In the Year 2000...

--Conan O'Brien

What have we Learned?

• Sources of Data
  • Clinical databases
  • Narrative text
  • Genomic information
  • Standards for describing data

• Modeling
  • Space of models, learning methods, noise
  • Probabilities
  • Bayesian reasoning
  • Networks
  • Information theoretic methods

... Learned? (cont’d)

• Decision Support
  • Probabilities and Utilities
  • Predictive models
  • Expert Systems
  • “Deep” expertise via pathophysiologic models

... Learned? (Guest Lectures)

• Alvin Kho
  • High throughput quantitative genomics
  • Gene expression data representation and modeling

• Leo Celi
  • Critical Care
  • Mobile Health

• Amin Zollanvari — GWAS

• Zak Kohane — Instrumenting the HC Enterprise

• Ken Mandl — Personal Health Records & Architecture

• Hamish Fraser — HC for developing world, OpenMRS

• Bill Long — Heart Disease Program

• David Margulies — Genomic Medicine

• John Brownstein — Public Health

• John Glaser — The Health IT Industry
What have we Missed?

- Imaging
- Additional novel instrumentation
  - Precision diagnostics
- Guidelines & Careplans
- Role of Communication
  - Computer-supported Cooperative Work
  - Collective Intelligence
- Improving workflow
  - to prevent “dropped balls”
  - to increase efficiency
- Evaluation methodology
  - E.g., do EMR’s really improve health care?
  - Can we conduct controlled experiments?
- Human-Computer Interaction
  - Don Norman — *The psychology of everyday things*
  - Cognitive Modeling

Evidence-Based Prognostication

---Slides from Bill Stead, Vanderbilt University

- Review NAS committee charged with finding ways in which computer science can bear on improving healthcare.
  - By charge, clearly oriented toward technology
  - We found that other components of the triad are perhaps even more important

Prognostication

- “There is nothing so hard to predict as the future.”
- --Yogi Berra
- Sources of insight:
  - Technology
  - Policy
  - Economics

Committee on Engaging the Computer Science Research Community in Healthcare Informatics

Computer Science and Telecommunications Board

National Research Council of the National Academies

Chartered by the National Library of Medicine
Project Scope

CSTB would conduct a 2-phase study to examine information technology (IT) challenges faced by the health care system in realizing the emerging vision of patient-centered, evidence-based, efficient health care using electronic health records (EHR) and other IT. The study would focus on the foundation issue of the EHR.

Phase 1

- Conduct a series of site visits to a variety of health care delivery sites.
- Provide a phase 1 report, based on the site visits
  - Match between today’s health information systems and current plans for using EHR nationwide
  - Problems that could be solved relatively easily and inexpensively by today’s technologies
  - Illustrate how today’s CS knowledge could be used to gain short term improvements
  - Important questions that future reports should address

Phase 2

- Provide a phase 2 report
  - Technical areas where additional H/BMI or CS research is needed to advance health care IT
  - Priorities for research that would yield significantly increased medical effectiveness or reduced cost
  - Information management problems whose solutions require new practices and policies
  - Public policy questions that need to be resolved to allow such research to proceed

Committee Membership

- William W. Stead, Chair, Vanderbilt University
- G. Octo Barnett, Massachusetts General Hospital
- Susan B. Davidson, University of Pennsylvania
- Eric Dishman, Intel Corporation
- Deborah L. Estrin, University of California, Los Angeles
- Alon Halevy, Google, Inc.
- Donald A. Norman, Northwestern University
- Ida Sim, University of California, San Francisco
- Alfred Spector, Independent Consultant
- Peter Szolovits, Massachusetts Institute of Technology
- Andries Van Dam, Brown University
- Gio Wiederhold, Stanford University
Site Visits

- University of Pittsburgh Medical Center
  Pittsburgh, PA
- Veterans Administration
  Washington, DC
- HCA TriStar
  Nashville, TN
- Vanderbilt University Medical Center
  Nashville, TN
- Partners Healthcare
  Boston, MA
- Intermountain Health Care
  Salt Lake City, UT
- University of California, San Francisco
  San Francisco, CA
- Palo Alto Medical Foundation
  Palo Alto, CA

