Ethical Principles for Research with Native American tribes / communities / people

IRB 101sm
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The Belmont Report (review)

The three basic ethical principles underlying its proposed regulations (and their application):

- Respect for persons (application: Informed Consent)
- Beneficence (application: Maximize Potential Benefits —and- Minimize Potential Risks [Harms])
- Justice (Equitable Selection of people in the research)

(The Belmont Report in effect asked: “Under what circumstances is research ethical?”, the answer - When, & only when, the research complies with all 3 principles and applies them.


Ethical Principles & Applications-1

Principles: Apply to Individual

Respect: Individual's consent

Beneficial: Max individual benefit and Minimize individual risk

Justice: Appropriate individuals
The Belmont Report - 1979

- “Risks and benefits of research may affect the individual subjects, the families of the individual subjects, and society at large (or special groups of subjects in society).”

National Bioethics Advisory Commission*: “Risks to Those Other Than Participants”

- “Risks may accrue not only to research participants, but also to persons not directly involved in research, such as to the participants’ family, loved ones, other contacts, social groups, and to society in general.”

* Ethical and Policy Issues in Research Involving Human Participants. 2001

Ethical Principles & Applications-2

<table>
<thead>
<tr>
<th>Principles: Apply to Individuals</th>
<th>Apply to Communities</th>
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<tr>
<td>Respect:</td>
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<td>Individual’s consent</td>
<td>Community’s consent</td>
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<td>Beneficial:</td>
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<td>Max individual benefit</td>
<td>Max benefit community</td>
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<td>and Minimize individual risk</td>
<td>Minimize community risk</td>
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<td>Justice:</td>
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<tr>
<td>Appropriate individuals</td>
<td>Appropriate communities</td>
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Types of Potential Harms ("Risks")-1

Types*
- Physical
- Psychological
- Social
- Economic
- Legal
- Dignitary

  https://repository.library.georgetown.edu/handle/10822/559360

Types of Potential Harms ("Risks")-2

Types | Individual
--- | ---
Physical | injury
Psychological | suffering
Social | external-stigmatization
Economic | no insurance
Legal | arrest
Dignitary | no consent

Types of Potential Harms ("Risks")-3

Types | Individual | Community
--- | --- | ---
Physical | injury | infection
Psychological | suffering | self-stigmatization
Social | external-stigmatization | external-stigmatization
Economic | no insurance | lower bond rating
Legal | arrest | attack legal status
Dignitary | no consent | no consent
Tribal-defined benefits in research

- Protect and benefit the Tribe/community
- Respect elders & knowledge of Tribe/community
- Promote resiliency, assist Tribe/community in its activation and problem finding/addressing/solving
- Respect Tribe/communities, strengths, and survival
- Incorporate traditional spirituality into the project
- Have pride in community’s role in the CBPR project
- Have ownership in/of the CBPR project
- Respect/promote Tribal sovereignty/community power
- Express hope for the Tribe’s/community’s future

Tribal-defined benefits in research

Others ....

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