New Technologies :
Moving Targets in Research Ethics

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Objective

- Generate awareness about the application of ethical principles with some new technologies.
  - Technologies generally limited to:
    - Mobile device applications
    - Mobile devices (e.g. smartphones, wearable technologies, eHealth devices)
    - Online questionnaires
    - Online focus groups

Outline

- Introduction

- Recruitment

- Informed Consent

- Weighing Risks

- Right to Privacy

- Resources

Introduction

Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS 2), 2010

✓ Underlying value:
  ✓ *Respect for human dignity*

✓ Expressed through three core principles:
  ✓ **Respect for Persons**
  ✓ **Concern for Welfare**
  ✓ **Justice**

Recruitment

Ethical Principal of Justice

- **Do new technologies facilitate recruitment?**
    - Online communities

- **Do new technologies ensure that all eligible participants are able to take part?**
    - Do they have easy access to technology (e.g. internet)?
    - Are potential participants familiar with the use of the technology?

Recruitment (Cont'd)

Respect for persons

- How are participants recruited?
  - In person?
  - Online?
    - Where are advertisements placed?
    - What information must advertisements contain?

Informed Consent

Ethical Principal of Respect for Persons

- How should online consent be obtained?

- What information should be provided?
    - How to dispel possibility of therapeutic misconception?

Informed Consent (Cont'd)

Ethical Principal of Respect for Persons

- Authenticity of consent

Weighing Risks

Concern for Welfare

- Risks
  - Severity
  - Probability

Weighing Risks (Cont'd)

Concern for Welfare

Risks

- Right to privacy
  - Disclosure of health information
  - Inappropriate disclosures
    - Text messaging reminders?
  - Tracking and monitoring
    - IP addresses, location
  - Expectation of privacy
  - Security

Weighing Risks (Cont'd)

Concern for Welfare

- Risks
  - Social
    - Stigma
  - Psychological
    - Lack of direct contact (Cohen, 2013)
      - Follow up
      - De-briefing
      - Referral
  - Other

Weighing Risks (Cont'd)

Concern for Welfare

- Risks
  - Is the technology burdensome?
    - E.g. Malfunction, theft, etc.
  - Can participants be assured access to mobile devices, applications, after a study has ended, if they improve health outcomes?
    - E.g. eHealth devices, smart phones

References

- **TCPS2 (2010). http://www.pre.ethics.gc.ca/eng/policy-politique/initiatives/tcps2-eptc2/Default/**

- **Labrique, A., Kirk, G. Westergaard, R. & Merritt, M. (2013). Ethical Issues in mHealth Research Involving Persons Living with HIV/AIDS and Substance Abuse, Aids Research and Treatment, http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3792525/**