



Wearables, Apps and Big Data in the Age of Precision Medicine

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Center for Law, Science and Technology
Spring 2018/Study Group on Biological Revolutions
11 January 2018

#### The US Healthcare Ecosystem

- economically unsustainable
  - \$3.5 trillion, 18% GDP and projected 3-5% CGR
- looming clinical and economic impact of aging population
- dominance of reactive episodic interventions to overt disease versus proactive risk monitoring and mitigation
- lags other sectors in access and proficient use of information to optimize care allocation of high cost resources
- waste, inefficiency, error and wide variation in standards of care

### **Aspirations for the U.S. Healthcare System: National Academy of Medicine**

The Triple Aim

- improved outcomes
- reduced cost
- value-based care

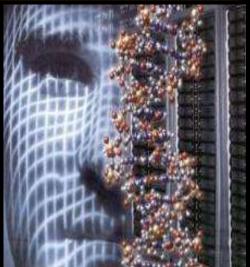
- right information
- right decisions
- right culture

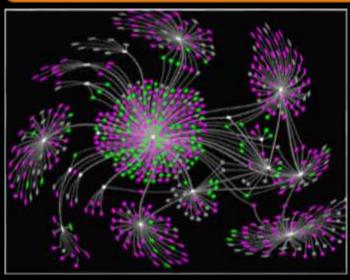
The Learning Healthcare System

#### **Precision Medicine:**

(Epi)Genomics

Causal Relationships Between Molecular Signaling Network Disruptions and Disease









Patient-Specific Signatures of Disease or Predisposition to Disease

- •00terabytes1penindividual
- Dettabyte Option yottabyte Option of the O

**Big (Messy) Data** 

#### Consortium for Exome Sequencing of 500,000 **UK Biobank Samples by 2020**



#### REGENERON













- announced January 2018: each company committed to \$10MM investment
- integration with medical records, lab test data and psychological assessments

### Precision Medicine and Data-Intensive Medicine: Obligate Inter-Dependencies

**Individual Data** 

#### **Population Databanks**



Toron Beach

Toron State Soston

Demonstrate State Soston

Wirginia Beach

Clack sonville

Miami

Mixico

integration and analysis of large scale, diverse data

"matching" individual profiles to 'best match' cohorts with data or outcomes

### The Slow Adoption of Precision Medicine Into Routine Healthcare

precision medicine early adoption

routine healthcare delivery



individual-centric protocols

- one-size-fits-all protocols
- reimbursement policies
- fragmented data

estimated \$ 20 - 50 billion

\$3.2 trillion

### Most Events That Affect Our Health Occur Outside of the Healthcare System And Are Not Monitored

#### **Need for Continuity of Care Record: From Womb to Tomb**



**Behavior** 

**Environment** 

#### Social Spaces 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
- the confessional of social media
- the blurring of private and public spaces
- complex ethical and legal issues
  - consent, privacy, security, surveillance

# Large Scale Databanks and "People Analytics": Blurring the Data Boundaries Between Biomedical Research, Clinical Care and Daily Life

- every recorded action (clinical and non-clinical) is a data point
- every individual is a data node
- every individual is a research asset
- every individual is their own control
- every contact builds a personal risk profile (social contagion)





"I don't think of Humana so much as an insurance company as an IT company who is helping us with the data that we need in order to deal with our population health tools."

Dr. Roy Beveridge, M.D.

CMO, Humana

Cited in Fierce Healthcare 9 May 2017

#### **A Data-Intensive World**

**Ubiquitous Sensing** 

Internet – of – Things (IoT)

**Biometrics and Surveillance** 

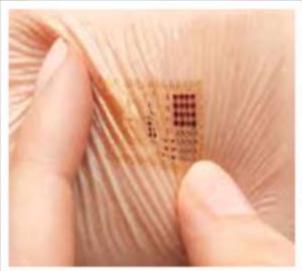
**AORTA: Always On, Real Time Awareness** 

