A Rapid-Learning System for Cancer Care

Two Perspectives: System-Centered & Patient-Centered

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A Rapid-Learning System for Cancer Care

• Generates the evidence needed to deliver the best care for each cancer patient – as rapidly as possible

  – Produces definitive evidence on the comparative effectiveness of current and future cancer care options

  – Engages system-wide learning, using the experience of all cancer patients as well as clinical trials

  – Delivers the information needed by patients and physicians for personalized care
Rapid Learning Healthcare

Data routinely collected in patient care feed into an ever-growing databank, or set of coordinated databases.

The system learns by routinely and iteratively:
(1) analyzing captured data,
(2) generating evidence,
(3) implementing new insights into subsequent care, and
(4) evaluating outcomes.
Toward A Rapid-Learning Cancer Care System

• The US has extraordinary potential for building a rapid-learning cancer care system

  – HHS: the leading funder for cancer research, cancer patient care, comparative effectiveness research, HIT/EHRs, CaBIG, cancer registries, computerized biomedical databases (GenBank), quality measures, regulation of cancer Rx & devices, on-line consumer health information (Medlineplus.gov); VHA (leading delivery system) +

  – A large, technologically-advanced cancer care enterprise, w/ foundation for collaborative learning, e.g. National Cancer Centers, National Comprehensive Cancer Network, Cancer Research Network, Cancer Clinical Trials Cooperative Groups +

  – Professional society leadership, networked patient groups, first-rate researchers, large bio-tech industry
Toward A Rapid-Learning Cancer Care System

- Recent & pending initiatives for research, HIT, databases, and delivery system infrastructure
  - $1.1 B for CER (AHRQ, NIH, OS), Federal Coordinating Council for CER & HHS plans ($400M databases), IOM “Top 100” CER priorities report
  - FDA Sentinel Network, up to 100 M records
  - $17 B EHR funding, EHRs for everyone by 2014, ONC
  - $10 B NIH increase + commitment to double cancer research; $ 1 B for cancer genetic studies
  - Coverage & $800 B financing for 30M+ uninsured (reform bills)
  - $10 B for Medicare, Medicaid innovations center (reform bills)
In Silico Research, EHRs & HIT For Rapid-Learning

• *In silico* research = research on computerized databases

• Complements and adds capabilities to *in vitro* and *in vivo* methods

• Uses the extraordinary new potential of:
  – *High speed computing* (petaflop = 1 quadrillion operations per second) +

  – Very large computerized databases and distributed database networks (up to millions of patients), e.g. electronic health records (EHRs) with genetic information for a *data-rich future* +

  – International, WWW-linked research networks
Why Demonstrate in Cancer?

• Compelling

• National urgency for better CER data in cancer
  – Fundamentally requires linkage of complex basic science and clinical science data
  – Inherent concept of clinical trials, continuous research, discovery and evidence implementation

• Patient-centeredness
  – Motivated patients/families, urgency of the disease and its inherent threat to life
  – Palliative care and relief of suffering must be monitored through patient/family reported data
  – Substantial need for patient education

• Opportunity to transfer lessons learned to other diseases
System-centered vs patient-centered?

• Perspective is fundamental, determines structure and approach.
  – CER and Quality seek change at the health system, national, and societal levels.
  – Personalized medicine and patient-centered care seek change at the patient level.

• Explore development of a rapid learning healthcare model built at the patient level, and scaling to societal level.
  – Practice in microcosm environments.
  – Establish methods, feasibility, acceptability, functionality.
Data collected at the individual patient level informs care for that person, contributes to evidence development and implementation projects at the clinic level, and can be used for large-scale evidence synthesis, CER, discovery, and evidence implementation on health system and higher levels.

Critical elements are:
- linked information
- motivated individuals and systems engaged to provide reliable integrated information
The opportunity

Rapid learning clinics: a prototype for evidence development, implementation, and CER:

• Build RLHC model using most fundamental components (patients and clinics).
• Engage patients at the core of the activity.
• Create on-the-ground real-time infrastructure for CER and discovery.
• Establish a mechanism for QA/QI, first at the clinic level and then more systemically.
Rapid Learning Cancer Clinic

Patient-centered rapid learning cancer care

Conduct CER; analyze data

Implement new evidence

Assess impact of implementation of new evidence; refine interventions; recurrent CER
New datasets can be sequentially added, starting at the patient level, with warehousing or federated models. Key element = patient-level linkage.

- ePRO data
- Clinical and administrative data
- Clinical trials and research related data
- Molecular and biological data
Converging themes

- Comparative effectiveness research (CER)
- Healthcare quality
- Personalized medicine
- Patient-centered care

‡ Application of rapid learning healthcare at the patient level
Rapid-Learning: converging themes

Common elements:
- Evidence
  Development
  Implementation
  Review
- Information
  Linkage
  Analysis
  Learning
- Value
  Efficiency
  Positive cost-benefit
  Patient perspective

- CER, EHR, *in silico* research
- Healthcare quality
- Personalized medicine
- Patient-centered care
- Rapid learning healthcare
Elements of a Rapid-Learning Cancer Care System & Workshop Agenda

• A national cancer learning agenda, CER research funding, rapid-learning networks

• Cancer registries, databases, and distributed database networks

• Research use of all cancer-related databases (confidentiality protected) for open science

• EHRs that support rapid-learning for cancer care & new decision tools

• Patients, physicians & institutions networked & activated in rapid-learning

• Leadership, collaboration & action !!