(Stead’s) Personal Observations

- Patient records are fragmented
- Clinical user interfaces mimic paper without human factors & safety design
- Biomedical devices are poorly integrated
- Systems are used often to document what has been done, after the fact
- Support for evidence-based medicine and computer-based advice is rare
- Clinical research activities are not well integrated into clinical care
- Legacy systems are predominant
- Centralization is the predominant method of standardization
- Implementations timelines are long and course changes are expensive
- Response times are variable and long down times occur

(Szolovits’) Personal Observations

- Absence of “systems” view of healthcare
- Local optimization: e.g., documentation whose main purpose is to avoid losing lawsuits
- Focus on “things”, not processes: e.g., do we really need to capture all data about every patient encounter?
- Surprising heterogeneity of computer systems ==> tower of Babel
- Awful system designs, poor HCI, no principles; all legacy
- “Mainframe medicine”: conventional views of where leverage might come from
- Poor support for communications

Report:
Computational Technology for Effective Health Care: Immediate Steps and Strategic Directions
Released 1/9/2009, to good press

- Today’s healthcare is broken: high costs, low accomplishments
- Poor compliance with evidence-based guidelines: inadequate care and inappropriate care
- Estimated 40 mins/year to apply guidelines to “average” patient, yet patient sees doctor about 60 mins/year.
- Causes:
  - complex tasks and workflows
  - Institutional structure and economics
  - Deficient healthcare information technology
Complex Tasks and Workflows

- Uncertainty
- Interrupted workflows, poor information flow
- Time pressure, aging population, more knowledge

Economics and Institutions

- Large number of payers, each with different rules
- Survey of medical centers: 578-20K different plans
- Typical doc spends 50 mins/day with health plan hassles
- Perverse incentives: $$$ for procedures, little for prevention
- Greater pay for patients who develop complications!
- Siloed institutions
- Shortage of nurses, primary care docs, etc.

(IOM) Goals of Healthcare

- Safe
- Effective
- Patient-centered
- Timely
- Efficient
- Equitable

How can HCIT support these?

- Comprehensive data on a patient's conditions, treatments, and outcomes.
- Cognitive support for HC professionals to help integrate patient-specific data
- Cognitive support to apply evidence-based guidelines
- Instruments for tracking a panel of patients, highlighting developing problems
- “Learning” health care system--integrate new biology, instrumentation, treatments; use experience as basis for new knowledge
- Provide care in many locales: home, drug store, clinic, hospital, ...
- Empowerment of patients and families
But, with rare exceptions, we saw...

- IT not integrated into clinical practice
- Little support for feedback or evidence-based practice
- Process improvements are all external to practice
- Research is external to practice
- No integrated overview of patient data
- Software much harder to use than Quicken
- No cognitive support for data interpretation, planning, collaboration
- Systems oriented around transactions, not “state of patient”

Four Domains of HCIT
--Marc Probst, Intermountain Health Care

- **Automation**: IT to do repetitive tasks. E.g., medication administration, lab results, invoice generation
- **Connectivity**: From physical to logical to people
- **Decision Support**: Provide information at a high conceptual level, related to decisions about care.
- **Data Mining**: Analyze all collected data

Strategies

- Evolutionary change
  - Focus on improvements in care; technology is secondary
  - Incremental gain from incremental effort
  - Record available data for care, process improvement, research
  - Design for human and organizational factors
  - Support cognitive functions of HC professionals, patients and organizations

- Radical change:
  - Architect to accommodate disruptive change
  - Archive data for subsequent re-interpretation
  - Develop technologies to eliminate ineffective work processes
  - Develop technologies to clarify the context of data
Framework for HCIT Challenges

