

Big Data and the Evolution of Precision Medicine

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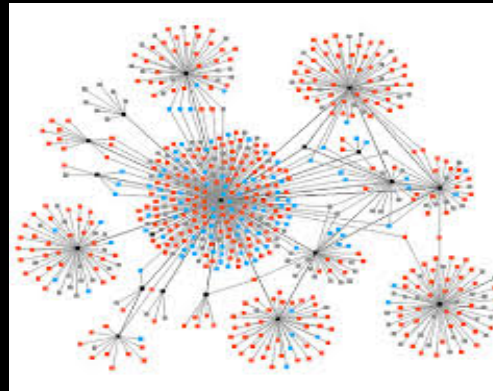
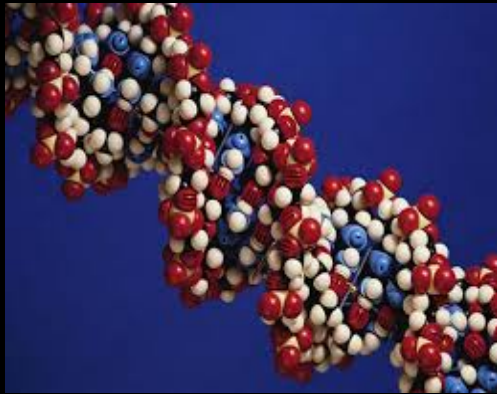
Precision Medicine: Understanding the Organization of Complex Molecular Networks in the Health-Disease Continuum

