

# The Ethics of Data Access, Use, and Sharing for Human Subjects Research

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# Research Exceptionalism

- Worries about security breaches
- Concerns about intentional misbehavior by researchers
- Changing social norms about privacy and self-disclosure
- Context-specific differences in the boundary between public and private space
- Notions of harm sometimes theoretical, not material

# Individual Rights vs. Common Good

- Traditional paradigms for subject protection emphasize individual autonomy at expense of beneficence and justice
- Limits on sharing and use imposed to address historical imperatives related to prior unethical acts punish everyone via opportunity costs, and (ironically) diminish autonomy
- Communitarianism (in this case, “informational altruism”) should be encouraged
- Given conditions of scarce resources, the expense of collecting new data (specimens) also is a relevant consideration