



Privacy and Confidentiality in Human Subject Research

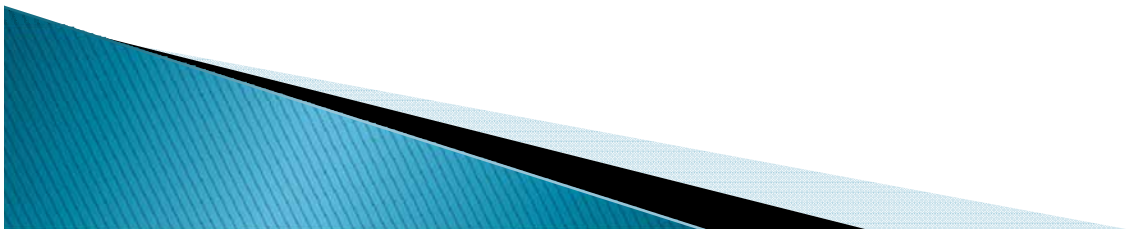
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Privacy

- ▶ A concept from common morality.
- ▶ Identifies areas that are safe guarded from the scrutiny and intervention of others.
- ▶ Marked off from public space by natural boundaries.
- ▶ Protected from the intrusion of others by laws and social practices and social sanctions.



Domains of Privacy

Inside:

- ▶ My thoughts
- ▶ My body
- ▶ My room
- ▶ My home
- ▶ My computer



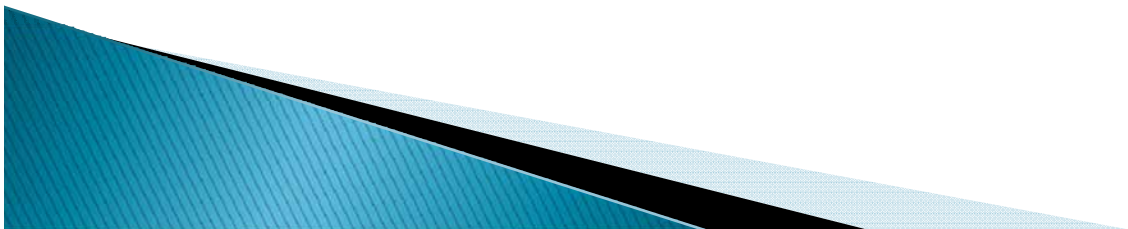
Parts of the Body



Domains separated by natural boundaries.

Privacy

- ▶ In common morality, privacy protection is **not absolute**.
- ▶ Primarily, privacy is protected from unwanted government intrusion.
- ▶ Exceptions from privacy protection are allowed for the sake of public good.
- ▶ Aside from protection from government intrusion, the task of maintaining privacy is largely left in the hands of individuals.



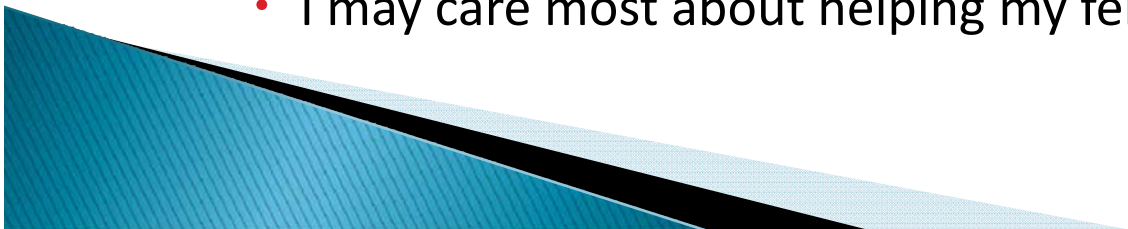


If you wanted to protect your child from harm, what would your bike riding policy be?

Would that be a **good** policy?
Would it be **reasonable**?

