Precision Medicine and Data Ethics
PM5 March 5, 2018
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Conflict of Interest (30pt Verdana)

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Has no real or apparent conflicts of interest to report.
Learning Objectives

1. Data Governance Challenges of Precision Medicine
2. Trust Deficit Barrier to Scale and Agility
3. Human Centered Design = Ethical Data Use
4. Data Strategy and Applied Data Ethics
5. Data Governance and Accountability
Global Data Ethics

Innovation through Data Governance, Protection, and Privacy

Sheila Colclasure, Global Chief Data Ethics Officer and Public Policy Executive, Acxiom and LiveRamp
Agenda

1. Precision Medicine Data Future: Inevitability and Complexity
2. Trust Deficit, Trust Imperative
3. Data Ethics in Precision Medicine
4. Applied Data Ethics – Data Governance
Precision Medicine – Data Future

Approach to Disease Treatment and Prevention that Takes Into Account Gene Variability, Environment and Lifestyles for Each Person

The Future of Medicine: Personal, Ubiquitous, Mobile
The perfect storm of technology trends is about to transform healthcare as mobile tech, genomics, connected devices and artificial intelligence combine.
Data Future: Big Bets on Precision Medicine

- 2016 Precision Medicine Institute launched w/ $215 million from Fed. Gov
- 2017 Dr. Priscilla Chan & Mark Zuckerberg donated $10 million to UCal-SF Precision Medicine Lab
- 2017 NIH funded initiative to collect genetic, environmental information to create precision medicines
- 2017 Precision Medicine Group (PMG) Lands Berkshire Partners & TPG Growth $275 million investment
- 2018 Microsoft, Google invest in precision medicine startup DNAnexus $58 million to advance cloud-based platform to effectively gain insight from large genomic and biomedical datasets
- 2018 Roche to take 56% stake in molecular, genomic diagnostic company Foundation Medicine, deal to pour $1+ billion in the company
Precision Medicine – **Data Future**

*Most Successful Companies are Most Effective Users of Data*

- Everything and Everyone Creating Data
- 90% of Worlds Data Created Last 24 Months
- Observational vs. Actively Collected Data
- Individuals Expect Data Driven Experiences
- Advanced Analytics: Machine Learning, Artificial Intelligence
- Better Decisions, Better Outcomes
ARCHITECTURAL DISPLAY GLASS
Durable, Seamless, Electronics Enabling, Touch Sensitive
Travel and Entertainment

DISNEY'S $1 BILLION BET ON A MAGICAL WRISTBAND

Magicband wields access to the park, replacing virtually every transaction you'd make inside.

CARNIVAL'S HIGH-TECH CRUISE WEARABLE KNOWS YOUR EVERY NEED

goes further than its predecessors in ways that make it feel like a ship can read your mind.
Smart Medicine

FDA Approved Co-encapsulation
Improves Adherence 40+% to 80+% Outcomes, precision, patient control, economics
Comprehensive Longitudinal Data Illuminates adverse reactions & efficacy failures
Secondary uses... Ethics?
Bringing AI To Life

Everyday comfortable apparel that captures medical-grade biometric data paired with revolutionary AI algorithms that will inevitably change the course of human health.

Our Data and Algorithm Libraries

**Raw**
- Raw ECG signal
- Raw respiration signal
- Raw accelerometer data

**Advanced**
- Heart rate
- Heart rate variability
- Breathing rate
- Steps
- Calories

**Custom**
- OMsignal can build:
  - Detection of sleep apnea events
  - Detection of COPD symptoms
  - Detection of ECG signature
  - Predictive analytics including machine learning algorithms
Digital Tattoo: Human-Computer Interface

lights up: heart rate, body temp, blood ox, muscle fatigue, blood pressure
Trust is Essential

“rewriting genetic code with CRISPR brings nearly limitless promise for disease elimination, but also the possibility of peril”

“without communication there is no relationship, without trust there is no reason to continue”

– Henry Ford
Data Exchange: Who Benefits Most...

- **Businesses**: 80%
- **Individual**: 7%
Trust Deficit

- Business Failures in General
- Data Use Incidents, Data Protection Failures
- Surveillance: Commercial and Government
- Global Signs: GDPR, ePriv Reg, Brexit, Forced Localization
- Secondary Uses
- Legal Probability vs Legal Certainty
- Risk of NOT using Data (we don’t trust ourselves)

Trust gap exacerbated by complexity…
Practical Challenges

Precision Medicine and Health System Interoperability

- Data
- Data Silos
- Data Matching
- Data Accuracy
- Fraud Detection and Prevention
- People Based

*Identity Layer and *Algorithmic Rules Engines
Two Big Ideas…

1. Individual at the Center
2. Fairness as the Targeted Outcome

Two Big Changes…

1. Ask Different Questions
2. Interrogate at Design Phase

Applied Data Ethics: Operational data governance that delivers ethical outcomes
Human Centered Data Ethics

Legal Requirements (minimum)

Applied Data Ethics

- **Characterize Project:** Purpose, Sources, Preparation, Accuracy, Insights, Accountability, Benefits, Risks, Analysis and Mitigations, Outcomes, Insights, Quality

- **Just:** Interrogate for Harms, hidden bias, discrimination, social embarrassment, reputational damage

- **Fair** Apply Judgement Based on Documented Facts for All Stakeholders

Regulators, Individuals, Marketplace Expect Us to Get it Right
Applied Data Ethics

Values Built into Data Strategy, System Designs, Processes, Data Activation
- Operational Data Governance
- Data Use in Context
- Business Accountability
- Fairness
- Good outcomes for all stakeholders
- Gap: what can you do vs what you should do

Individuals, Regulators, Societies Expect Us to Get it Right
The Path Forward:

1. Commitment to Data Ethics
2. Design Centered on Individual Benefit
3. Data Ethics by Design: Interrogate Engineering Layer, Data Governance Through Lifecycle
Questions

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- Remind attendees to complete online session evaluation