

The limited potential of IRBs to protect marginalized communities

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Research that harms marginalized communities

- Hahn et al. (2015). Structural connectivity networks of transgender people. *Cerebral Cortex*, 25, 3527-3534.
 - “We investigated the structural connectome of 23 female-to-male (FtM) and 21 male-to-female (MtF) transgender patients before hormone therapy as compared with 25 female and 25 male healthy controls.” (3527)
 - “Our understanding of sex differences in the human brain is reflected in gender differences and endocrine influences in the prevalence and treatment of various psychiatric disorders (Bao and Swaab 2011). In this context, it is particularly interesting to study gender identity disorder.” (3527)
 - “This study was approved by the Ethics Committee of the Medical University of Vienna, and procedures were performed according to the Declaration of Helsinki.” (3528)

Terminology:
transsexual

Disease/disorder

Patients vs.
healthy controls

Interesting
for whom?

Harms:
Pathologizing transgender identity
Knowledge for scientific curiosity rather than to help
transgender people

How were participants recruited?
How was the purpose of the study
described?

Human subjects research: balancing risks and benefits

- Institutional Review Boards (IRBs) or Research Ethics Committees (RECs)
 - Review research projects (experimental protocols) prior to conducting experiment
 - Good science (scientifically valid)
 - Protects human research subjects
 - Risk to subject
 - Contributes to generalizable knowledge (scientific value, social value)
 - Benefit – if not to subject but to science, medicine, or society (Binik and Hey 2019)
- Problem: clinical research as model
 - What about social or behavioral research?



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Risk/benefit table (Adapted from Edwards 2010)

	Low risk for subjects	High risk for subjects
Small benefit to society	Controversial	Unacceptable
Large benefit to society	Acceptable	Controversial



Edwards: “wasted opportunities”

“The committee could thus effectively and implicitly prioritize research by rejecting research it judges is of little value (whatever the risk to subjects)” (99-100).

Who is benefiting from the research? Who is being harmed?

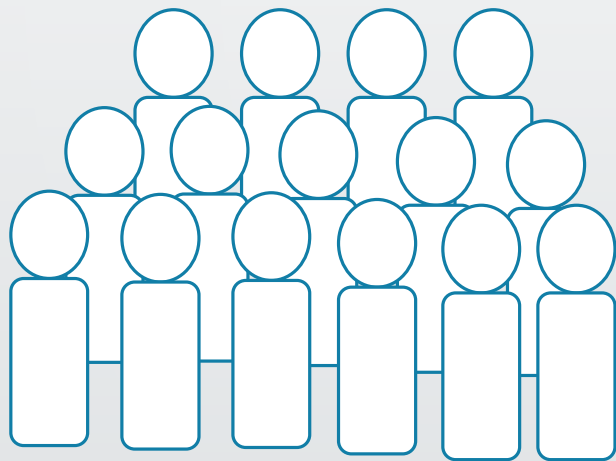
What if the research may help some community and harm another community?

Who gets to define the social benefit?

Who gets to define the social benefit?

