Rise of the Data Tiger
Will Asia Assume Global Leadership in Health Informatics

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**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.

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**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 1) to enable discoveries generated in the lab (basic science) to become human trials and studies, and 2) to enhance 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

And there is no opting out
Translational Medicine/Research is Ground Zero for Health Informatics

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

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

**Patient/Public Services**
- Current research/clinical trials
- Health education

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Photo of Affymetrix GeneChip removed due to copyright restrictions.

Photo of Mobile Computing C5 system removed due to copyright restrictions.
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
- Accelerate Investigator/Patient Recruitment process
- Mine internal databases/external healthcare data
- 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
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.

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

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

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

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

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

National EHR system in place in Taiwan.

National EHR system in place in New Zealand.

National EHR system in place in New Zealand.
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:
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/
Anecdote: Beijing Ministry of Health supports the development of an EMR for TCM at The People’s Hospital Peking University
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 (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.
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.

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

Anecdote: Singapore is Registry Happy

<table>
<thead>
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<th>Data Source Examples</th>
<th>Strengths</th>
<th>Weaknesses</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Singapore Cancer Registry (SCR)</strong>&lt;br&gt;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%</td>
<td>• Complete demographic information&lt;br&gt;• Data accuracy</td>
<td>• Data access: No direct access for external organizations</td>
</tr>
<tr>
<td><strong>Singapore Childhood Cancer Registry (SCCR)</strong>&lt;br&gt;It was established in 1997. SCCR data is also submitted to SCR</td>
<td>• Data accuracy: Contains all children, aged &lt;=18, diagnosed with haematological or solid malignancies.&lt;br&gt;• SCCR also facilitates multi-institutional clinical trials in the evaluation of treatment efficacy</td>
<td>• 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</td>
</tr>
<tr>
<td><strong>Renal Registry</strong>&lt;br&gt;It gathers comprehensive data and statistics on kidney disease from dialysis centers and hospitals in Singapore.</td>
<td>• Comprehensive data on&lt;br&gt;  a. Glomerulonephritis&lt;br&gt;  b. End-Stage Renal Disease&lt;br&gt;  c. Transplantation&lt;br&gt;  d. Annual dialysis status reports</td>
<td>• Data access: No direct access for external organizations</td>
</tr>
</tbody>
</table>
Anecdote: China’s Health Infrastructure is About to Quadruple

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

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.

<table>
<thead>
<tr>
<th>Physician ID</th>
<th>Last Name</th>
<th>First Name</th>
<th>Therapeutic Area</th>
<th>Institution</th>
<th>City</th>
<th>School</th>
<th>Grad Year</th>
<th>Age</th>
<th>Years</th>
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</thead>
<tbody>
<tr>
<td>200</td>
<td>李</td>
<td>张国</td>
<td>肝胆</td>
<td>南方医院，珠江医院</td>
<td>广州市</td>
<td>广州中医药大学</td>
<td>1997</td>
<td>40</td>
<td>12</td>
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<tr>
<td>201</td>
<td>王</td>
<td>朱明</td>
<td>肝胆</td>
<td>南方医院，珠江医院</td>
<td>广州市</td>
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<td>陈晨</td>
<td>肝胆</td>
<td>南方医院，珠江医院</td>
<td>广州市</td>
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<td>25</td>
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<tr>
<td>203</td>
<td>刘</td>
<td>陈健</td>
<td>眼科医生</td>
<td>南方医院，珠江医院</td>
<td>广州市</td>
<td>中国医科大学</td>
<td>1993</td>
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<tr>
<td>204</td>
<td>陈</td>
<td>曹莉</td>
<td>眼科</td>
<td>广东省人民医院</td>
<td>广州市</td>
<td>附属大学</td>
<td>2000</td>
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<td>杨辉</td>
<td>肝胆</td>
<td>广东省人民医院</td>
<td>广州市</td>
<td>首都医科大学</td>
<td>1991</td>
<td>55</td>
<td>28</td>
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<td>刘洋</td>
<td>肝胆</td>
<td>广东省人民医院</td>
<td>广州市</td>
<td>南方医科大学</td>
<td>2002</td>
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<tr>
<td>207</td>
<td>周</td>
<td>周杰</td>
<td>眼科医生</td>
<td>广东省人民医院</td>
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<td>1997</td>
<td>50</td>
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<tr>
<td>208</td>
<td>赵</td>
<td>赵勇</td>
<td>肝胆</td>
<td>广东省第二人民医院</td>
<td>广州市</td>
<td>中国医科大学</td>
<td>1974</td>
<td>61</td>
<td>36</td>
</tr>
<tr>
<td>209</td>
<td>吴</td>
<td>吴晨</td>
<td>肝胆</td>
<td>广东省第二人民医院</td>
<td>广州市</td>
<td>清华大学</td>
<td>1992</td>
<td>44</td>
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<td>210</td>
<td>徐</td>
<td>徐辉</td>
<td>肝胆</td>
<td>广东省第二人民医院</td>
<td>广州市</td>
<td>清华大学</td>
<td>1997</td>
<td>36</td>
<td>12</td>
</tr>
</tbody>
</table>

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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.
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
Tianjin Tissue Bank Steering Committee Meeting.
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
Thank you for your time
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