(Epi)Genome

**Cell- and Organ-
Specific Molecular
Information Networks**

**The Phenotype and
Individual Variation**

Health



Disease

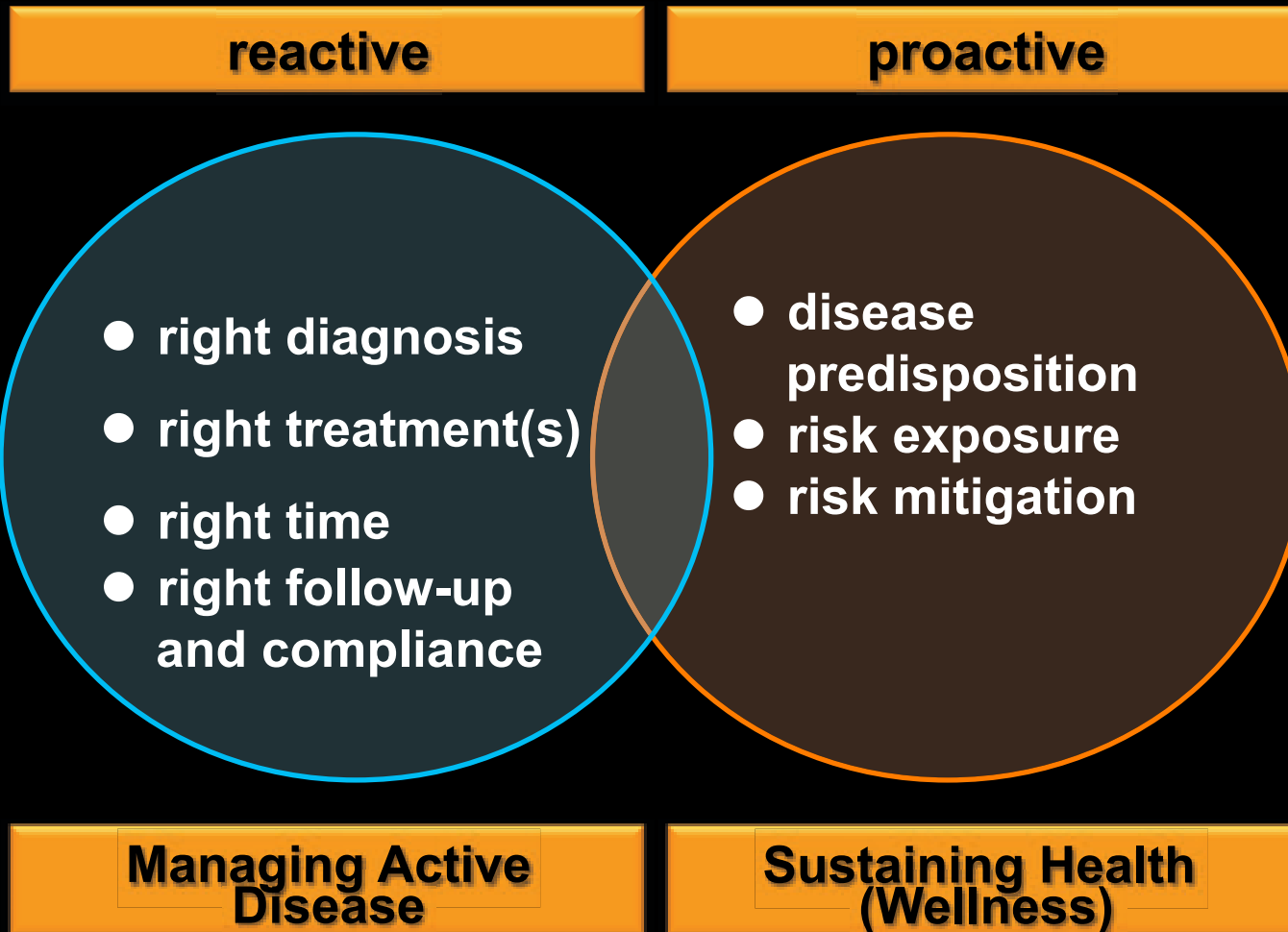


Instructional Code

**Disease-Induced
Network Changes**

**panOmic Individual
Profiling and Optimum
Care Decisions**

Precision Medicine: Managing Individual Health Risk



Precision Medicine: The Complexity of Genotype-Phenotype Relationships

The Need for Deep Phenotyping

Genome Sequencing Alone Will Not Suffice

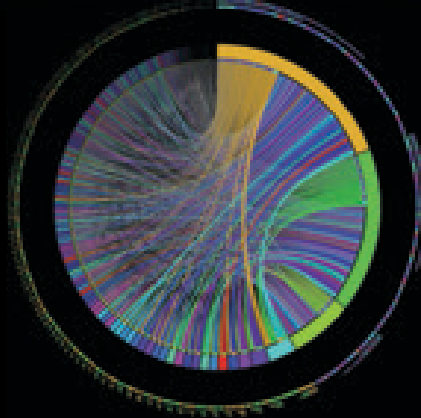
**Understanding the Complex Interplay Between
PanOmics, Environment and Lifestyle**

Establishment of Causal Relationships Between Alterations in Molecular Networks and Disease Risk, Disease Progression and Intervention Outcomes

**Large Scale
Population
Profiling**



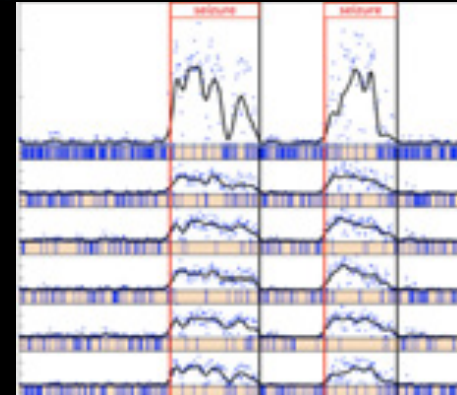
**Integrated
Molecular, Clinical,
Environmental and
Lifestyle Data**



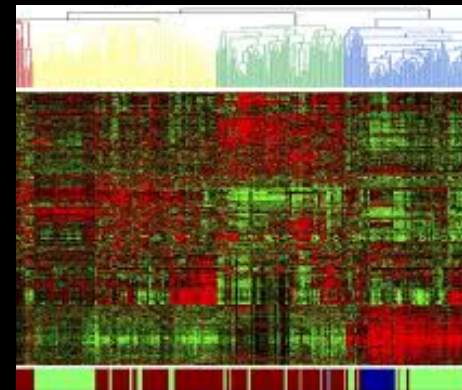
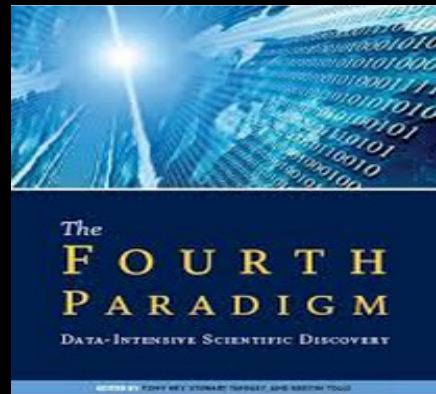
**Pattern Analysis
of the
Health-Disease
Continuum**