Faster Data, Smarter Analytics, Better Decisions

**Robotics, Machine Learning and Artificial Intelligence** 

#### **Remote Monitoring of Health Status**





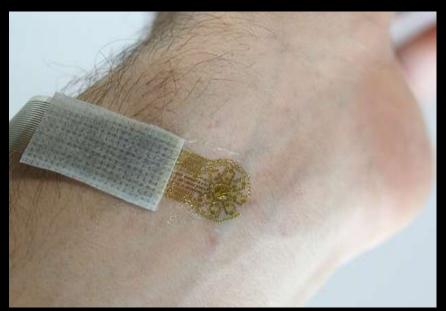


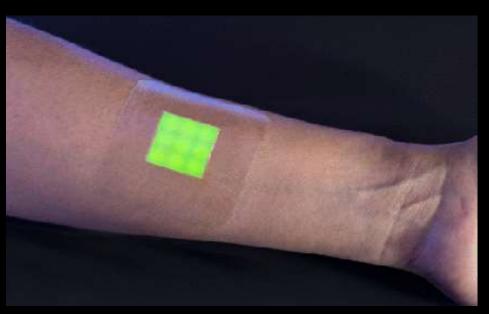






#### **Smart Materials for Improved Therapeutic Adherence**









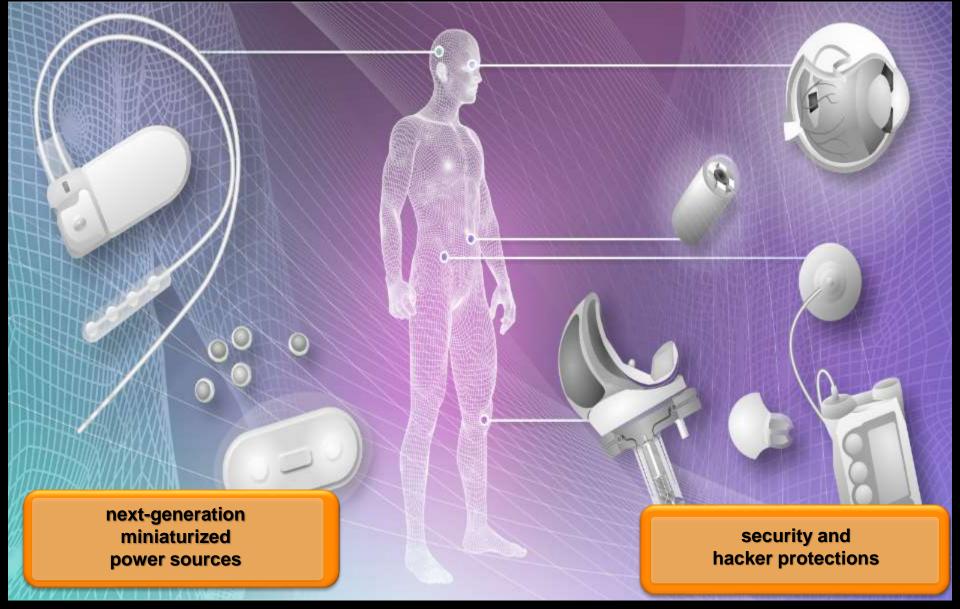


#### Swallowing a Spy — The Potential Uses of Digital Adherence Monitoring NEJM (2018) 378, 107

Lisa Rosenbaum, M.D.

- improve clinical outcomes
- financial penalties/coercion for non-adherence?
- privacy protections ?
- stealth reporting of non-R<sub>x</sub> issues?

### Implantable Devices and Wireless Monitoring (and Modulation)



#### NavCog: Carnegie Mellon University Sensory Substitution Devices: Hearing Sights



From: Comm. ACM 2018 61, 15

#### "Medical Selfies": The Proliferation of Mobile Devices in Healthcare









### The Growth of Telehealth and Telemedicine: Expanding the Care Space

- estimated use by 60% HCl's and 50% hospitals (NEJM 2017, 377, 1585)
- virtual consults in Kaiser Permanente exceeded in-person visits in 2016
- reduced cost, travel time for patients
- healthcare consumerism and Ux expectancy
- 21<sup>st</sup> Century Cures Act and efficacy evaluation for Medicare services

