Connected & Open Research Ethics

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Objectives

• Describe the changing landscape of 21st century research
• Identify key ethical challenges introduced by the use of new methods and tools.
• Describe stakeholders and their respective role in shaping the ethical conduct of 21st century research.
MISST

Mobile

Imaging

Pervasive Sensing

Social Media

Location Tracking

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@UCSDtheCORE
MISST data collection methods are challenging researchers and Institutional Review Boards (IRBs) due to new ethical issues introduced by these technologies.
A design-thinking process driven by participatory action research

Ideate
Define
Prototype
Test
Repeat
Empathize
Stakeholder Engagement

IRB + Researchers
Methods

• Qualitative research methods are being used to guide the CORE content and functionality. Stakeholders are active participants in this process.

• Stakeholders (i.e., IRB affiliates, researchers) are contributing to the CORE design.

• Six focus groups were conducted with IRB stakeholders in fall 2015.
Formative Research

- What are the risks?
- How to stay current?
- Dynamic solutions?
Analysis and Findings

- Audio recordings were transcribed and analyzed using qualitative methods.
- A growing demand for greater guidance and expertise to inform protocols and best practices for research involving MISST technologies.
- Challenges included unfamiliarity with MISST technologies and related difficulties determining the potential risks to research subjects.
Our solution:

The CORE Platform
where stakeholders can
access a Q&A Forum,
contribute to dynamic “best
practices” within a Resource
Library and Network with
experts to facilitate the ethical
design and review of MISST
research.
CORE Main Features

• The CORE platform will host a Q&A Forum to facilitate stakeholder dialogue.

• A Resource Library (i.e., protocols, consent language) will be accessible to stakeholders designing or reviewing MISST-related research studies.

• A Network directory
What can CORE do?

IRBs and Researchers using MISST methods

Resource Library
House best practices (i.e., protocols and consent language)

Q&A Forum
IRBs & Researchers share questions/expertise

Network
Interdisciplinary expertise (i.e., research, privacy, technology, regs.)
CORE Benefits

• Assist researchers to design ethical research
• Assist IRBs in the timely and relevant review
• Potential application to other emerging fields (i.e., ‘omics’)
• Credible resource for diverse research organizations
  • Academic
  • Industry
  • Community
Join the CORE Network:

thecore.ucsd.edu/network

View CORE Tutorial:

bit.ly/COREtutorial
Mobile Imaging, pervasive Sensing, Social-media and location Tracking (MISST) data collection methods are challenging researchers and Institutional Review Boards (IRBs) due to new ethical, legal and social implications (ELSI) introduced. The Connected and Open Research Ethics (CORE) project is working with stakeholders, including IRBs and researchers, to address these challenges.

Qualitative research methods are being used to guide the CORE content and functionality. Stakeholders are active participants in this process.

- Stakeholders (i.e., IRB affiliates, researchers) are contributing to the CORE design.
- Six focus groups were conducted with IRB stakeholders in fall 2015.

The CORE platform will host a discussion forum to facilitate stakeholder dialogue. Likewise, a library of resources (i.e., protocols, consent language) will be accessible to stakeholders designing or reviewing MISST-related research studies.

- Audio recordings were transcribed and analyzed using qualitative methods.
- A growing demand for greater guidance and expertise to inform protocols and best practices for research involving MISST technologies.
- Challenges included unfamiliarity with MISST technologies and related difficulties determining the potential risks to research subjects.