IRB Accreditation and Local IRB Operations

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"privacy has several meanings and guises, depending on the period and location with which one is dealing."  

*Hanneke Ronnes*
Hot issues in the continuing debate on privacy and confidentiality

- Consumer guidelines
- User-generated content
- Third-party applications
- Data sharing summit
Human Subjects Guidelines ~
International Perspectives

- International Compilation of Human Subject Research Protections
- Research Ethics Committees in Europe
- CESSDA (with thanks to Hillary Beedham)
Evaluation and Accreditation

- Association for the Accreditation of Human Research Protection Programs
  - Benefit to the institution
  - Benefit to review boards
  - Benefit to the researcher
  - Benefit to research subjects
  - Benefit to data access and data sharing?
Effect of accreditation on local practices

Changes in the way public data are defined!

Public data is not covered by human subjects research guidelines.
Human Subjects Decision Tree

Data has PID

PID is coded separately from data

Does PI have access?

Yes

Data is pre-existing AND subjects cannot be identified

NO

Expedited or Full review

Yes

Exempt Certification

No

NOT human subjects research

Data has no PID

Data is pre-existing AND subjects cannot be identified

Exempt Certification

Certification
Researchers, Archives and Review Boards

- Change in perspective
- Push-back from faculty
- Constant communication
- Next steps for IASSIST
Next Steps for IASSIST

- Engage the ethics review groups in discussion
- Train and educate our users and ourselves
- Work to develop a global “conscience” that leads to common practices
- Communicate with other constituencies
Interest group on human subjects protections

- Role and function of human subjects review boards
- Influence on data management, dissemination, curation and preservation
- Issues related to protection of human subjects laws and policies established in IASSIST member countries
Thank You!

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