

Avoiding Group Harms - U.S. Research Perspectives

Content Author

- **Helen McGough, MA**
University of Washington (ret.)

Introduction

The *Belmont Report* emphasizes individual autonomy, but also recognizes that it is not fair or just to select research subjects only from classes of people who are conveniently available, susceptible to manipulation, or compromised. The federal regulations also require that selection of human research subjects must be equitable and identify some specific vulnerable populations (such as, prisoners, pregnant women, fetuses, children, mentally disabled persons, and educationally or economically disadvantaged persons). However, these are not the only groups that could be harmed. In some cases, when vulnerable populations are involved in research, the harms may fall not necessarily on the individual subjects, but on the group as a whole - including those who did not actually take part in the research. While neither the *Belmont Report* nor the federal regulations mention this risk specifically, it is important to consider. The dangers of not considering this issue before conducting research are:

- That actual and irremediable harm may come to the larger group or community
- That members of the group may refuse to take part in valuable and useful research in the future

This module provides examples of situations in which research may have unintended consequences that harm groups of people and describes some steps researchers can take to reduce the risks of such harm.

Learning Objectives

By the end of this module, you should be able to:

- Describe some distinct groups or communities of people who are vulnerable.
- Identify examples of research that has harmed groups.
- Identify strategies that researchers can take to reduce the risk of group harms.

What Is Meant by "Groups?"

Researchers use the terms "populations," "groups," and "communities" in a variety of ways. Sometimes people are members of ethnic or racial groups (such as, Black or African-American, Hispanic, or Bantu), or religious groups (such as, Islamic, Taoist, or Christian Scientist). They

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may belong to groups described by geographic location (such as, New Yorkers, Parisians, or Paraguayans), or by occupation (such as, agricultural workers, physicians, or teachers). Other groups may be defined by physical condition (such as, obese, sight-impaired, or diabetic), or by behavior (such as, smokers, men who have sex with other men, or marathon runners). Each individual person often belongs to many such overlapping groups. People may choose to describe themselves as members of groups, or others may assign membership to them.

What Is Meant by "Harms?"

Because of their special position in society, some groups may be at increased risk of suffering harm that may result if individual group members take part in research, including those who:

- Have suffered and continue to suffer discrimination (such as, Blacks or African-Americans, American Indians, and Alaska Natives);
- Have less access to education, social services, and healthcare (such as, underserved and low-income populations); or
- May be behaviorally or politically stigmatized (such as, commercial sex workers, injection drug users, or members of religious cults).



Group harms result when many or all of the group members are harmed, including those who did not consent to being research subjects. Harms that can result from research findings include:

- **Economic** - group loses access to economic services, employment
- **Political** - group is disenfranchised
- **Social** - group is stigmatized or discriminated against in social arenas
- **Educational** - group may be identified as less educable or not worthy of education
- **Genetic determinism** - group is assumed to have certain genetic characteristics or relationships
- **Cultural** - group norms and values are violated

Each of these harms may also result in emotional distress (such as, damage to sense of self-worth, depression, and loss of dignity) among group members who did not take part in the research. Some of these harms, especially social, psychological, and political harms, may be difficult to predict, measure, and remediate. However, this makes it even more important that researchers pay attention to the possibility that these harms may occur.

Examples of How Research Has Harmed Groups In The Past

Although some studies that have resulted in harms to groups were designed poorly, even well designed studies can have unintended consequences for members of specific groups that could have been avoided. What follows are examples of studies that have had negative effects on groups of people who were not necessarily study subjects.

