

Connecting Science and Research to Clinical Care through Informatics

Amy P. Abernethy, MD

Director, Duke Center for Learning Healthcare
Director, Duke Cancer Care Research Program

May 2012



DukeMedicine



Objective: Better approximation between research and the clinic in order to facilitate clinical and translational sciences



(Rapid) Learning Healthcare



The system learns by routinely analyzing captured information, iteratively generating evidence, and constantly implementing new insights into subsequent care.

Bridge between clinical care and research

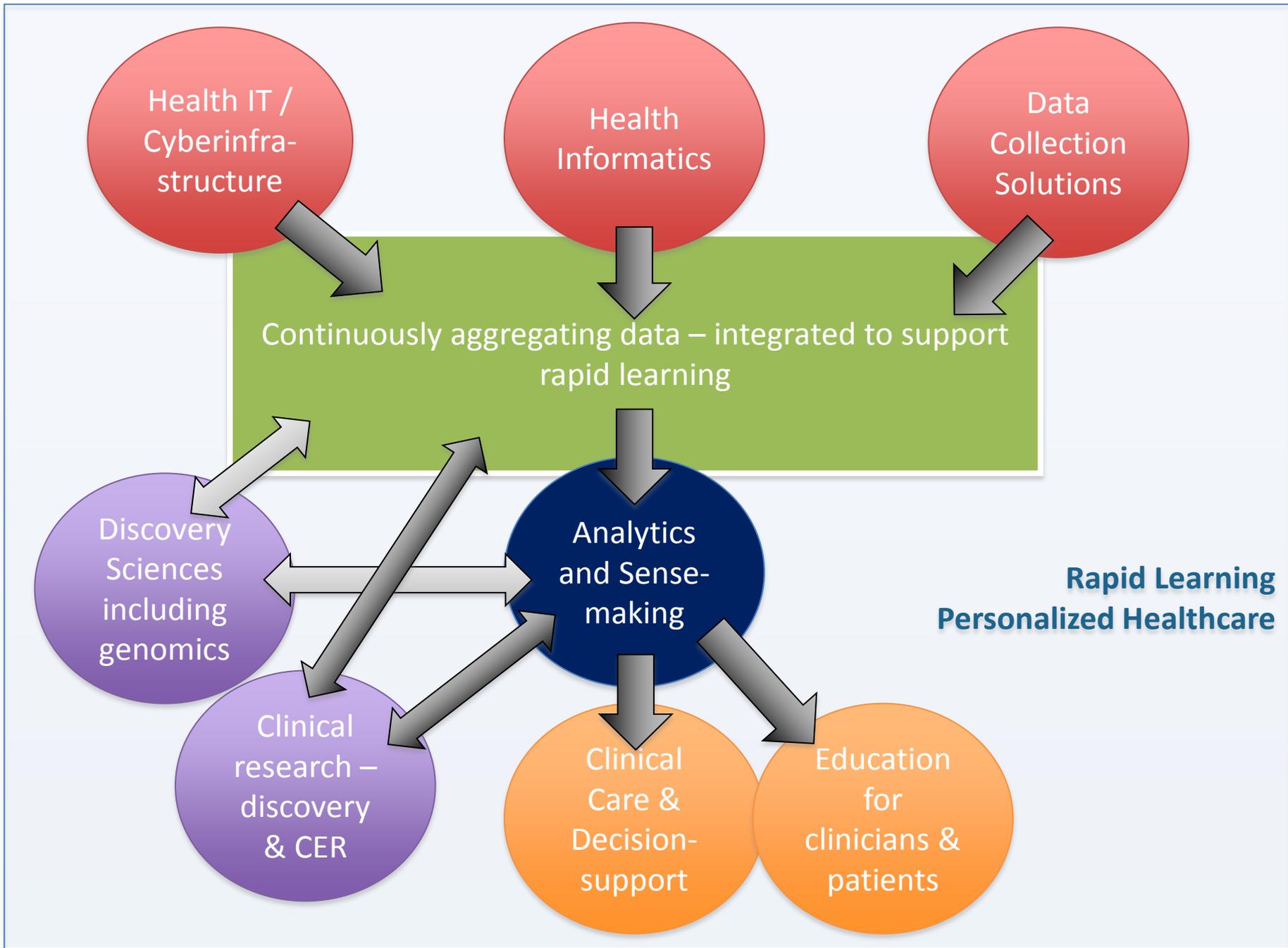
Explicitly incorporate discovery sciences