#### The Eldercare Gap

10,000

boomers turn 65 every day

**79 %** 

increase in boomers 80 or older from 2010 to 2030

1 %

 projected increase in number of caregivers aged 45 to 64 from 2010 to 2030

348,000

projected number of home health aide jobs needed in next decade

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



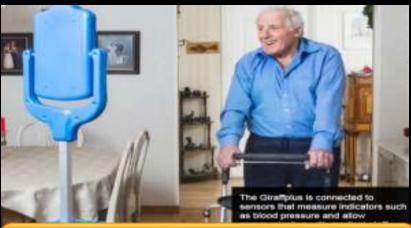
Rx adherence



cognitive stimulation



in home support and reduced readmissions

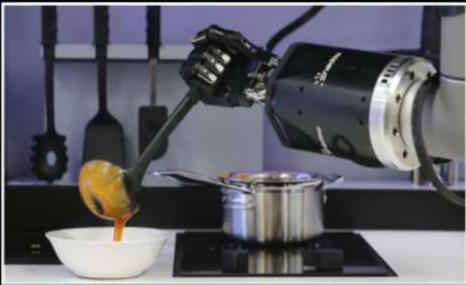


reduced office visits

#### **Digital Assistants and Support Robots in Healthcare**









#### **The Omnipresent Digital Assistants**





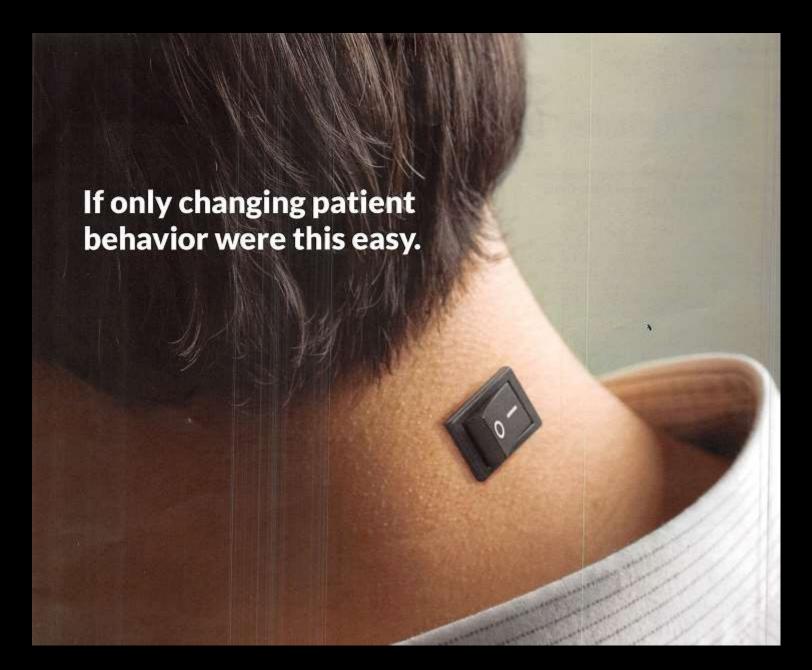






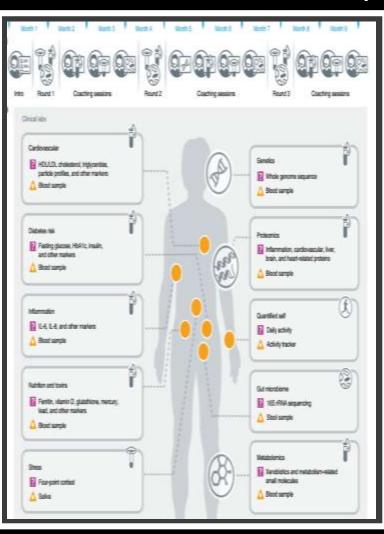






#### Personal, Dense, Dynamic Data Clouds: Comprehensive Profiling of Health Status of 108 Individuals Over 9 Months

N. D. Price et al. (2017) Nature Biotechnology 35, 747



- WGS
- daily physical and sleep activities
- 3 month blood, saliva, urine and stool analysis
- 643 metabolites
- 262 proteins

- cost
- scalability
- data interpretation
- clinical utility

### **Use of Incentives and Rewards for Adoption of Wearables in Treatment Adherence and Wellness Initiatives**





#### tap wearable electronics

Google spin-off explores combining data from smart devices with other health metrics

### Welltok

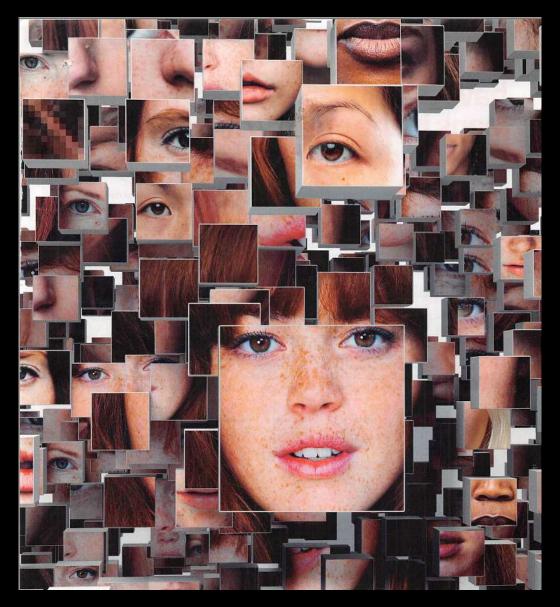
#### Optimizing Health, Maximizing Rewards.

At MediFuture, Welltok will bring the Health Optimization ecosystem to life by allowing attendees to interact with the CafeWell platform and other offerings from key ecosystem partners





### Digital Psychiatry: Digital Psychometrics and Evaluation of Mental Illness



## Computational Analysis of Facial Expressions, Voice and Social Interaction Patterns in Diagnostic Profiling of Psychiatric Disorders

- high variation in assessment of same patients by different psychiatrists
- major need for objective measurements of nuanced behavior
  - gaze, microsaccades, facial muscles, skin galvanics
  - speech prosody (rhythm, tone, volume)
  - stimulus response reactions and interaction speed
- Al and learning from large video banks
  - bipolar disorder, schizophrenia, depression
  - suicidal ideation
  - PTSD
- signal alerts to care teams when interventions indicated

#### **Avatar Personalities in Gaming Reveal Behavioral Clues** to Match With Other Aspects of User Activities



- risk profiling
- predispositions to anti-social actions/susceptibilities
- mapping correlation with real world actions, including law breaking

#### Digiceuticals: Software as Therapy



"We envision empowering individuals with digital therapeutic solutions that address underlying motivational and technical deficits by deciphering neural pathways that support motivation, decision-making and reinforcement to prompt health."



Dr. Ben Wiegand
Global Head, Janssen R&D
World Without Disease Accelerator
PharmaVoice 2017

### Mobile Apps, Wearables, Sensors and Continuous Health Status Monitoring

- who sets the standards?
- who integrates and interprets the data?
- who pays?
- who consents?
- who owns the data?



