Qualcomm Institute at UC San Diego

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

Core Areas
- Culture
- Energy
- Environment
- Health
- Technology

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Center for Wireless and Population Health Systems

The Design Lab

A Center for Interdisciplinary Design

Focused on providing research, education, and community interaction to advance best practices in human-centered design and to address complex problems facing society.

Learn More

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Research on Research Ethics

**Research Literacy**: BRIC is education designed to increase research literacy and awareness of ethical and regulatory dimensions. The BRIC programs have received support from the NIH, NSF, ORI and local sources.

@UCSD_BRIC | bric.ucsd.edu

**Tech Ethics**: CORE is a learning community developed to elevate safe conversations about ethical, legal and social implications of research and innovation. The CORE initiative is supported by the Robert Wood Johnson Foundation.

@COREethics | thecore.ucsd.edu
# My Work

<table>
<thead>
<tr>
<th>NIH</th>
<th>NSF</th>
<th>ORI</th>
<th>RWJF</th>
<th>UC San Diego</th>
<th>ACTRI</th>
<th>CA-DOR</th>
<th>IBM</th>
</tr>
</thead>
</table>

**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 *Quantified Self Labs* and *Project Apollo participants* to reflect upon and apply ethical principles, design self-studies, analyze data and share results.

**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.
Many Determinants of Health

Current estimates indicate genetics explain an important but modest portion (~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 environmental factors, social circumstances, and healthcare utilization and delivery.

Image courtesy of Dr. Kevin Patrick, Principal Investigator, Health Data Exploration Project
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Tools used to capture personal data are pervasive and ubiquitous.
Increasing interest in studying “free-living” behavior “in the wild” prompts increased use of visual methods.
Sensing Methods

Passive, Pervasive, Ubiquitous
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>
</tr>
</thead>
<tbody>
<tr>
<td><img src="image1" alt="Wearable Cameras" /></td>
<td><img src="image2" alt="GPS Tracking" /></td>
<td><img src="image3" alt="Smart Phones" /></td>
<td><img src="image4" alt="Social Media" /></td>
</tr>
</tbody>
</table>

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Commercial Products

Subject to Fitbit's adherence with the privacy settings you select within the Fitbit Services, you hereby grant to Fitbit a perpetual, irrevocable, non-exclusive, worldwide, royalty-free license, with the right to sublicense, to reproduce, distribute, transmit, publicly perform, publicly display, digitally perform, modify, create derivative works of, and otherwise use and commercially exploit any text, photographs or other data and information you submit to the Fitbit Services ...


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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 may not be realistic.

- Not all in this emerging digital research ecosystem are regulated.
Your Computer May Know You Have Parkinson’s. Shall It Tell You?
What Might be Unknown Unknowns?

HEALTHYSELF, ALGORITHM

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.

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EMPIRICAL RESEARCH ON RESEARCH ETHICS

- IRB Content Analysis
  - Inconsistent Risk Assessment
  - Bystander Rights
  - Data Management

- IRB Focus Groups
  - Threats to Participant Privacy
  - IRB Expertise Gaps
  - Interest in Sharing Resources

- Participant Survey
  - Device Comfort
  - Consent Gaps
  - Privacy Bystanders & Participants

- Participant Digital Divide
  - Legal Risks
  - Consent Gaps
  - Social Implications

- Participant Terms & Conditions
  - Privacy Policy Missing
  - Above Avg. Reading Level
  - Not Accessible to Youth

- NIH RePORTER
  - Nature & Scope
  - MISST research increased 384% between 2005-2015
  - 35% PA
  - 31% Substance Use
  - 25% Contextual
  - 15.6% disease mgmt
Ethical, Legal and Social Implications

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

**Legal/Regulatory**
- OHRP
- FDA
- Liability
- Privacy Expectations
- Intellectual Property

**Societal**
- Downstream impact
- Unknown Unknowns
- Sociotechnical systems
- Privacy expectations

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How scientists can take the lead in establishing ethical practices for social media research

Abstract
Social media use has become ubiquitous in the United States, providing unprecedented opportunity for research. However, the rapidly evolving research landscape has far outpaced federal regulations for the protection of human subjects. Recent highly publicized scandals have raised legitimate

Using Participatory Design to Inform the Connected and Open Research Ethics (CORE) Commons

John Harlow¹ · Nadir Weibel² · Rasheed Al Kotob³ · Vincent Chan² · Cinnamon Bloss⁴ · Rubi Linares-Orozco⁵ · Michelle Takemoto⁴ · Camille Nebeker⁴

Received: 16 May 2018 / Accepted: 21 January 2019
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Engaging research participants to inform the ethical conduct of mobile imaging, pervasive sensing, and location tracking research

Camille Nebeker, EdD, MS  Tiffiny Lagare, MPH, Michelle Takemoto, BS, BA, PhDc, Brittany Lewars, MPH, Katie Crist, MPH, Cinnamon S. Bloss, PhD, Jacqueline Kerr, PhD

Author Notes

Translational Behavioral Medicine, Volume 6, Issue 4, 1 December 2016, Pages 577–586,
https://doi.org/10.1007/s13142-016-0426-4
Published: 29 September 2016
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)

**Related topics:**
- Mobile
- Imaging
- Pervasive Sensing
- Social Media
- Location Tracking

**Contact:**
- thecore.ucsd.edu
- @COREethics
- linkedin.com/company/core-ucsd
CORE Tools

Digital Health Decision-Making Checklist: Designed for Researchers

This checklist is intended to help researchers think through what technologies are appropriate for a study with respect to protecting research participants. The checklist was developed in consultation with researchers affiliated with the Society for Behavioral Medicine and other stakeholders who are interested in safe and responsible digital health research. We thank those who have contributed to the development of this checklist and welcome comments so that we can make iterative improvements. Your feedback is important and can be noted on our SurveyMonkey form. Thank you!
Tools for Researchers: Decision-Making Framework Development

Developed for Clinicians

Developed for Researchers

@cnebeker
### Ethical Principles

Place a check to indicate the ethical principle(s) to consider for each item within a domain evaluated.

<table>
<thead>
<tr>
<th>Domains</th>
<th>Autonomy</th>
<th>Beneficence</th>
<th>Justice</th>
</tr>
</thead>
<tbody>
<tr>
<td>- Ethical Principles</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Privacy</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>- Risks &amp; Benefits</td>
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<tr>
<td>- Access &amp; Usability</td>
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<tr>
<td>- Data Management</td>
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</tr>
<tr>
<td><strong>Privacy (respect for participants)</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Personal information collected is clearly stated</td>
<td></td>
<td>Yes/No/Unsure</td>
<td>Yes/No/Unsure</td>
</tr>
<tr>
<td>What data are shared is specified</td>
<td></td>
<td>Yes/No/Unsure</td>
<td>Yes/No/Unsure</td>
</tr>
<tr>
<td>With whom data are shared is stated</td>
<td></td>
<td>Yes/No/Unsure</td>
<td>Yes/No/Unsure</td>
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</tbody>
</table>

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<tr>
<th>Researcher Responsibility</th>
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<tbody>
<tr>
<td>Addressed in the Research Protocol</td>
</tr>
<tr>
<td>Addressed during the Informed Consent Process</td>
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</tbody>
</table>
Increase action within UC San Diego and across the UC system to proactively address the ethical, legal and societal implications of artificial intelligence and other emerging technologies.
Acknowledgements

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