The Health Information Future: Evolution and/or Intelligent Design?

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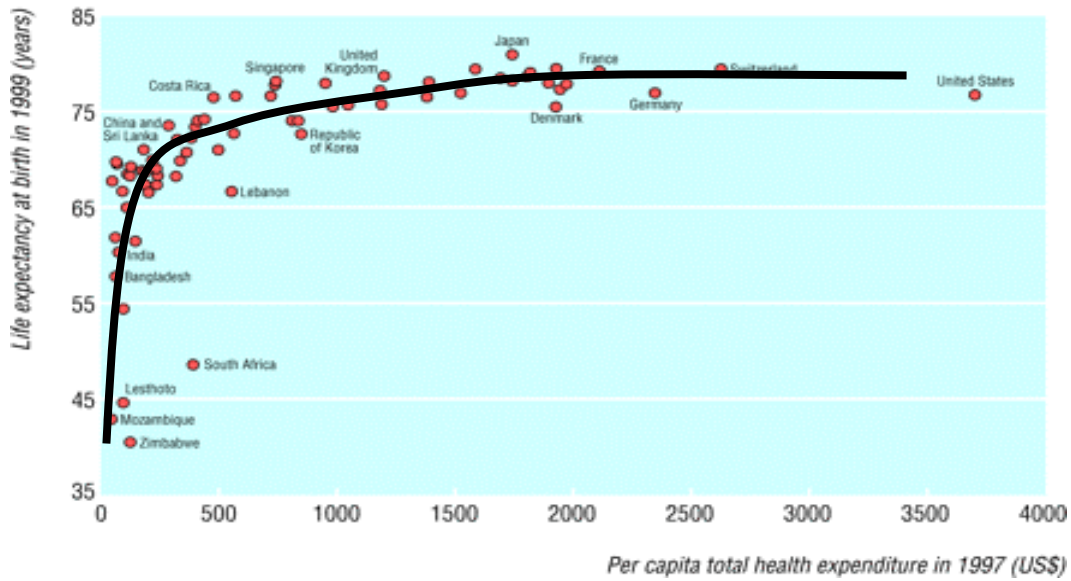
Main Premises

- The future of health and health care will depend largely on:
  - Our conceptual approach to health
  - The broad approach to health policy and resource allocation
  - Our ability to generate and use health information
- The more complex the system, the greater it taxes human ingenuity
- Health-related data has the potential to revolutionize health care – or not

Viewing Health Differently: The Population Health Revolution

- Highlights non-medical determinants of health
- Focus shifts from *numerator* (individual/case) to *denominator* (population)
- Preoccupied with SES-related health disparities that are mainly impervious to health care
- Individual destinies greatly influenced by formative years (0-3)
- Raises issue of diminishing returns from health care

Life expectancy at birth in1999 by per capita total health expenditure in 1997 in 70 countries



Source: Leon, Gill & Gilson, BMJ 2001;322:591-4

The Biomedical Revolution

- Increasing understanding of relationship between genes, health, and environment
- Individual genetic signatures may predict health outcomes with and without therapies
- Plausible to envision drug and other therapies tailored to individual biological signatures
- Complicates and layers understanding of epidemiology

Implications for Science

- Need to move beyond correlations and inferences (we know something happened but don't know why)
- Greater need to fully explain causal pathways (why something happened)
- Challenges some venerated methodologies, e.g., RCTs (because randomized groups may not in fact be identical in key aspects)
- Suggests a need for more comprehensive, integrated studies by interdisciplinary teams

Implications for Health Information

- Need more and more particular information to understand a person's condition(s)
  - Genetic features and predispositions
  - Occupational and environmental exposures
  - Sentinel life events (SES, family, geographic)
- Architecture of health information will change at the clinical and analytical levels
- Linkability of "determinants" and health care use databases becomes critical
- Reporting will evolve to reflect changing understanding of cause and effect

The Electronic Health Record

- Widely endorsed in theory, many skeptics in practice
- Expectations and uses vary greatly:
  - Simple replacement for paper
  - Billing and productivity management
  - Interactive “smart” systems that link diagnostic data to evidence-based practice
  - Analysis of patient populations and impact of interventions
- Design and training will determine its value

Where Will IT Take Us?

- Huge potential for creating unique and powerful databases
- Ability to harvest and group world-wide data to discover most effective protocols for various conditions and groups
- Capacity to generate real-time, constantly updated reports at various levels of aggregation
- Insight into the outcomes of natural experiments arising from variations in practice
- Huge potential to reduce costs of intelligence-gathering

The APPROACH Database

- Alberta Provincial Project for Outcome Assessment in Coronary Heart Disease
- Collects data on conditions, treatments, outcomes
- Patients sent questionnaires at regular intervals to assess clinical, economic, and health status outcomes
- 10 years and 100,000 cases now entered
- Generates reports for clinical and administrative purposes
- Generates population-based studies and evaluations

Conceptual Challenges (I)

- Deciding what information is relevant to health, illness, and outcomes
- Defining and recording information on prominent but vague conditions such as frailty
- Single-disease, fixed registries vs. virtual, flexible, on-demand groupings
- Role of narratives and notes vs. closed-ended variables (and software to mine them)
- Standardization of growing array of variables and inputs

Conceptual Challenges (II)

- Privacy issues – especially where data may be used for commercial purposes
- Relative importance of:
  - Clinical data
  - Socio-economic data
  - Community and environmental data
- Inclusion of decision-aid software (e.g., drug interactions, clinical guidelines)
- Ideological disagreements about inequality, disparities, and social policy

Implementation Challenges

- Scale of investment required
  - Most projects are underfunded
  - Often inadequate investment in training
  - Compromise is to start narrowly (and not terribly usefully)
- Interoperability of systems
- Creating a culture of receptivity to IT and its potential—especially among aging workforce
- Lack of capacity or inclination to use data to maximum extent possible

Evolution, Yes; Intelligent Design, Maybe

- Health care IT will continue to expand
- The pace of evolution needs to accelerate to
  - Generate new knowledge
  - Improve patient safety
  - Improve quality of care
  - Improve efficiency
- There is no perfect, ideal IT system
- It has to be adaptable, linkable, flexible
- Design should be compatible with emerging concepts of health and its determinants

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