Ethical Challenges in the Collection and Use of People-Provided Data

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Sharing Patient-Centered Outcomes Data: Building a Better Mousetrap Based on Learnings from the Research Community
Washington, DC
October 17, 2018
Qualcomm Institute at UC San Diego

People
• 350 Faculty
• 120 Technical & Support Staffs
• 200 Industry Partners
• Students

Core Areas
• Culture
• Energy
• Environment
• Health
• Technology
Research Literacy: BRIC is education designed for novice-research team members to increase research literacy and awareness of ethical practices. The BRIC programs have received support from the NIH, NSF, ORI and local sources.

Tech-Ethics: CORE is a learning “ethics” community developed to facilitate the sharing of resources and access to digital health research experts to foster ethical and responsible research and innovation. The CORE is supported by the Robert Wood Johnson Foundation.
**My Work**

**Citizen Science via Participant-Led Research:** People and groups motivated to conduct self-study (e.g., QS, DIY), yet they lack the infrastructure needed. We are working with Project Apollo patients to reflect upon and apply ethical principles, design self-studies, analyze data and share what they learn.

**AI to Support Healthy Aging:** We are working with residents of a retirement community to identify barriers to tech adoption and learn whether they want to be involved in co-design of tech to support their aging independently.

**All of Us** Research Program infrastructure development and bioethics research. We conducted qualitative research to learn about informed consent via “broad” consent and return of information to achieve return of value.
Determinants of Health

Current estimates indicate genetics explain an important but modest portion (e.g., ~30%) of an individual’s variability in health. Health behaviors (e.g., physical inactivity, diet, tobacco use) explain an additional 40% of variance, with the remaining variance attributed to environment factors, social circumstances, and healthcare utilization and delivery.

Image courtesy of Dr. Kevin Patrick, Principal Investigator of the Health Data Exploration Project
Visual Methods

Increasing interest in studying “free-living” behavior “in the wild” prompts increased use of visual methods.
Sensing Methods

Passive, Pervasive, Ubiquitous

With permission of Dr. Todd Coleman, UC San Diego Professor of Electrical & Computer Engineering and CORE Advisor
Social Media Methods
New Methods = New Data

<table>
<thead>
<tr>
<th>Wearable Cameras</th>
<th>GPS Tracking</th>
<th>Smart Phones</th>
<th>Social Media</th>
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<tbody>
<tr>
<td><img src="image1.png" alt="Wearable Cameras" /></td>
<td><img src="image2.png" alt="GPS Tracking" /></td>
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<td><img src="image4.png" alt="Social Media" /></td>
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Characteristics of Digital Research

We live in an increasingly smart and connected environment and research methods and tools are changing.

Now people can monitor or be monitored and/or intervened with 24/7, on the fly and in real time.

Research isn’t exclusively an academic venture – industry, non profits and citizens are in the game.

We can now know ‘everything’ at a granular level using new digital technologies.

Promising data anonymity is not realistic.

Not all in this emerging digital research ecosystem are regulated and not all are socialized in ethical practices.
Key Ethical Legal and Social Areas

**Ethical**
- Research Literacy
- Cultural Literacy
- Data Literacy
- Bystander Rights
- Risk / Benefits

**Legal/Regulatory**
- OHRP
- FDA
- Liability
- Legitimacy
- Intellectual Property

**Societal**
- Downstream impact
- Unknown Unknowns
- Obligations to share
- Sociotechnical
# Precision Health/Medicine Considerations

<table>
<thead>
<tr>
<th>Category</th>
<th>Considerations</th>
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<tr>
<td><strong>Capacity Building</strong></td>
<td>• Accessible Education</td>
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<td></td>
<td>• Authentic Engagement</td>
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<tr>
<td><strong>Informed Consent</strong></td>
<td>• Research Literacy</td>
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<td></td>
<td>• Data Literacy</td>
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<tr>
<td><strong>Bystander Rights</strong></td>
<td>• Right to Consent</td>
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<td></td>
<td>• Governance</td>
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<tr>
<td><strong>Risk Assessment</strong></td>
<td>• Subjective</td>
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<td></td>
<td>• Evidence-based</td>
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<td><strong>Data Management</strong></td>
<td>• Security</td>
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<td></td>
<td>• Sharing - Return of Information</td>
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<tr>
<td><strong>Team Science</strong></td>
<td>• Common Language</td>
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<tr>
<td></td>
<td>• Involvement of Behavioral and Social Sciences</td>
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<tr>
<td><strong>Participants as Partners</strong></td>
<td>• Authentic Engagement</td>
</tr>
<tr>
<td></td>
<td>• Capacity Development</td>
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@cnbebker
We asked: How Might People Shape Ethical Practices?

1. **Tool Makers**
   - make innovative technologies used in health research

2. **Participants**
   - participate in studies
   - contribute data to advance knowledge

3. **Researchers**
   - conduct health studies using 21st century tools/methods

4. **IRBs**
   - reviews research risks and benefits to make sure participants are protected from harm
The CORE is a “research ethics” learning community where people share their expertise to shape ethical practices in the digital age.

The Resource Library
Search for and share IRB-approved research protocols, best practices, and institutional policies

The Network
Connect with members who share an interest in the ethical design and appropriate review of MISST research

The Q&A Forum
Post Questions and share interdisciplinary expertise (i.e. research, privacy, technology, regulations)
Acknowledgements
Precision Medicine/Health Ecosystem
Digital Research Making Headlines

Facebook Manipulated User News Feeds To Create Emotional Responses

Social Science One And How Top Journals View The Ethics Of Facebook Data Research

Facebook and Cambridge Analytica: What You Need to Know as Fallout Widens

Researchers Caused an Uproar By Publishing Data From 70,000 OkCupid Users

简体中文
What Might be Unknown Unknowns?

If AI is going to be the world’s doctor, it needs better textbooks
By Dave Gershgorn • September 6, 2018

Fitbit leans hard into healthcare with a new enterprise offering

Fitbit Care can help businesses and organizations keep employees healthy.
What Can You Do to Change the Culture?

Courtesy of DJ Patil
What Can Employees Do?

what if every technologist asked during their interview how the org deals with ethical issues?

What Can You Read?

https://www.amazon.com/dp/B07GTC8ZN7/ref=cm_sw_r_cp_ep_dp_fKyLBboYVWVH94
<table>
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<th>What Can Organizations Do?</th>
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<tr>
<td>Develop a community culture where it is safe for people to question the questionable practices</td>
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<tr>
<td>Develop a code of ethics as a community</td>
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<td>Get to know a tech ethicist</td>
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<td>Know where to find resources</td>
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<tr>
<td>Contribute to shaping ethical practices in the digital age</td>
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Questions?

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Sources

- http://fortune.com/2016/05/18/okcupid-data-research/
- https://docs.google.com/document/d/1SN6hYeKe3eRK6x9D0Sr7GpCA4nirpy03u68xG1A6NDs/edit#
- https://qz.com/1367177/if-ai-is-going-to-be-the-worlds-doctor-it-needs-better-textbooks/
Related Publications