<table>
<thead>
<tr>
<th>General</th>
<th>Healthcare</th>
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<tbody>
<tr>
<td>Data &amp; process integration</td>
<td>Standardization</td>
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<tr>
<td>High-quality graphics, better UI</td>
<td>Codification of best practices</td>
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<td>design</td>
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<td>Human language translation</td>
<td>Open-source models for sharing</td>
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<td>capabilities</td>
<td>of information and knowledge</td>
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<td>Business process integration</td>
<td>Use &amp; develop medical</td>
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<td>Ontology management</td>
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<td>Search paradigms</td>
<td>Data prioritization</td>
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<td>Scalability</td>
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<td>Reasoning</td>
<td>Advanced models of differential</td>
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<td>Machine learning</td>
<td>diagnosis</td>
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<td>Explanation</td>
<td>Outcome-based population level</td>
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<td>Multi-modal interfaces</td>
<td>learning</td>
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<td>Meta-modeling</td>
<td>Super-“Archimedes”</td>
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<td>Adaptive models</td>
<td>Privacy management</td>
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<tr>
<td>Addition of semantics</td>
<td>Better uncertainty management</td>
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<td>Models of accuracy &amp; precision</td>
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Other Grand Challenges

- Comprehensive modeling, from molecular biology to public health; stops along the way for pathophysiology, organs, patients, populations
- Automation, from pill-counting to autonomous closed-loop control of post-surgical patients
- Data integration, sharing and collaboration
- Data management at scale, including text, annotations, metadata, ontologies, privacy, HCI, and performance
- Full capture of physician-patient interactions

Committee Recommendations

- **Comprehensive data** on patients’ conditions, treatments, and outcomes;
- Cognitive support for health care professionals and patients to help **integrate patient-specific data** where possible and account for any uncertainties that remain;
- Cognitive support for health care professionals to help **integrate evidence-based practice** guidelines and research results into daily practice;
- Instruments and tools that allow clinicians to **manage a portfolio of patients** and to highlight problems as they arise both for an individual patient and within populations;
- Rapid integration of new instrumentation, biological knowledge, treatment modalities, and so on into a “learning” health care system that encourages early adoption of promising methods but also analyzes all patient experience as experimental data;
- Accommodation of growing **heterogeneity of locales** for provision of care, including home instrumentation for monitoring and treatment, lifestyle integration, and remote assistance;
- **Empowerment of patients** and their families in effective management of health care decisions and their implementation, including personal health records, education about the individual’s conditions and options, and support of timely and focused communication with professional health care providers.
Strategic Health IT Advanced Research Projects (SHARP)

- Four $15M projects to focus on outstanding technical issues:
  - **Security of Health Information Technology** research to address the challenges of developing security and risk mitigation policies and the technologies necessary to build and preserve the public trust as health IT systems become ubiquitous. *(University of Illinois, Urbana-Champaign)*
  - **Patient-Centered Cognitive Support** research to address the need to harness the power of health IT in a patient-focused manner and align the technology with the day-to-day practice of medicine to support clinicians as they care for patients. *(University of Texas Health Sciences Center, Houston)*
  - **Health care Application and Network Platform Architectures** research to focus on the development of new and improved architectures that are necessary to achieve electronic exchange and use of health information in a secure, private, and accurate manner. *(Harvard University)*
  - **Secondary Use of Electronic Health Record Data** research to identify strategies to enhance the use of health IT in improving the overall quality of health care, population health and clinical research while protecting patient privacy. *(Mayo Clinic)*


Patient-Centered Cognitive Support

- Taking care of the whole patient, not individual facts
- Integration of individual patient information across modalities, time, doctors
  - Visualization of anatomical, functional and pathological conditions
  - Illustration of changes over time
  - “Drill down” to details
- Semi-automated application of evidence-based guidelines
- Background tracking of alternative actions consistent with guideline and patient state
- Monitoring and alerting on deviations from guideline
- Disease management “dashboard”
- Standard order sets
- Continuous instrumentation tracks real-time patient state: heart, temperature, movement, respiration, urine, eating, transdermal serum components (e.g., glucose)
- Ubiquitous cell phones
- Empower the patient

Based on Computational Technology for Effective Health Care, 2009

The iPhone(-like) Alternative

Mandi & Kohane prescription: “a flexible information infrastructure that facilitates innovation in wellness, health care, and public health.”