**Multi-parameter
Individual
Risk Profile**



M
**University of Michigan
Health System**



**Population Health
Management**

**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**

m.Health



**Real Time
Remote
Health
Monitoring
and
Chronic
Disease
Management**



**Lifestyle
and
Fitness**



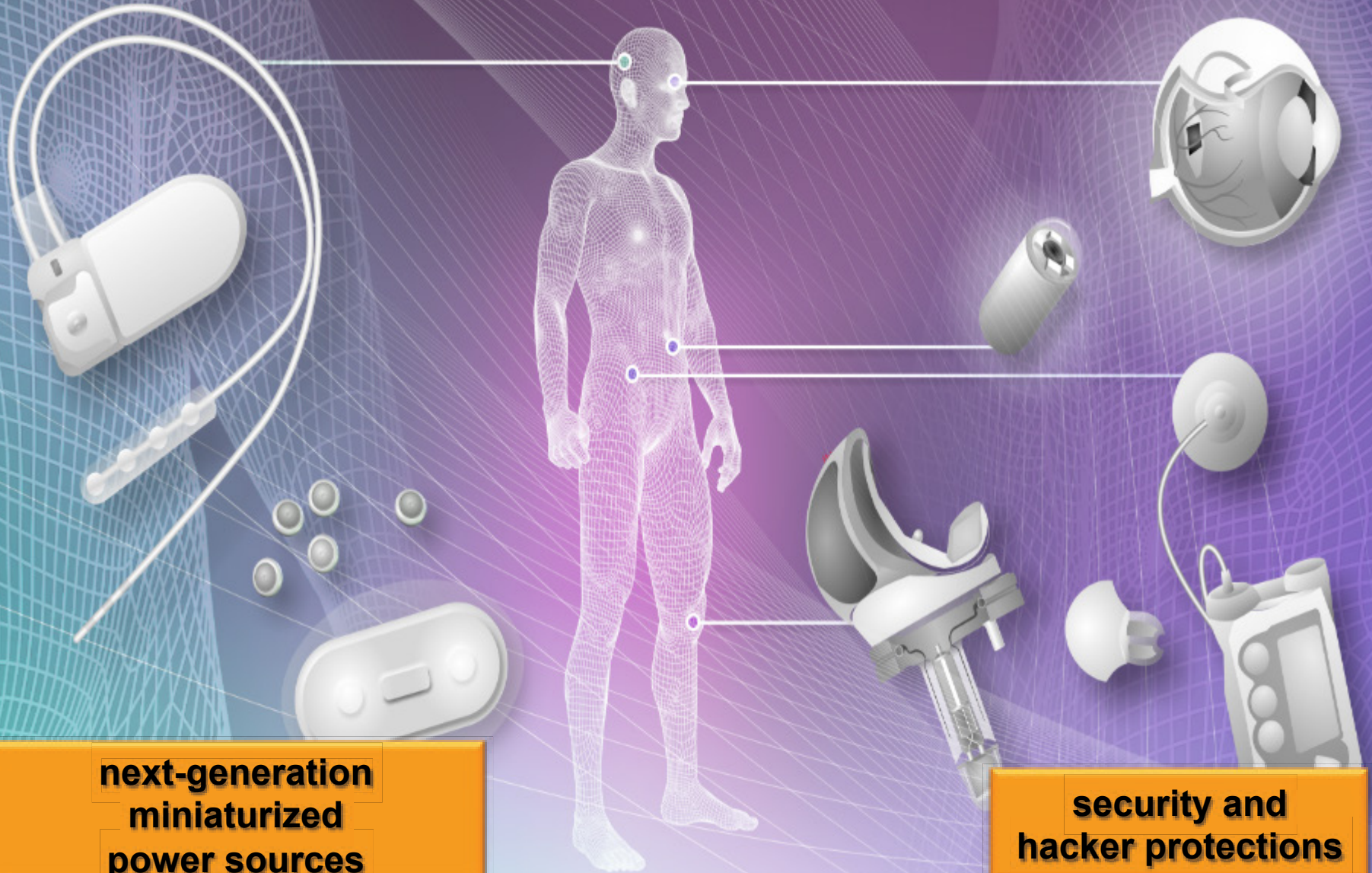
**Information
for
Proactive
Health
Awareness
(Wellness)**



Telemedicine: Diagnostics, Robotics, and Remote Monitoring of Health



Implantable Devices and Wireless Monitoring (and Modulation)



