CORE

Connected and 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.

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Imaging

Mobile

MISST

Pervasive Sensing

Social Media
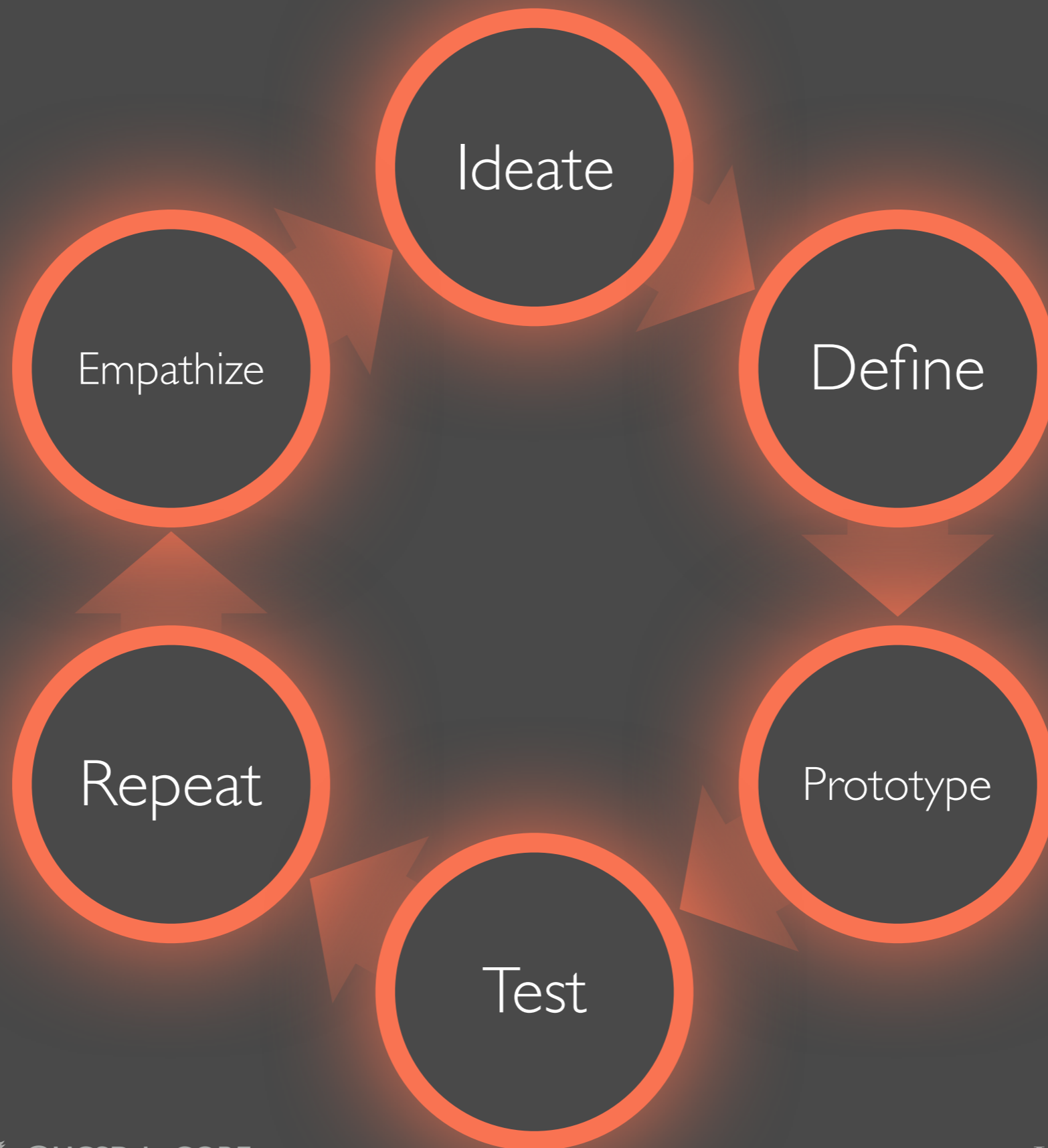
Location Tracking

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MISST data collection methods are challenging researchers and Institutional Review Boards (IRBs) due to new ethical issues introduced by these technologies

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A design-thinking process driven by participatory action research

Ideate

Define

Empathize

Prototype

Repeat

Test

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Stakeholder Engagement

IRB + Researchers

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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.

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Formative Research

- What are the risks?

- How to stay current?

- Dynamic solutions?

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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.

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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.)

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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

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thecore.ucsd.edu/network

View CORE Tutorial:

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thecore@eng.ucsd.edu

CORE
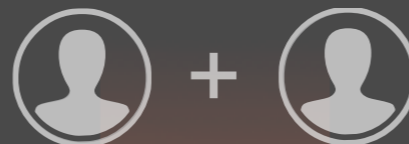## Connected and Open Research Ethics

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Background

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.

IRB + Researchers

Stakeholder-engaged participatory approach

Formative Research:
- Risk identification, strategies, platform requirements

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.

Evaluate the CORE functionality and utility.

Objective

The CORE Platform is 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.

Test and Improve

Driven by Participatory Action Research

Design & Build

Co-design and build the CORE prototype platform that will house MISST resources.

Analysis & Results

- 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.

Benefits

National resource

Facilitate ethical design and review of MISST research

Potential application to other emerging fields (i.e.,'omics')

Credible resource for diverse research organizations

Academic

Industry

Community

Deliverables

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.)

Use results to inform scaling and sustaining

Conclusion

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.

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