Disclaimer

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Overview

• Privacy & Confidentiality: Definitions
• Why Privacy & Confidentiality Matter
  – Respect
  – Risks of Harm
• Respecting Privacy in Research
• Ensuring Confidentiality
Privacy and Confidentiality

• Privacy
  – Limiting unauthorized, active or passive disclosure of personal, sensitive information

• Confidentiality
  – Protection of private information shared with investigator
Privacy and Confidentiality

Why are we concerned, morally speaking?

• Respect for persons
  – Respect desires of individuals to keep certain information private and their autonomy to choose who should have access to private information
  – Keep promises that private information shared in the context of research will be kept confidential
Privacy and Confidentiality

Why are we concerned, morally speaking?

• **Risk of harm**
  – The desire to keep certain information private can stem from a fear or real threat of harm, should that information become more widely known.
  – Obligation to respect privacy and avoid breaches of confidentiality increases as sensitivity of information increases (e.g. drug use, HIV status, etc..)
Risk of Harm

• Types of Individual Harm
  – Physical
  – Psychological
  – Social
    • Risks to reputation/stigma
      – Breaches of confidentiality
  – Economic
Risk of Harm

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Risk of Harm

• Types of Community Harm
  – Social
    • Risks to Reputation/Stigma
  – Economic
  – Exploitation
    • Harms to individuals by virtue of group membership
    • Harms to structured groups with ongoing existence/interests
Risk of Harm

- Types of Community Harm
  - Research examining the prevalence of an “alcoholism” gene among different racial/ethnic groups
  - Prevalence studies showing higher rates of mental illness in certain subgroups of population
Respecting Privacy

• Privacy
  – How will subjects be recruited?
    • Personal invitation from Investigator
    • Physician referral
    • Chart review
      – Email/Letter from physician
      – Email/Letter from investigator
Respecting Privacy

• Privacy
  – Where will research be conducted?
    • Private home
      – In-person
      – phone
    • Private office
    • Local clinic
HIV Vaccine Study
Respecting Privacy

• Privacy
  – Logistics of interview
    • How long will the interview last?
    • Who will conduct the interview?
    • Will the interview be tape/video recorded?
Respecting Privacy

• Privacy
  – Does participation alone lead to stigma?
Privacy

• Privacy
  – For longitudinal studies, how will subjects be contacted for future visits
    • Letter/Email
    • Phone
    • Visit to home
HIV Vaccine Study

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Confidentiality

- Protection of private information shared with investigator
Confidentiality

- Is there a need to collect identifiable information?
- Does signing the consent form and/or the consent form itself create an opportunity for a breach?
Confidentiality

• Confidentiality
  – Appropriate data management requires standard operating procedures/infrastructure
    • Data transport
    • Locking file cabinets/office
    • Computer that can be pass-word protected
    • Encryption of data
Confidentiality

• Procedures to Limit Breach of Confidentiality
  – Research staff training
  – Data management
    • Research materials should be labeled with a unique identifier rather than names
    • Keep list that links name and unique identifier separate and both of these separate from consent form
Privacy and Confidentiality

• Other considerations
  – Cultural norms differ
  – Partner notification
  – Publication of results may disclose sensitive information about an entire community
Privacy and Confidentiality

• Collect identifiable information only if you have a good reason to do so!