"Do you solemely swear to have no involvement in your own care?"

# **Empowered Patients: Social Networking Sites (SNS) and Their Role in Clinical Care**

- logical extension to healthcare of rapid rise of web/apps in mainstream culture
- increasingly proactive and engagement of consumers/patients/families
- more transparent information on treatment options, cost and provider performance
- new clinical practice tools to optimize HCP: patient relationships
- improved recruitment of patients into investigational and pragmatic clinical trials
- Ux

### Virtual Visits/Consultations: In-Person Healthcare as Option B

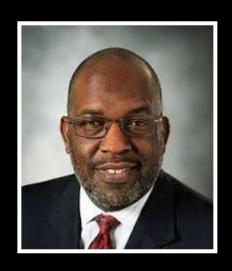
"What if ill-person visits were the second, third or even the last option for meeting routine patient needs rather than the first?"

S. Duffy and T.H. Lee **NEJM** (2018) 378, 104

### "The Medical Virtualist" and "Website Manners": The Next Clinical Specialty?

- the rise of virtual consultants
  - tertiary to primary care
  - investment by larger enterprises in centralized telehealth command centers
    - service provision across broad geographies including international
  - lack of direct training of MD/HCPs in using virtual systems for patient consultations (website manner)
    - multi-specialty, multi-skill teams
  - need for new training courses

#### Artificial Intelligence, Pattern Analysis and Medical Practice



"I don't think any physician today should be practicing without artificial intelligence assisting in their practice. It's just impossible otherwise to pick up on patterns, to pick up on trends to really monitor care."

Bernard J. Tyson
CEO, Kaiser Permanente
Cited in Forbes: The Future of Work
1 March 2017

### Major Investments in Digital Health by Major Corporations From Within and Outside of Traditional Healthcare Services























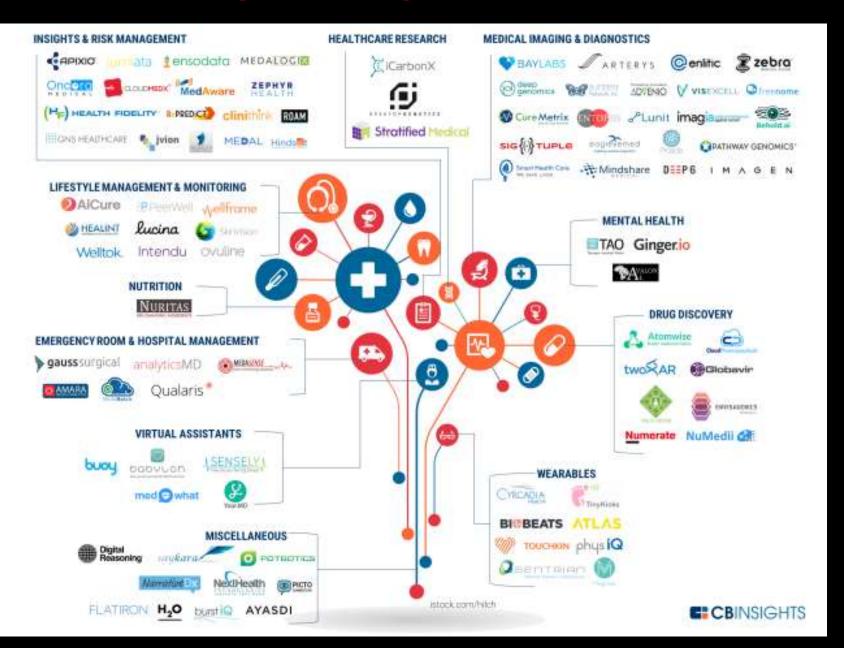








#### 90+ Startup Al Companies in Healthcare



#### The Worst Supply Chain in Society: The Health Information Supply Chain

- no area of the economy generates as much information as the health sector yet uses it so poorly
- fragmented, disconnected data
- incomplete and inaccurate data
- incompatible data formats as barrier to data integration
- slow transition from paper to electronic systems
- inadequate information on behavioral and environmental influences on health
- legislative barriers to data transfer based on well intentioned privacy protections

### Precision Medicine, Digital Health and A Learning Healthcare System

qualitative,
descriptive
information of
uncertain quality
and provenance



quantitative data of known provenance and validated quality

complex ecosystem of largely unconnected data sources



evolving,
inter-connected
networks of data
sources for robust
decisions and
improved care

#### **Protection and Privacy Provisions for Personal Healthcare Data**



legal provisions/ penalties for breach identifiable individual data aggregated de-identified databanks and metadata

- variable levels of consent
- probabilistic, multiparameter individual 'match'