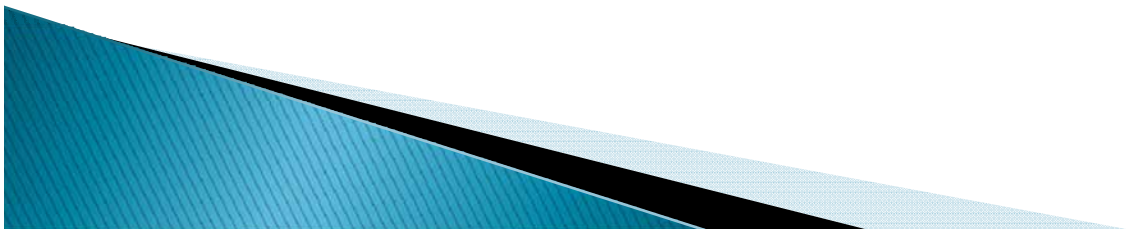
Privacy protections

- ▶ Such as:
 - HIPPA
 - Absolute guarantee of no breaches in privacy
- ▶ Are unreasonable.
- ▶ Fail to take into account other reasonable and legitimate social and personal goals.
- ▶ Paternalistic (what Madison Powers has called Marxist)
 - I may not care about protecting the privacy of my samples.
 - I may care more about advancing biomedical knowledge than I do about the absolute protection of my privacy.
 - I may care most about helping my fellow man.



Confidentiality

- ▶ A concept from the professions:
 - Priesthood
 - Law
 - Medicine
- ▶ Identifies a **space for professional interactions** where privacy is safe guarded from the scrutiny and intervention of others.
- ▶ Marked off from public space by constructed, non-natural boundaries.



Confidentiality



Privacy or Confidentiality

- “**Privacy,**” should be distinguished from the concept of medical “**confidentiality**”
- In treatment & biomedical research, information about people should be treated according to existing standards of confidentiality that govern other medical interactions.
 - Share information on a need to know basis.
 - Participant and public safety, as well as providing for the public good, may at times be more important than preserving privacy.



Because -- Confidentiality is already the prevailing standard in research that is given other names:

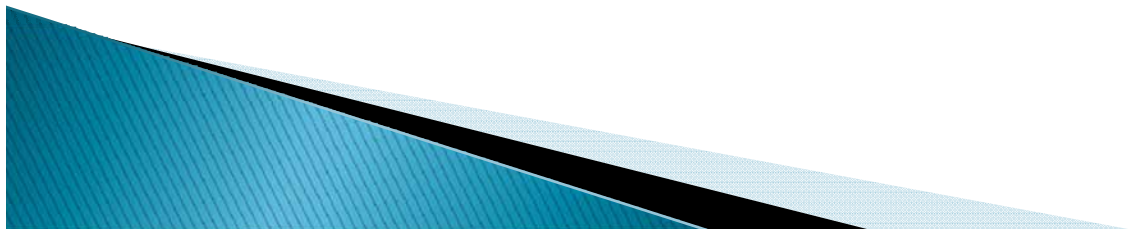
- ▶ Public health surveillance
- ▶ Quality assurance
- ▶ Quality improvement
- ▶ Registries

Have breaches in confidentiality caused harm?



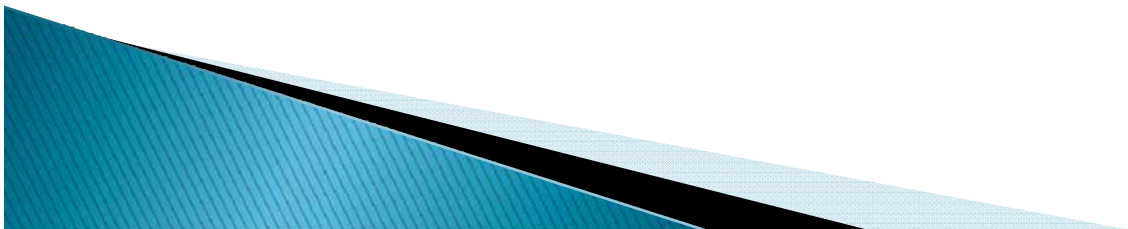
Because -- Growing need for more widespread research participation:

- ▶ Human microbiome research
- ▶ Genomics
- ▶ Personalized medicine
- ▶ New research techniques



Conclusion -- Confidentiality

- ▶ When medical confidentiality is upheld in medical treatment and research:
 - People are not harmed.
 - Research can provide a significant public good.



Conclusion -- Confidentiality

Keeping the desired benefits in mind –

- ▶ With appropriate confidentiality limitations, data from biobanks and sample banks should be shared in order to significantly increase the research use of samples.
- ▶ Identifying information should be limited to reflect the need to know (including the need to recontact).
- ▶ Where possible, and with informed consent when samples are taken, materials remaining from clinical uses and other research uses should be available for additional research purposes.

