JERHRE NOTES

Concepts, Tools, and Resources for Solving Ethical Problems in Human Research

What to Share and What to Redact:
Protecting Confidentiality while Preserving Usefulness

There are many reasons to share data, either as donor or recipient. Funding agencies and editors may require data sharing as a cost-effective way to build scientific knowledge. Secondary analysts can build on these existing data, develop and test new theories, extend preliminary findings, and answer new empirical questions. Unlike physical scientists who have pioneered data sharing, human subjects researchers must solve some challenging problems of confidentiality before sharing can occur. For example:

- If descriptors of the subjects or settings would enable one to deduce identities, confidentiality may be breached.
- If descriptors needed by secondary users are removed, the data may lose analytic value.
- It is costly to supervise qualified researchers who are given access to identified data.
- Data recipients who do not understand the de-identification measures used by donors may make serious analytic errors.

Suggested solutions to these and other data sharing problems appear in the following ***JERHRE*** articles:

Zarate, A., & Zayatz, L. (2006). Essentials of the Disclosure Review Process: A Federal Perspective. *JERHRE, 1*(3), 51 – 62.

O'Rourke, J., Roehrig, S., Heeringa, S, *et al.* (2006). Solving problems of disclosure risk while retaining key analytical uses of publicly released microdata. *JERHRE, 1*(3), 63 – 84.

Rodgers, W., & Nolte, M. (2006). Solving Problems of Disclosure Risk in an Academic Setting: Using a Combination of Restricted Data and Restricted Access Methods. *JERHRE, 1*(3), 85-98.

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