Big Data and the Evolution of Precision Medicine

Dr. George Poste
Chief Scientist, Complex Adaptive Systems Initiative and Del E. Webb Chair in Health Innovation
Arizona State University
george.poste@asu.edu
www.casi.asu.edu

Michigan Institute for Data Science (MIDAS)
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Medical Progress:
From Superstitions to Symptoms to Signatures
<table>
<thead>
<tr>
<th>(Epi)Genome</th>
<th>Cell- and Organ-Specific Molecular Information Networks</th>
<th>The Phenotype and Individual Variation</th>
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<tbody>
<tr>
<td>Health</td>
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<td>Disease</td>
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<td>Instructional Code</td>
<td>Disease-Induced Network Changes</td>
<td>panOmic Individual Profiling and Optimum Care Decisions</td>
</tr>
</tbody>
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Precision Medicine: Understanding the Organization of Complex Molecular Networks in the Health-Disease Continuum
Precision Medicine: Managing Individual Health Risk

Managing Active Disease
- right diagnosis
- right treatment(s)
- right time
- right follow-up and compliance

Sustaining Health (Wellness)
- disease predisposition
- risk exposure
- risk mitigation

reactive
proactive
The Need for Deep Phenotyping

Genome Sequencing Alone Will Not Suffice

Understanding the Complex Interplay Between PanOmics, Environment and Lifestyle
Establishment of Causal Relationships Between Alterations in Molecular Networks and Disease Risk, Disease Progression and Intervention Outcomes

- Large Scale Population Profiling
- Integrated Molecular, Clinical, Environmental and Lifestyle Data
- Pattern Analysis of the Health-Disease Continuum
- Multi-parameter Individual Risk Profile

- Big Data and Data Science
- The Molecular Taxonomy of Health and Disease
- Optimized Individual Care and Health Risk Reduction
The Evolution of a Data-Driven Health Ecosystem: Systematic Integration of Diverse Data Sets for Population Health Analytics

Continuity of Care Record: From Womb to Tomb

Behavior

Environment
AORTA (Always On Real Time Access): Continuous Monitoring of Health Status

- majority of events affecting an individual’s health occur outside of healthcare facilities

- new technologies and real-time, remote monitoring of health status and treatment compliance
  - wearables, sensors, social media

- new patterns of consumer/patient interaction with the healthcare system and healthcare professionals (“expanded touch points”)

- progressive evolution of a seamless blend of online and physical services for clinical care and individual health risk management
Real Time Remote Health Monitoring and Chronic Disease Management

Lifestyle and Fitness

Information for Proactive Health Awareness (Wellness)

m.Health
Telemedicine: Diagnostics, Robotics, and Remote Monitoring of Health
Implantable Devices and Wireless Monitoring (and Modulation)

next-generation miniaturized power sources

security and hacker protections
Gray Technologies and Aging in Place: Independent But Monitored Living for Aging Populations

- Rx compliance
- Cognitive stimulation
- In home support and reduced readmissions
- Reduced office visits
Mobile Apps, Wearables, Sensors and Continuous Monitoring

- who sets the standards?
- who integrates and interprets the data?
- who pays?
- who consents?
- who owns the data?
who knows why people do what they do?
  – the fact is that they do!
these actions can now be traced and measured with unprecedented precision
with sufficient data, the numbers reveal increasingly predictable behavior and individual risk patterns
rapid growth in new business opportunities in multiple sectors including healthcare
new ethical and legal issues
  – consent and data ownership
  – privacy, surveillance, security
• every individual is a data node
• every encounter (clinical and non-clinical) is a data point
• every individual becomes a research asset
“Do you solemnly swear to have no involvement in your own care?”
The Rise of Consumerism in Healthcare

Provider Performance, Pricing Transparency Plus Choice

UX: User Experience

- “liquid expectations”
  - positive consumer experience in one domain generates expectations of similar convenience/value in other domains
The Principal Forces Shaping Biomedical R&D and Healthcare Delivery

- Wearables
- Sensors
- Smart implants

- Remote health monitoring
- Telemedicine
- Robotics

- PanOmics profiling
- Analysis of disruption in biological networks in disease

- m.health/e.health
- Data- and evidence-based decisions and Rx selection

BIG DATA

- Outcomes-based healthcare and sustainable health
- New value propositions, new business models and services
The Worst Supply Chain in Our Society is the Health Information Supply Chain

- no area of the economy (15-20% GDP) generates as much information as the health sector yet uses it so poorly
- fragmented, disconnected data (data tombs)
- incompatible data formats as barriers to data integration
- incomplete and inaccurate data
The Worst Supply Chain in Our Society in the Health Information Supply Chain

- slow transition from paper to electronic systems
- inadequate information on behavioral and environmental influences
- poor data protection at rest and in transit
- legislative barriers to data transfer based on well intentioned privacy protections
- EMR vendor barriers to facile data exchange
The Painful Evolution of Electronic Medical Records (EMRs)

Scheduling and Billing

Compliance

Real Time Data and Decisions
The Pending Zettabyte Era
1,000,000,000,000,000,000,000,000

Managing Big Data in Biomedicine is Not a Simple Extrapolation from Current Practices