Data generation, use and reuse

Analyses have to do with perspective and learning loops

Definitions of Learning Healthcare

- ❖ Systematically linked process for evidence generation and implementation (Research / clinical trials)
- ❖ National system of linked data to generate novel insights and monitoring
- ❖ Continuously aggregating datasets to support point of care clinical decision making, personalized medicine, and research
- ❖ Closer approximation of research and practice so that each informs the other
- ❖ Organization that learns (quality & PI view)
- ❖ Learning laboratories of healthcare to optimize and prioritize innovations and solutions



Critical Tasks

- ❖ Informatics, data and cyberinfrastructure
- ❖ Data linkage across numerous dimensions (subjects, time, processes, systems)
- ❖ Plan, test and learn, with analytics built into the system
- ❖ Real-time data with data use and reuse
- ❖ Progressive personalization
- ❖ Levels of aggregation / aggregation by perspective
- ❖ Handshake between research and clinical care

Meta-Story

- ❖ Data and informatics infrastructure
- ❖ Process
- ❖ Culture
- ❖ Learning
 - **New integrating workforce**
 - Next generation of biomedical/clinical informaticians
 - Train clinicians and researchers to be informatics savvy

Informatics infrastructure must be integrated into the larger story

- ❖ Learning healthcare requires a focus on process, informatics exchange, and governance/trust
- ❖ Must consider the full cancer research ecosystem – how does the informatics infrastructure interdigitate with clinical trials, clinical care, registries, biologic sciences
- ❖ Health information exchange and continuously aggregating registries to provide clinical annotation for biology (and to improve healthcare)
- ❖ Must innovate in terms of regulatory and human subjects – and the security processes needed to support this work
- ❖ Must consider issues of data replicability, provenance, and sense-making

Person-centricity is critical

- ❖ Expectation of the public
- ❖ Incorporate the patient perspective and PROs
- ❖ This will also support a system of trust

- ❖ Longitudinality of data (and thinking)

- ❖ THE CANCER INFORMATION DONOR

Need a new workforce

- ❖ More than just “team science” thinking
- ❖ Clinicians, researchers, informaticians, IT folks, analysts learning how to value input of each other
- ❖ Need linking language, visualization, reporting
 - Critical for data quality and appropriate use / interpretation
- ❖ Need training and apprenticeship opportunities

- ❖ Informaticians
- ❖ Basic training for all

The Importance of Governance

- ❖ “Having rules that help”
 - Operating principles that serve everybody well
- ❖ Establish a culture of trust
 - Researchers, clinicians, patients, community, ...
- ❖ Reinforce interoperability
- ❖ Treat data as an asset, resource, and public good
- ❖ Ensure provenance and replicability
- ❖ National and local systems of governance
 - Process that starts with the CEO / Director

Integrate across clinical research domains

“Don’t screw up these data”

- ❖ Clinical trials
- ❖ Comparative effectiveness research
- ❖ Registries / observational studies
- ❖ Qualitative research
- ❖ Systematic review and secondary evidence aggregation
- ❖ Dissemination & implementation
- ❖ Quality monitoring and reinforcement

- ❖ EMR data sources

Stimulate an ecosystem of sponsors, participants and advocates

- ❖ Align incentives
- ❖ THE CANCER INFORMATION DONOR
- ❖ Public private partnerships
- ❖ Across government (NIH, White House, AHRQ, ONC, etc)
- ❖ Patient advocates & the public
- ❖ Professional bodies
- ❖ Payors

Contact

Amy P. Abernethy, MD

Director, Duke Center for Learning Healthcare
Director, Duke Cancer Care Research Program

amy.abernethy@duke.edu