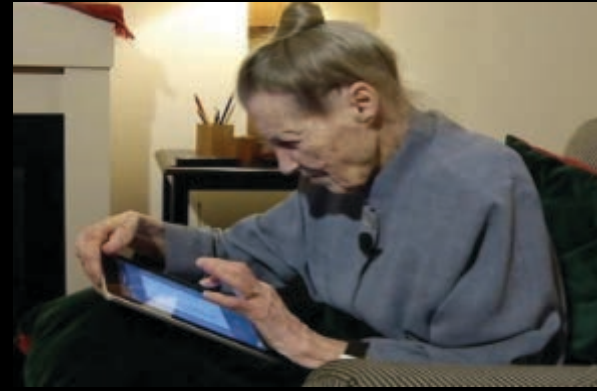
**next-generation
miniaturized
power sources**

**security and
hacker protections**

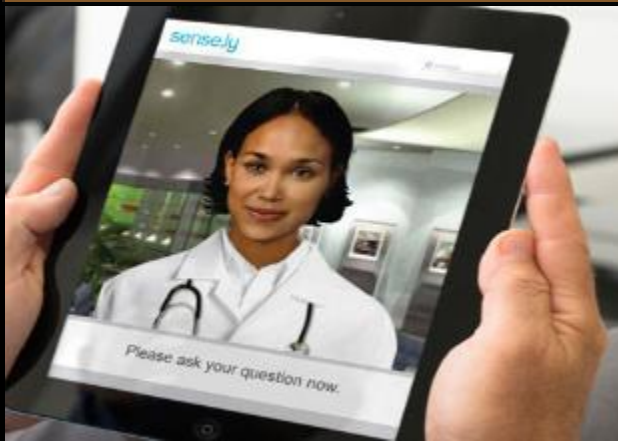
Gray Technologies and Aging in Place: Independent But Monitored Living for Aging Populations



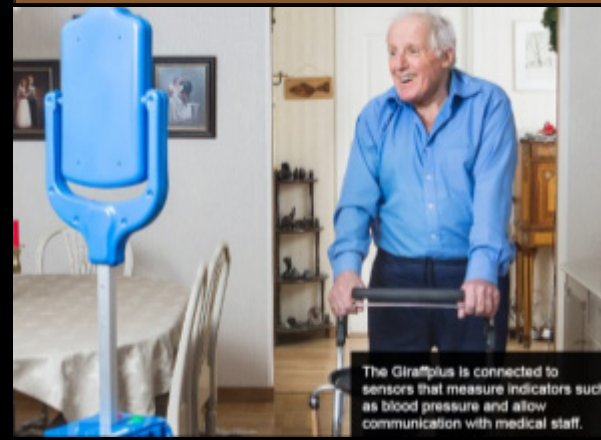
Rx compliance



**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?

Social Spaces and Individual Behavior Become Quantifiable

- **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**

Population Health Research and Precision Medicine: Blurring the Boundaries Between Research and Clinical Care

