　PRODUCTS　DATA　SERVICES　ABOUT　CONTACT

Chinese Healthcare Data

Accurate and timely information is paramount to decision-making. In a dynamic country with over 1.4 billion people, Yuxi Pacific Data's deep and authoritative database of physicians and patient treatment information is an essential tool for any pharmaceutical company doing business with China.

What Data is Available?

Our databases are continually updated and include physician, patient and patient treatment information. Because we monitor patient visits, we have developed a longitudinal data set of treatments to include physician information, place of treatment, diagnosis and prescription.

| Physician ID	Last Name	First Name	Therapeutic Area	Institution	City	School	Grad Year	Age	Years
200	李	強國	肿瘤	南方医院，珠江医院	广州市区	广州中医药大学	1997	40	12
201	王	东风	肿瘤	南方医院，珠江医院	广州市区	中山大学	1995	41	14
202	高	懷民	肿瘤	南方医院，珠江医院	广州市区	南方医科大学	1984	52	25
203	刘	達賢	眼科医生	南方医院，珠江医院	广州市区	中国医科大学	1993	44	16
204	陈	慧君	肿瘤	广东省人民医院	广州市区	暨南大学	2000	35	9
205	杨	龍	移植	广东省人民医院	广州市区	首都医科大学	1981	55	28
206	黄	明昼	肿瘤	广东省人民医院	广州市区	南方医科大学	2002	34	7
207	周	志杰	泌尿生殖系统	广东省人民医院	广州市区	北京大学	1987	50	22
208	赵	建国	肿瘤	广东省第二人民医院	广州市区	中国医科大学	1974	61	35
209	吴	海潮	肿瘤	广东省第二人民医院	广州市区	清华大学	1992	44	17
210	徐	瑞峰	肌肉骨骼系统和结缔组织	广东省第二人民医院	广州市区	清华大学	1997	39	12

Courtesy of Yuxi Pacific. Used with permission.

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Comparing US and Asia Pacific Health Informatics Leadership

- The following countries in the Asia Pacific region were considered:
  - China and Taiwan
  - South Korea
  - Japan
  - Singapore
  - Malaysia
  - Australia
  - New Zealand

- Some conclusions:

  - Asia-Pacific is a fast growing patient-level data source, but prodigious barriers exist:

    - HIT adoption varies widely, but "digital hospitals" are on the rise

    - Most HIT systems are proprietary or home-grown (few international HIT vendors have a meaningful presence in Asia);

    - While fears over exploitation of personal health data drives policy, ironically, most residents lack a cultural appreciation for the personal ownership/control of health information.

    - In many countries, such as China, Taiwan, Singapore, South Korea, etc. the government plays a central role in collecting and distributing patient-level data, but regulations are neither clear nor uniform, which increases the risk of accessing it.

