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

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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

- improved outcomes
- reduced cost
- value-based care
- right information
- right decisions
- right culture

The Triple Aim

The Learning Healthcare System
Precision Medicine:

(Cepi)Genomics

Causal Relationships Between Molecular Signaling Network Disruptions and Disease

- terabytes per individual
- zettabyte – yottabyte population databases

Patient-Specific Signatures of Disease or Predisposition to Disease

Big (Messy) Data
Consortium for Exome Sequencing of 500,000 UK Biobank Samples by 2020

- 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

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**
  - Individual-centric protocols
  - Estimated $20 - 50 billion

- **Routine Healthcare Delivery**
  - One-size-fits-all protocols
  - Reimbursement policies
  - Fragmented data
  - $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

Lisa Rosenbaum, M.D.

- improve clinical outcomes
- financial penalties/coercion for non-adherence ?
- privacy protections ?
- stealth reporting of non-R_x issues?
Implantable Devices and Wireless Monitoring (and Modulation)

next-generation miniaturized power sources

security and hacker protections
NavCog: Carnegie Mellon University
Sensory Substitution Devices: Hearing Sights

From: Comm. ACM 2018 61, 15
“Medical Selfies”: The Proliferation of Mobile Devices in Healthcare

Siri, does this look malignant?
The Growth of Telehealth and Telemedicine: Expanding the Care Space

- estimated use by 60% HCI’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
- 21st Century Cures Act and efficacy evaluation for Medicare services
The Eldercare Gap

- boomers turn 65 every day
- increase in boomers 80 or older from 2010 to 2030
- projected increase in number of caregivers aged 45 to 64 from 2010 to 2030
- projected number of home health aide jobs needed in next decade

10,000
79%
1%
348,000
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
If only changing patient behavior were this easy.
Personal, Dense, Dynamic Data Clouds: Comprehensive Profiling of Health Status of 108 Individuals Over 9 Months


- 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

Nature (2017) 547, 13
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
• AI 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
“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 solemnly 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
“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 AI 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

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

complex ecosystem of largely unconnected data sources
Protection and Privacy Provisions for Personal Healthcare Data

- Informed consent
- Legal provisions/penalties for breach
- Variable levels of consent
- Probabilistic, multi-parameter individual ‘match’

- Identifiable individual data
- Aggregated de-identified databanks and metadata
Protection and Privacy Provisions for Personal Healthcare Data

- Informed consent
- Legal provisions/penalties for breach
- Variable levels of consent
- Probabilistic, multi-parameter 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
- Voluntary or involuntary capture
- ‘Exposome’ profiling and escalating prospect of individual identification
- Variable levels of consent
- Probabilistic, multi-parameter individual ‘match’
- Social media ‘firehose’
- Purchasing preferences
  - Diet, food, alcohol, travel
- Political versus
- Social graphs: network contagion
  - Ratings of ‘friends’ impact personal rating
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 choose 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

Wearable Mobile Computing

Gesture Based UIs

Augmented Reality (AR)

Facial & Eye Recognition

Holographic Imaging

Mobile Biometrics
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
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 AI”

- 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 AI-directed manipulation of social networks, advertising and personal data
- corruption of critical military and civilian systems and decision control tools
Deep Learning, AI 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

Automated Analytics and Decision Support

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
Artificial Intelligence (AI) and Healthcare

- will physicians, payers and patients trust AI?
- how will AI tools be integrated into current work flow or will radical reorganization/re-training be required?
- how will AI platforms alter payment schemes?
- how will AI algorithms/decision analytics be regulated?
- which clinical specialities/processes be at risk of replacement by AI and when?
- how will professional competencies in using AI 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
- AI, national security and military advantage
The Rise of Data-Intensive Medicine: The Pending Disruption and Reorganization of Care Delivery
“So, as you can see, health care is so complicated you may never get well.”
<table>
<thead>
<tr>
<th>Technology Convergence and Acceleration</th>
<th>Precision Medicine and Digital Healthcare</th>
<th>Big Data</th>
<th>Networked Data</th>
</tr>
</thead>
<tbody>
<tr>
<td>Data Security Privacy</td>
<td>Robotics and Human Machine Interactions</td>
<td>Artificial Intelligence and Decision Support</td>
<td>Identity, Ethics, Risk and Regulation</td>
</tr>
</tbody>
</table>

The Evolution of Data-Intensive Computational Medicine