- **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

**engineering and
device-based
medicine**

- remote health monitoring
- telemedicine
- robotics

**molecular (precision)
medicine**

- panOmics profiling
- analysis of disruption in biological networks in disease

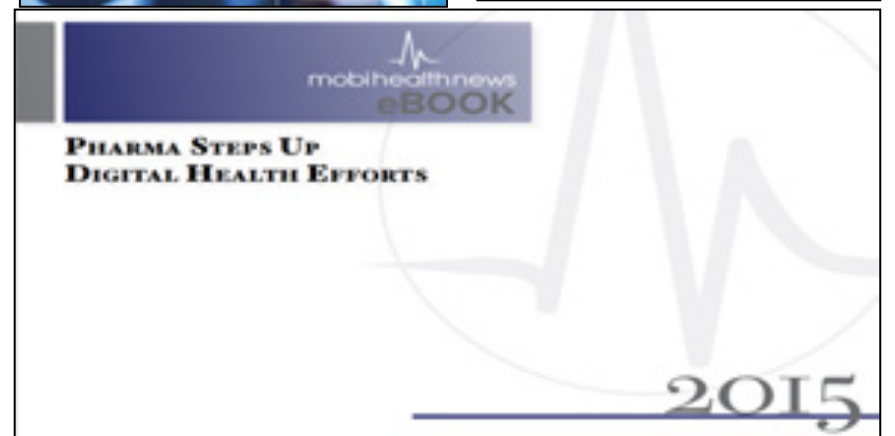
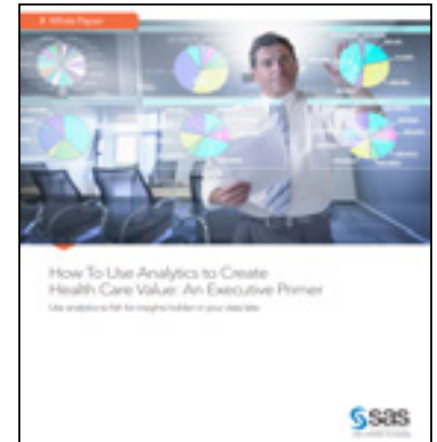
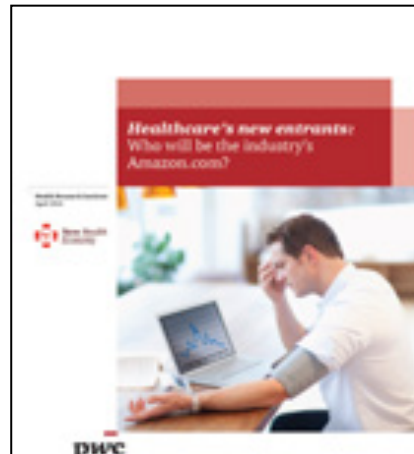
**information-based
healthcare**

- 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






**The V5 Big Data Challenge:
Volume, Variety, Velocity, Veracity and Value**

**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**

Big Data 2025: Astronomical or Genomical?

(Z. D. Stephens et al. (2015) PLOS Biology 1002195)

- **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**

“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, life style**
 - **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?**

Computational- and Data-Enabled Science

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

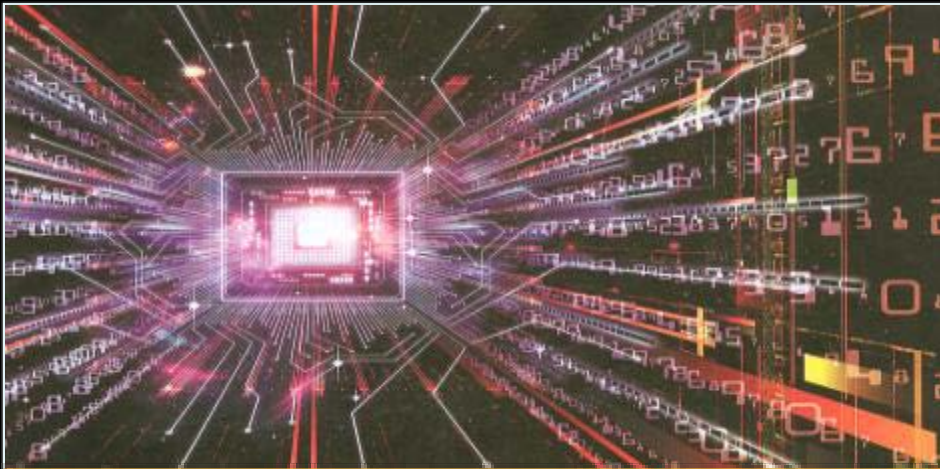
“helping the slow brain catch up with the fast machine”

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?**

Big Data: Changing the Intellectual Framework for Discovery and Knowledge Acquisition