Current Institutional Structures and Competencies Are Ill-Prepared for Pending Disruptive Change
human genome sequencing data doubling every 7 months

projected 1 exabase/year within 5 years

projected 100 million to 2 billion human genomes sequenced by 2025

data storage needs of 2 to 40 exabytes (@30x coverage)

1-2 exabytes for video storage

1-17 petabytes/year

Square Kilometre Array 1 exabyte/year
The Unavoidable Data-Intensive Evolution of Healthcare: Major Challenges Ahead

**PB and TB Data Streams**
- Volume
- Data Size

**Ontologies and Formats for Data Integration**

**Longitudinal Data Migration and Inter-operable Dbases**

**New Data Analytics, Machine Learning, NLP Methods**

**Infrastructure, Storage and Privacy**

**Data Science and Data Scientists**
“Digital Darwinism”: Stark Selection Pressures Will Create Haves and Have Nots

- growing imbalance between different end user populations and their ability to embrace large data scale and complex analytics
- institutions unable to access and analyze large data sets will suffer ‘cognitive starvation’ and relegation to competitive irrelevance
- understanding the structure of information and its productive application/customization will emerge as a critical institutional competency
  - “intelligence at ingestion”
The Big ‘N’ Challenge in Making Precision Medicine a Reality: Building the ‘Data Commons’

- Development of a robust molecular taxonomy for the health-disease continuum will require comprehensive data capture and pattern analysis of multiple features
  - panOmics, clinical, risk exposure, lifestyle
  - longitudinal continuity

- Required scale will transcend the population cohort(s) available in all but the largest healthcare providers/payors

- New models for open data sharing and meta-analysis
The Big ‘N’ Challenge in Making Precision Medicine a Reality: Building the ‘Data Commons’

- urgent need for new policies and incentives for data sharing and open infrastructure (international?)
- how to integrate proprietary databases into an open infrastructure
- privacy and security: is individual de-identification illusory?
Bigger Data and Better Questions

Data Science: Thinking More Deeply About Data and Knowledge Generation

Big Data and Data Science Will Generate Destabilizing and Disruptive Knowledge
The Pending Era of Machine Intelligence and Cognitive Systems: Overcoming the “Bandwidth” Limits of Humans

- limits to individual expertise
- limits to our multi-dimensionality
- limits to our sensory systems
- limits to our experiences and perceptions
- limits to our objective decision-making

“helping the slow brain catch up with the fast machine”
Technology Acceleration and Convergence: The Escalating Challenge for Professional Competency, Decision-Support and Future Medical Education Curricula

Data Deluge

Cognitive Bandwidth Limits

Automated Analytics and Decision Support

Facile Formats for Actionable Decisions
Living in a World Where the Data Analytics and Interpretation Algorithms Are Obscure to the End User

- ceding decision authority to computerized support systems
- resistance and push back in a MD-centric culture
- culturally alien to professionals in their expertise domains while they accept machine-based decision-support in many other aspects of their lives
- who will have the responsibility for validation and oversight of critical assumptions used in decision tree analytics for big data?
  - regulatory agencies and professional societies (humans)?
  - machines?
Multi-disciplinary: team-based, systems-focus, big data sets

Reductionist: Individual investigator-centric, single discipline datasets

Defining an optimum balance
changing the nature of discovery
  – hypothesis-driven versus unbiased analytics of large datasets (patterns, rules)
changing the cultural process of knowledge acquisition
  – large scale collaboration networks, open systems versus individual investigators and siloed data
changing knowledge content
  – increased quantification and complexity
  – integration of diverse data streams
changing the cognitive and intellectual competencies for knowledge-intensive competitiveness in multiple domains
changing education, training and research
The Evolving Data-Intensive Healthcare Ecosystem

**Technology Convergence**
- Computing and automation
- Sensors, robotics
- Life sciences and medicine

**Big Data**
- Population data
- Precision medicine
- Data science

**Connectivity, Continuity, and Consumerism**
- Social media
- Patient engagement
- Life style metrics

**Analytics for actionable Information and improved outcomes (value)**

**Integration (systems)**

**The expanded care space (individuals)**
Leveraging the Potential of Precision Medicine Will Require **PROFOUND CHANGES** in the Organization and Proficiency of Healthcare Services

- **technology**
  - seamless integration of complex, diverse and dynamic data for real-time monitoring of health status and risk management

- **competencies**
  - shift from reactive episodic care encounters to increasingly proactive risk mitigation

- **efficiency**
  - progressive shift from management of overt disease to sustained wellness and continuity in care

- **incentives**
  - new financial reward systems

integration of molecular, clinical and lifestyle data

Infrastructure, data science, new clinical skills

continuity in care

new financial reward systems
Data Science at the University of Michigan

Michigan Institute for Data Science (MIDAS)

Data Science Services & Infrastructures

Health System Data and Analytics Integration

Department of Computational Medicine and Bioinformatics

UMHS-IT

UMMS Disruptive Care at Home Program

Institute for Health Policy and Innovation

Michigan Metabolomics and Obesity Center

School of Public Health FUSION Project

Michigan Health Communication Center

MIDAS: Transportation Science, Social Media, Personalized Health, Personalized Education

SNRE Geospatial Health Informatics Center

UMMS Dept. Learning Health Systems

Michigan Center for Critical Care
Slides available @ http://casi.asu.edu/