#### **Protection and Privacy Provisions for Personal Healthcare Data**



legal provisions/ penalties for breach

identifiable individual data aggregated de-identified databanks and metadata

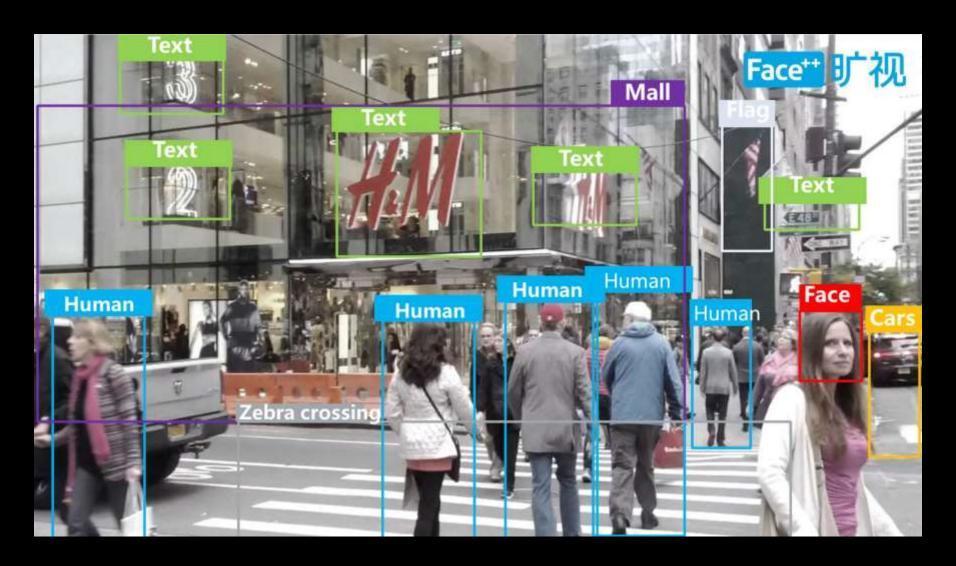
- variable levels of consent
- probabilistic, multiparameter individual 'match'

Are Anonymity and Privacy Illusory in Today's e. Universe?

### Individual-Specific Patterns of App Use and Keyboard Dynamics



### **Computer-Based Computer Facial Recognition and Idiosyncratic Patterns of Body Language, Gait, and Routes**



#### **Making Faces**





















#### **Your Car Knows A Lot About You**



#### **Protection and Privacy Provisions for Personal Healthcare Data**

- informed consent
- legal provisions/ penalties for breach

identifiable individual data and metadata

personal digital dust in

non-healthcare

settings

- variable levels of consent
- probabilistic, multi-parameter individual 'match'

- voluntary or involuntary capture
- 'exposome' profiling and escalating prospect of individual identification

- social media 'firehose'
- purchasing preferences
  - diet, food, alcohol, travel
- political versus
- social graphs: network contagion
  - ratings of 'friends' impact personal rating



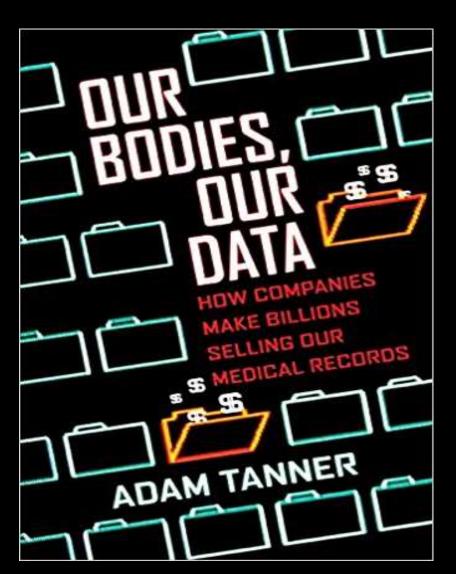
6 April 2010

#### Guide to Protecting the Confidentiality of Personally Identifiable Information (PII)

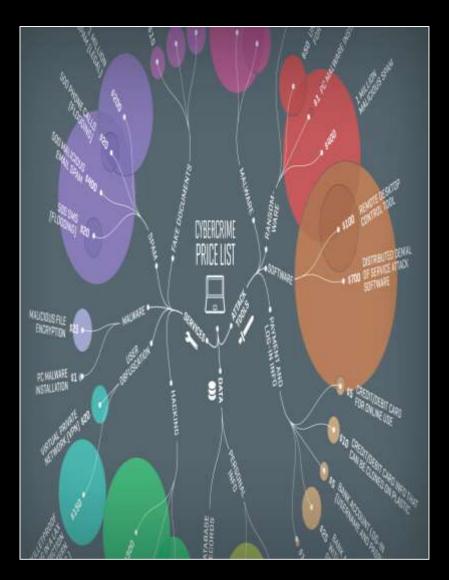
### Recommendations of the National Institute of Standards and Technology

Erika McCallister Tim Grance Karen Scarfone

#### Data Brokers ('Selling-On')



#### **Data Theft**

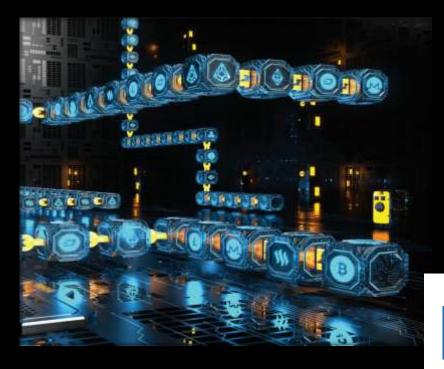


#### **Consumer Genomics**



over 7 million samples sequenced in 2017

#### Early Entrants Into The Use of Blockchain for Secure Contract Transactions in Healthcare

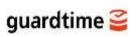






















#### **Big Data and Individual Rights**

- agency, autonomy and consent
- right to port/share
- right to know
- right to amend/correct
- right to be forgotten
- protection(s) from harms
- legacy and inheritance rights
- complexities of entangled co-ownership