- Liquidity of data
- Substitutability of applications
- Open standards, supporting both free and commercial software
- Natural selection in a health information economy, based on value and cost
  - permits disruptive innovation
  - avoids “design by committee”

Mandl KD, Kohane IS. No small change for the health information economy. NEJM 2009:360:1278-81
Images from http://www.technologyreview.com/biomedicine/22360/

Categories of Substitutable Applications

<table>
<thead>
<tr>
<th>Category</th>
<th>Examples</th>
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<tbody>
<tr>
<td>Medication management</td>
<td>Prescribing, clinician order entry, medication reconciliation, drug-safety alerts</td>
</tr>
<tr>
<td>Documentation</td>
<td>Structured text entry, dictation</td>
</tr>
<tr>
<td>Panel management</td>
<td>Disease management, appointment and testing reminders, care instructions, results notification, behavior modification</td>
</tr>
<tr>
<td>Quality improvement</td>
<td>HEDIS measurement, management of patient transfer and transition</td>
</tr>
<tr>
<td>Administrative tools</td>
<td>Billing, referral management, risk stratification</td>
</tr>
<tr>
<td>Communication</td>
<td>Doctor-patient communication, multispecialty or team communication, patient support, social networking</td>
</tr>
<tr>
<td>Public health reporting</td>
<td>Notifiable disease reporting, biosurveillance, pharmacosurveillance</td>
</tr>
<tr>
<td>Research</td>
<td>Clinical trial eligibility, cohort study tools, electronic data capture for trials</td>
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<tr>
<td>Decision support</td>
<td>Lab test interpretation, genomics, guideline management</td>
</tr>
<tr>
<td>Data acquisition</td>
<td>Lab data feed, dispensed meds feed, PCHR data feed, public health data feed</td>
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</table>
Secondary Use of Clinical Data

- Goals:
  - Phenotype = f(Genotype, Environment)
  - Public Health reporting, modeling
  - High Throughput Genotyping demands high-throughput sources of Phenotype and Environment
  - Clinical record is our best proxy for these
- Approaches
  - Share data
  - Ontologies to make meaning shareable
  - Natural language processing to turn narrative text into data

Bulk of Valuable Data are in Narrative Text

Mr. Blind is a 79-year-old white male with a history of diabetes mellitus, inferior myocardial infarction, who underwent open repair of his increased diverticulum November 13th at Sephsandpot Center.

The patient developed hematemesis November 15th and was intubated for respiratory distress. He was transferred to the Valtawnprinceel Community Memorial Hospital for endoscopy and esophagoscopy on the 18th of November which showed a 2 cm linear tear of the esophagus at 30 to 32 cm. The patient's hematocrit was stable and he was given no further intervention.

The patient attempted a gastrografin swallow on the 21st, but was unable to cooperate with probable aspiration. The patient also had been receiving generous intravenous hydration during the period for which he was NPO for his esophageal tear and intravenous Lasix for a question of pulmonary congestion.

On the morning of the 22nd the patient developed tachypnea with a chest X-ray showing a question of congestive heart failure. A medical consult was obtained at the Valtawnprinceel Community Memorial Hospital. The patient was given intravenous Lasix.

A arterial blood gases on 100 percent face mask showed an oxygen of 205, CO2 57 and PH 7.3. An electrocardiogram showed ST depressions in V2 through V4 which improved with sublingual and intravenous nitroglycerin. The patient was transferred to the Coronary Care Unit for management of his congestive heart failure, ischemia and probable aspiration pneumonia.

Secondary Use SHARP Project

- Clinical Data Normalization Services and Pipelines
- Natural Language Processing
- High-Throughput Phenotyping
- Scaling to enable near-real-time throughput
- Data Quality
- Real-world evaluation framework

Theme

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<tr>
<th>Static/Passive</th>
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<th>Dynamic/Active</th>
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<td>Data</td>
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<td>Interpretation</td>
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<td>Documentation</td>
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<td>Decision Support</td>
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<td>Retrospective</td>
<td>=&gt;</td>
<td>Real-time</td>
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- Each such move requires advances in Artificial Intelligence, Data Mining, Natural Language Processing, Human-Computer Interaction, Computer Performance Engineering, ...
“Oh, the future’s so bright, we’ll have to wear sunglasses!”

-- Barbara Kooymen, Timbuk 3
-- with thanks to Phil Greenspun