Human Ethics Considerations

Nathaniel Osgood

University of Saskatchewan

Measuring and Modeling Health Behavior with Smartphone Mediated Data Collection

August 9, 2016

Notable Issues

- Particularly sensitive information being collected
  - Names of devices (e.g., via Bluetooth)
  - Geographic information
- Network recruitment requires blinded referrals
- Collectively identifiable information
- Notifiable behavior
- Lawbreaking activities
- Smartphone use in vehicles
- Special ethics handling required in context of clinician-patient relationship
  - Advised: separate notification or study personnel to approach
- Tighter scrutiny over intervention studies

Tips

- Engage early, engage often with IRB/REB
  - Develop a relationship with the IRB/REB
- Point IRBs/REB to precedent (EULAs, published work, …)
- Warn in consent form about legal obligations wrt subpoenas
- Refer IRBs/REB to other IRBs/REBs with history of handling
- Reuse earlier documentation
- Use pilots and feasibility studies prior to large-scale studies
- Be patient (IRBs/REB learn over time)
  - Err on side of complying with concerns
- Consider tiered opt-in strategies

Some Points for Discussion with IRBs

- Precedent with other studies

- Public nature of much visible information

- Capacity to opt out

- Commercial exploitation of such information

Support for ongoing and retroactive participant opt-out

- Opting out from a specific data source

- Pausing data collection

- Dropping out of study

- Option to deleting the data anytime after the study: (Data ownership: Data is generated by participants and owned by them, and they should always have a way to access it, and delete it if needed.)

Data Escrow-Based Studies:
Addressing Concerns via Contingent Use

- Some potential participants
  - May be uncomfortable with providing sensor and self-reported data in general
  - May be comfortable with data being used in urgent contexts
- One option is to guarantee participants that
  - Data will not be examined except in stated contingencies
  - Data that is not analyzed will be deleted after a specified period of time