#### European Union General Data Protection (25 May 2018) A Death Blow to Precision Medicine?

- precision medicine requires large scale population data
- requires consent from every individual whose genetic sequence is in a database every time a clinician/researcher needs to access
- undermines individual rights to chose how and where they share their data and engage/promote medical research

#### **Big Data**

- the merciless memory of ubiquitous (meta) data
- apps become increasingly anticipatory and automatic
- dataveillance and privacy: sacrificing privacy for utility
- risk profiling: individuals and their connected social graphs ("social fitness")
- social and economic discrimination/coercion
- opt-in versus opt-out

#### Principle for the Post-Privacy Age: Connections

- identity in both personal and extended social domains
- the way we behave today will determine the choices we will face, or are allowed to make, in future decades
- an individual's place in the social graph (network contagion)
- much of the data about you is entangled with data about others

#### From Credit Score to Social Credit Score (Lifescore)





- 14 June 2014
- "Planning Outline for the Construction of a Social Credit System"
- implemented for 1.3 billion citizens on 'voluntary' basis but mandatory by 2020



#### **Human-Computer Interactions/Integration**



#### **Virtual Reality and Training for Complex, Dynamic Tasks**



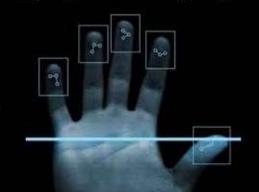
#### Will We Even Call It A Phone In 2020?



**Bendable LED Screens** 



Gesture Based UIs



Holographic Imaging

Augmented Reality (AR)



Mobile

Computing

Facial & Eye Recognition

**Mobile Biometrics** 



The message of protests in Iran

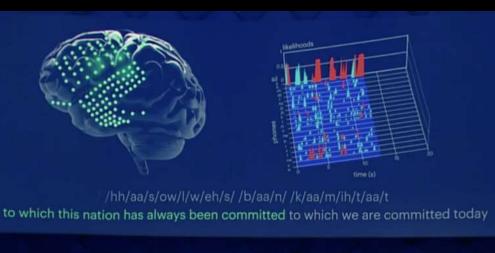
Blue-state Republicans: no right left

**Education lessons from Pakistan** 

The world's worst airports

### The next frontier When thoughts control machines









#### **Non-Invasive Brain Computer Interface**













#### **Inside the Black Box of Algorithms**

**Data is Inherently Dumb** 

**Algorithms Define Action and Value** 

**Algorithms with Agendas** 

Risk, Regulation and Responsibility

#### **Algorithms with Agendas: Channeled Lives**

- social media and 'filter bubbles'
  - online "echo chambers" of 'facts-to-fit'
  - bias ideologies/perceptions
- facts and authentication tools swept away in a flood of falsehoods and trivia
- influence of purposely biased data mining to support/manipulate individual/group opinions



# EVERYBODY LIES

BIG DATA, NEW DATA,

AND WHAT THE INTERNET

CAN TELL US ABOUT WHO

WE REALLY ARE



SETH STEPHENS-DAVIDOWITZ
FOREWORD BY STEVEN PINKER



How to Think Critically in the Post-Truth Era

**Daniel J. Levitin** 

NEW YORK TIMES BESTSELLING AUTHOR OF

THE ORGANIZED MIND AND THIS IS YOUR BRAIN ON MUSIC

Previously published as A Field Guide to Lies

THE NEW DOGS OF WAR:

#### THE FUTURE OF WEAPONIZED ARTIFICIAL INTELLIGENCE

A Threatcasting Report from the Army Cyber Institute at West Point and Arizona State University's Threatcasting Lab

### Deep Learning and The Rise of the Algorithmic Black Box(es)

- deep learning systems do not have explanatory power
- algorithms increase accuracy but how and why are becoming increasingly unpredictable/ unanswerable
- the more powerful the system becomes the greater opacity and complexity of deconvolution
- generative adversarial networks



#### "Explainable Al"

- need to better characterize the evolution of decision algorithms
  - keeping humans in the loop
- deconvolution of how and why machine learning algorithms reach flawed conclusions
- broad national security issues related to data integrity
- concern over Al-directed manipulation of social networks, advertising and personal data
- corruption of critical military and civilian systems and decision control tools

#### Deep Learning, Al and New Automated Decision Support Tools for Data-Intensive Environment

What the Data Ordered: The Future of Healthcare?