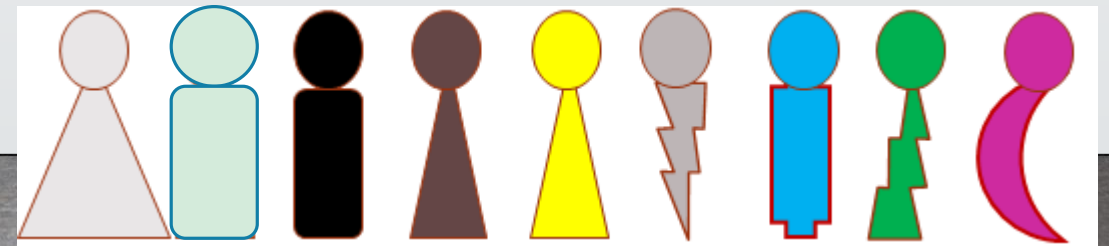
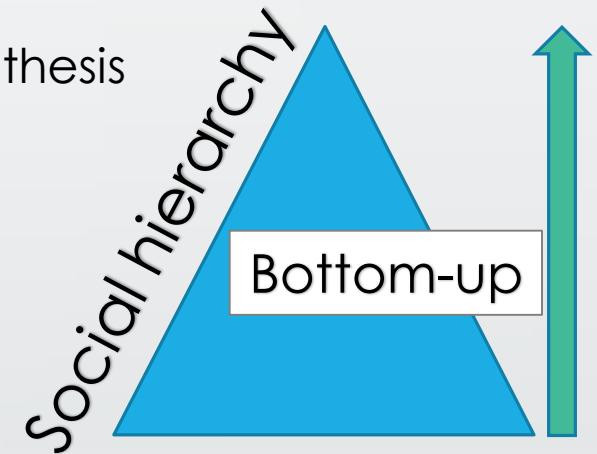
Traditional approach

- Homogeneous
 - White, cisgender male, heterosexual, middle-class, etc.



Feminist standpoint theory

- Intemann 2010
 1. Situated knowledge thesis
 2. Epistemic advantage thesis
 3. Methodological thesis



Social benefit?

- Social benefit may not be same for all.
- IRBs should seek to include perspective of those most affected by the research.
 - Precedent: protected communities
 - Neurodiversity example: Autistic Self-Advocacy Network: Nothing About Us Without Us (<https://autisticadvocacy.org/about-asan/what-we-believe/>)
 - Transgender neuroimaging suggestions
- Expanding on the bioethical principle of justice (Belmont Report)
- Objection: Assessing scientific value is out of the IRB's scope
 - Scientific value vs. social value?

Limits, objections

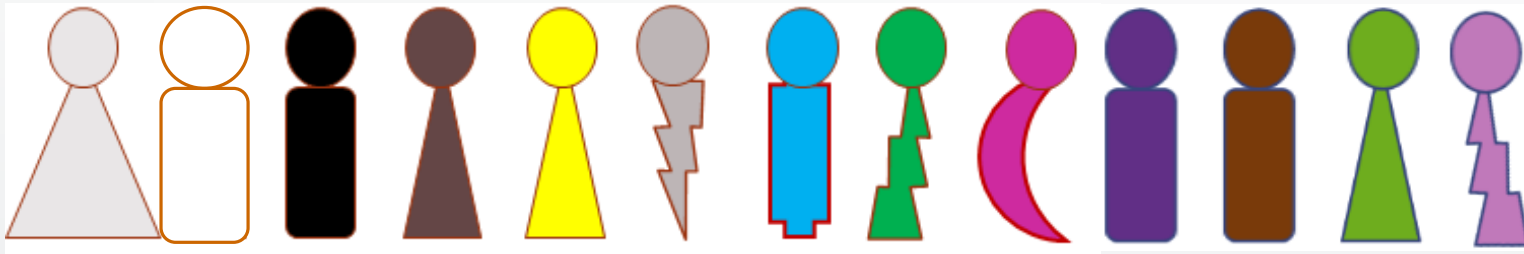
- Academic freedom
- Different conceptions of science (value-free vs. value-laden)
- Administrative problems (REC/IRB members overworked and unpaid)
- Non-scientific members are outnumbered and undervalued (Bauer, 2001; Sengupta and Lo, 2003)
- Lack of training (Sengupta and Lo, 2003)
- Lack of diversity (Sengupta and Lo, 2003)
- Human research – doesn't address research in animals that is meant to be translated to human cases
- Blanket consent forms – re-analyses of data collected for one purpose may not undergo IRB review if anonymized

Addressed on previous slide

Discussed in philosophy of science

- Problems aren't new
- Draws attention to continuing need to value and support research ethics
 - Scientists
 - Institutions
 - Funding agencies

Just recognizing the limitations at this time



Thank you!

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Disclosures: None

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