**hypothesis
driven
research**

**multi-disciplinary:
team-based,
systems-focus,
big data sets**

**unbiased
datasets
and
new analytics
for
pattern
mining**

**reductionist:
Individual
investigator-
centric,
single discipline
datasets**

Defining An Optimum Balance

Data Science, Machine Intelligence and Decision Science

- **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

**connectivity, continuity
and consumerism**

BIG DATA

**computing
and
automation**

**life
sciences
and
medicine**

**sensors,
robotics**

- Population Data
- Precision Medicine
- Data Science

**patient
engagement**

**social
media**

**life
style
metrics**

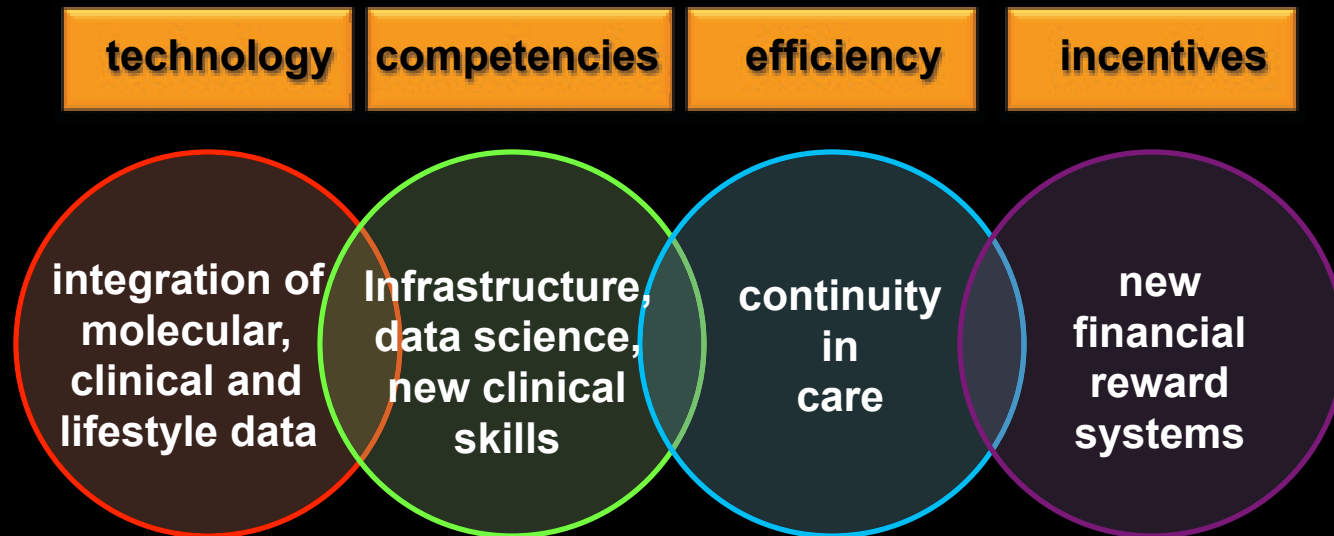
**services
integration
(systems)**

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

**the expanded
care space
(individuals)**



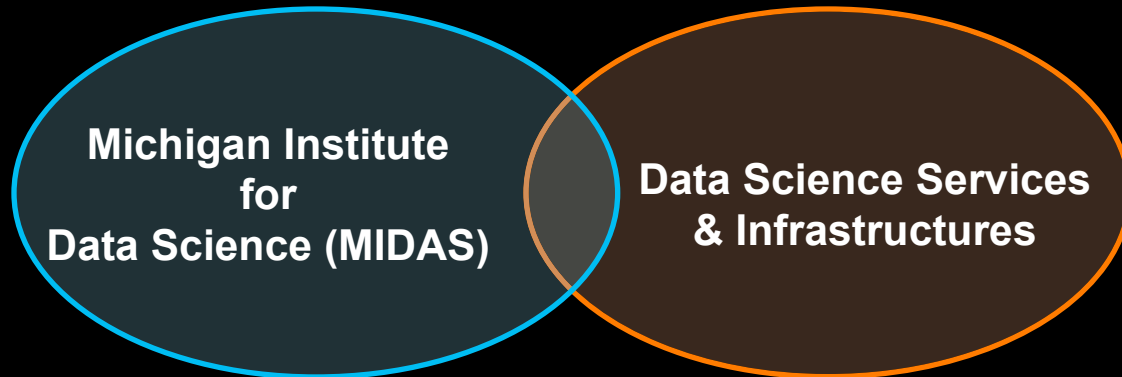
Leveraging the Potential of Precision Medicine Will Require **PROFOUND CHANGES** in the Organization and Proficiency of Healthcare Services



- seamless integration of complex, diverse and dynamic data for real-time monitoring of health status and risk management
- shift from reactive episodic care encounters to increasingly proactive risk mitigation
- progressive shift from management of overt disease to sustained wellness and continuity in care



Data Science at the University of Michigan



**Health System
Data and Analytics
Integration**

**Department of
Computational Medicine
and Bioinformatics**

UMHS-IT

**UMMS Disruptive
Care at Home Program**

**Michigan Center
for Critical Care**

**Michigan Metabolomics
and Obesity Center**

**Institute for Health
Policy and Innovation**

**UMMS Dept.
Learning Health Systems**

**SNRE Geospatial
Health Informatics Center**

**School of Public Health
FUSION Project**

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

**Michigan Health
Communication Center**

Slides available @ <http://casi.asu.edu/>