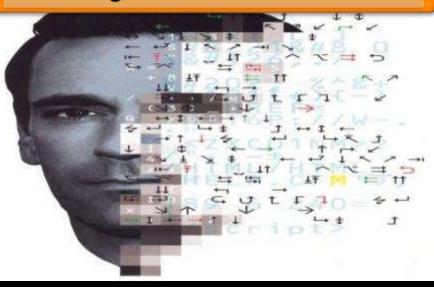
Why Wait for the Slow Brain to Catchup With the Fast Machine?

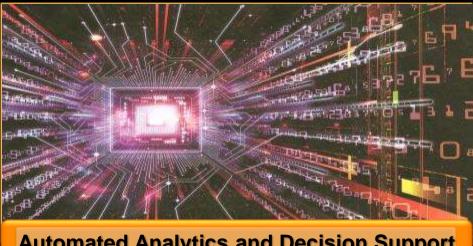
#### **Technology Acceleration and Convergence:** The Escalating Challenge for Professional Competency, Decision-Support and Future Medical Education

#### **Data Deluge**



#### **Cognitive Bandwidth Limits**









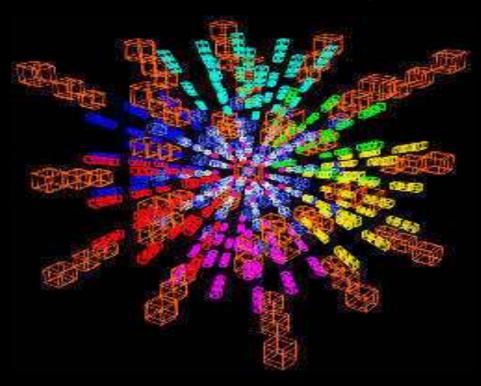
**Facile Formats for Actionable Decisions** 

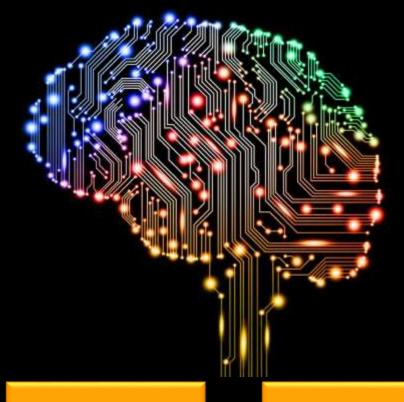
## The Pending Era of Cognitive Computing and Decision-Support Systems: Overcoming the "Bandwidth" Limits of Human Individuals



- 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

#### Automated Context: Data Finding Data "Intelligence at Ingestion"





Feature
Extraction
and
Classification



**Context Analysis** 



Persistent Context



Relevance Detection

Learning Systems



Situational Awareness

Rapid,
Robust
Decisions

### Robotics, Artificial Intelligence and Workforce Automation and Replacement

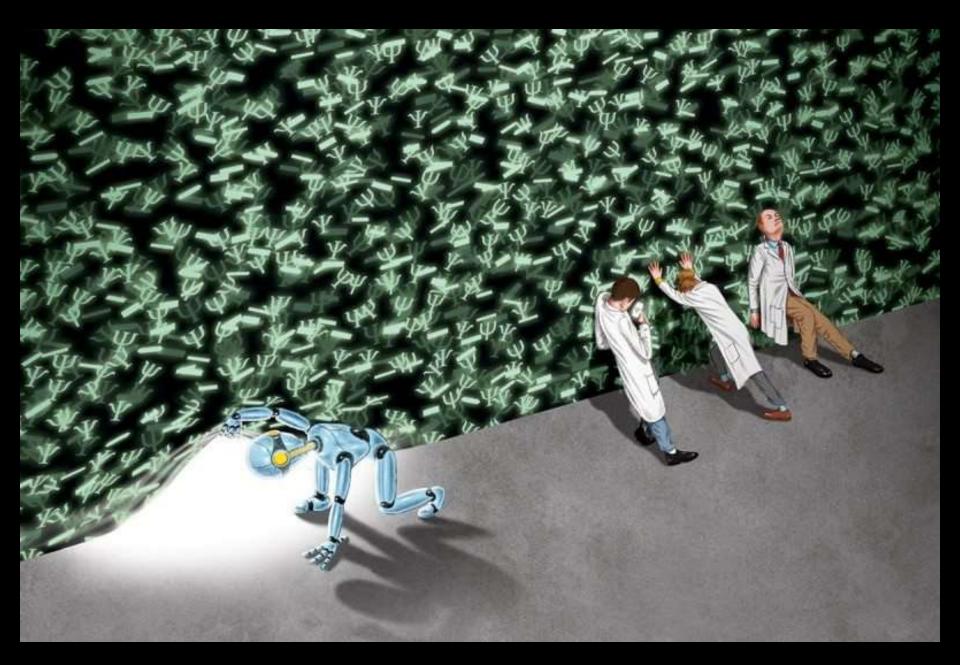




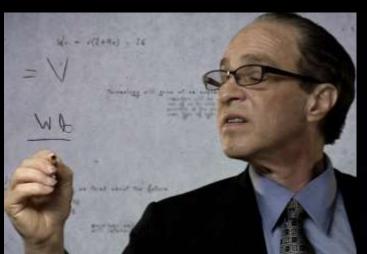
#### Machine Learning and Image Analysis in Clinical Medicine