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Workshop with the Board of Directors of CHIMA (Chinese Hospital Information Management Association), the HIMSS of China
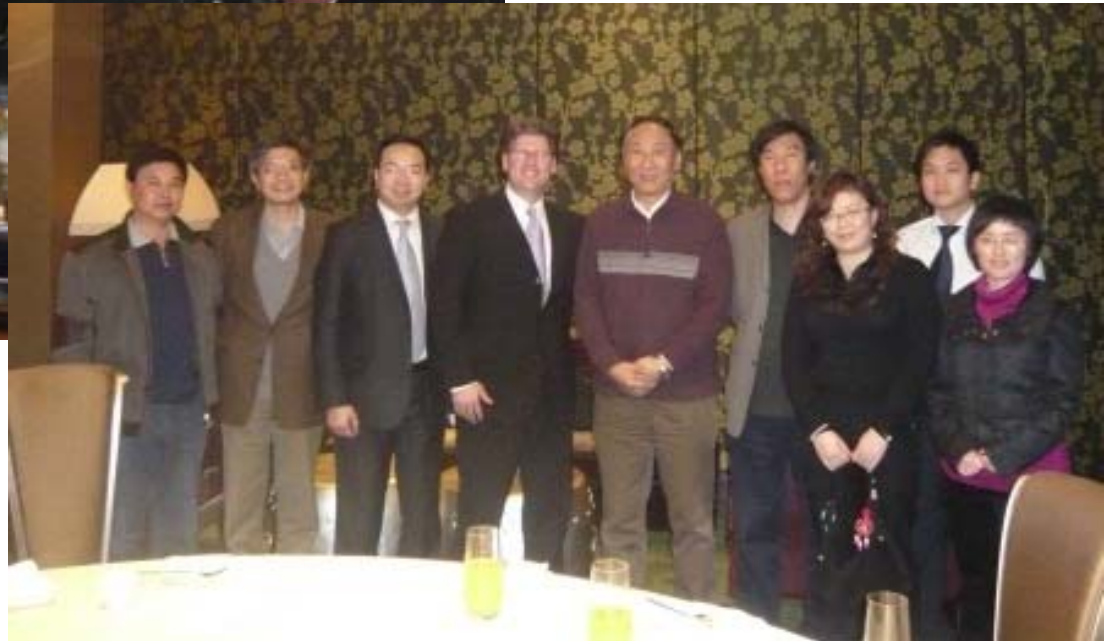
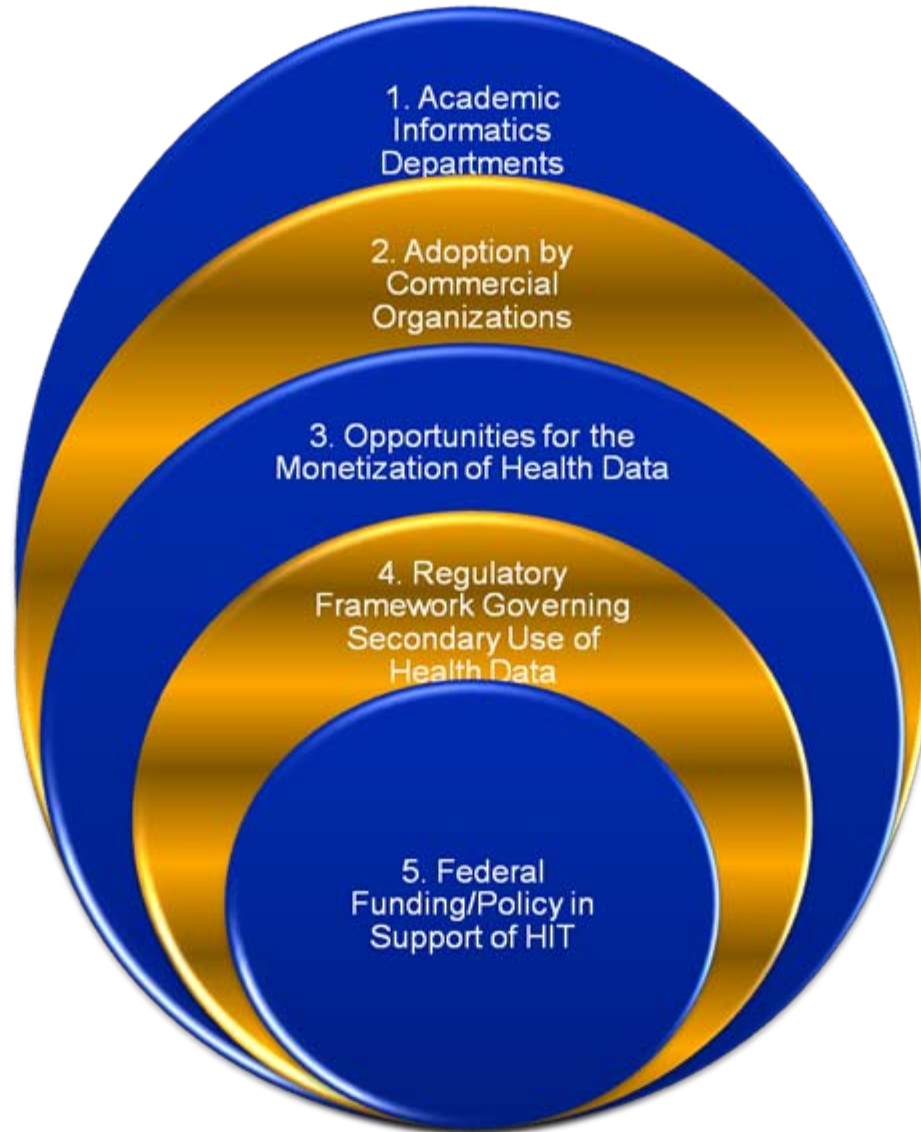# Lecture on Health Informatics to Peking Union Medical College Resident Class

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Tianjin Tissue Bank Steering Committee Meeting.

China Tianjin Breast Cancer Prevention and Cure Research Center

Tumor Tissue Banking Facility Jointly Supported by TMUCIH & NFCR

Comparing Current Attributes of US and Asia Pacific HI Current State

US

1. Draw
2. Leader
3. Leader
4. Leader
5. Draw

AP

1. Draw
2. Laggard
3. Laggard
4. Laggard
5. Draw

1. Academic Informatics Departments

2. Adoption by Commercial Organizations

3. Opportunities for the Monetization of Health Data

4. Regulatory Framework Governing Secondary Use of Health Data

5. Federal Funding/Policy in Support of HIT

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