- large scale training sets and classification parameters
- standardized, reproducible and scalable
- 260 million images/day for \$1000 GPU



### Smart Machines, Deep Learning, Artificial Intelligence and Existential Threats





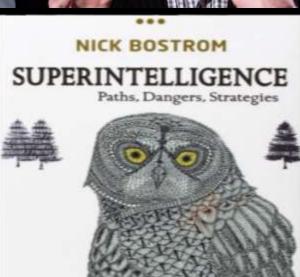


#### PREPARING FOR THE FUTURE OF ARTIFICIAL INTELLIGENCE

Executive Office of the President National Science and Technology Council Committee on Technology

October 2016







#### Artificial Intelligence (AI) and Healthcare

- will physicians, payers and patients trust Al?
- how will Al tools be integrated into current work flow or will radical reorganization/re-training be required?
- how will Al platforms alter payment schemes?
- how will Al algorithms/decision analytics be regulated?
- which clinical specialities/processes be at risk of replacement by Al and when?
- how will professional competencies in using Al decision-support tools be defined?
  - MD curriculum, CME
- what new malpractice liabilities will emerge by failure to use/interpret AI platforms

# Deep Learning, Machine Learning and Artificial Intelligence in Data Analytics and Decision Support



"I Can't Let You Do That Dave"

Automated Decision Support Tools and "Gated Autonomy" in the Management of Complex Systems

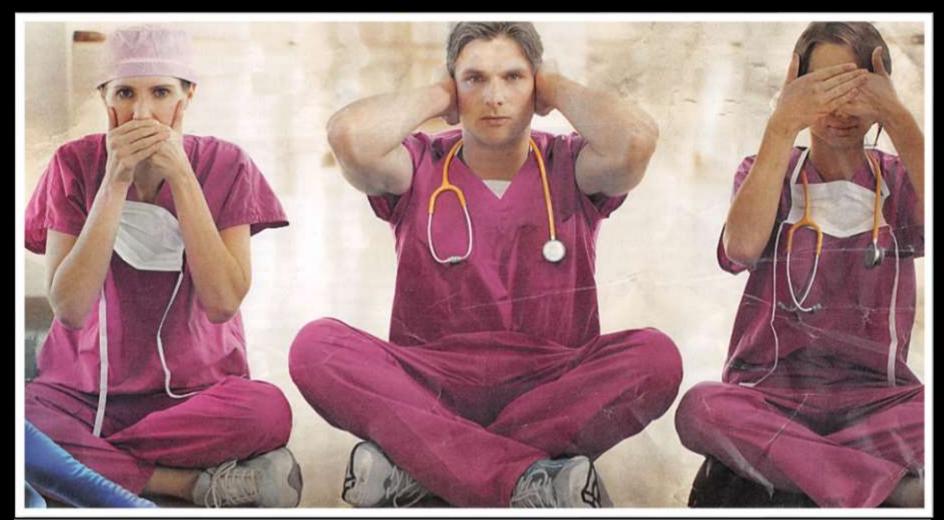
### Living in a World Where the Data Analytics and Interpretation Algorithms Are Obscure to the End User

- ceding decision authority to computerized support systems
- culturally alien to professionals in their claimed expertise domain but they accept in all 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?

#### **Digital Darwinism**

- information asymmetries in access to data and mastery of large scale data analytics
- enterprise competitiveness, relevance and viability
- individual status
  - from credit score to social credit score
  - employability
- impact of peer network behavior on personal classification
- danger of digital monopolies
  - corporations and state surveillance
- Al, national security and military advantage

### The Rise of Data-Intensive Medicine: The Pending Disruption and Reorganization of Care Delivery



DNR

Denial Negativity Resistance



"So, as you can see, health care is so complicated you may never get well."

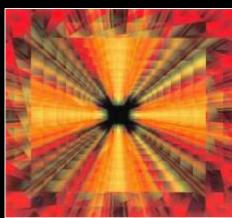
#### The Evolution of Data-Intensive Computational Medicine

Technology Convergence and Acceleration

Precision Medicine and Digital Healthcare

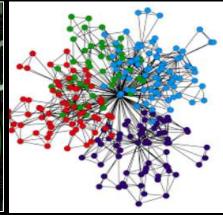
**Big Data** 

Networked Data

















Data Security Privacy

**Robotics and Human Machine Interactions** 

Artificial Intelligence and Decision Support

Identity, Ethics, Risk and Regulation

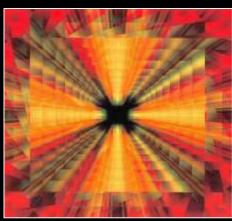
#### Slides Available @ https://casi.asu.edu/presentations

Technology Convergence and Acceleration

Precision Medicine and Digital Healthcare

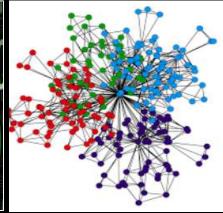
**Big Data** 

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Data Security Privacy

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