- Publication of research results conducted in Ashkenazi Jewish families contributed to the un-validated assumption that Jews are more prone to genetic defects and diseases. There was concern in the Ashkenazi Jewish community that this information would lead to health and life insurance discrimination, even for those who did not undergo genetic testing (Phillips et al. 2000, 376-83).
- Publication of the results from a study purporting to show high rates of alcoholism among Alaska Native residents of Barrow, Alaska resulted in a negative economic rating for the city's bond with subsequent economic effect on all Barrow residents (Klausner and Foulks 1982).
- Several studies purporting to study the intelligence of various racial groups (Herrnstein and Murray 1994) have resulted in stigmatization of these groups. Many of these studies were poorly designed and resulted in inappropriate characterizations of members of racial groups as less educable.
- During the Cold War, the U.S. Army supported a social science study (Project CAMELOT) to improve understanding of the processes of social change to serve the Army's counterinsurgency program (McFate 2005, 24-38). Conducted in Chile, the U.S. government cancelled the project in 1965 after protests in the Chilean press and a complaint from the Chilean government over concerns that the project was designed to undermine wars of liberation and aid the U.S. government in channeling or suppressing social change.

Unfortunately, even well intentioned studies can result in low levels of participation in future research because of the distrust and fears of scientific research engendered by these unintended consequences.

What Steps Can Researchers Take to Minimize These Risks of Group Harms?

By asking the following questions of themselves and their research, researchers can reduce the risks of group harms.

1. What are the possible harms that could result from my research? Is it possible that there will be harms to the group(s) of which my research subjects are members?
2. Are there any possible unintended consequences of my research such as stigmatization or discrimination?

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3. If I were a member of this group, how would I feel about the research findings - positive and negative?
4. Do the potential benefits of my research outweigh the harms to the subjects and to the population?
5. Can I predict how the results of my research findings could be used by others (such as, the media or government)?

The answers to these questions can lead researchers to take actions to reduce the risk of group harms.

Additional Steps

- **Community consultation** - Researchers can work with the community of interest to make sure that:
 - The group has an opportunity to identify harms the researcher may not have considered
 - The researcher understands and has taken steps to minimize the risk of the harms that might result
 - The group understands the potential effects of the harms on both individuals and the group
- **Collaborative Institutional Review Board (IRB) review** - Some groups (such as tribes, retirement communities, and school districts) have their own ethical review process for research. Researchers who are working with these groups should apply to the local ethics review body for review and approval of their research.
- **Plan ongoing consultation** - Researchers should make sure that group leaders are provided with accurate information about the research as it progresses and changes. Researchers must anticipate that their research may have to change or even stop in order to minimize potential harms
- **Plan disclosure of research results ahead of time** - Most group harms result from inappropriate disclosure of research results. Researchers should work with the group to inform the members about how the researcher plans to disclose the research results and what the implications of disclosure may be. This approach may reduce the possibility of harms resulting to the group as the research is published or presented, and will reduce the chance of unpleasant surprises for the group or the researcher along the way.
- **Make benefits available to groups** - Researchers must design studies so that they will provide benefits to the communities involved.



Summary

It is essential that researchers evaluate whether or not their research could result in potential group harms and, if this is a possibility, take appropriate steps to minimize this risk.

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Perspectives

Dr. Collin has designed a research plan to categorize and describe oncologists' opinions, perceptions, and participation in physician-assisted deaths for terminally ill patients. He plans to collect data by distributing an anonymous survey to members of one of the professional associations of oncologists in the U.S. The survey will ask subjects to identify the region of the United States where their practice is located (New England, Mid-Atlantic, etc.), their race and ethnicity, gender, religious affiliation (if any), and the decade during which they were born. Dr. Collin intends to present the data in a nation-wide aggregate format along with select subsets. Dr. Collin recognizes that the research may garner a lot of attention and has taken steps to minimize the likelihood that individual physicians can be identified.

- [What actions, if any, could be taken in order to minimize the risk of harm to physicians who participate in this research?](#)

Before designing and conducting the research Dr. Collin could meet with groups of the association's members to get their feedback and perspective. He also could meet with them to discuss the results prior to publication. These strategies of ongoing consultation would engage the subject population and give them the opportunity to weigh in on the design of the research. The association's members could also advise Dr. Collin about potential harms that he may not have considered and prepare the community for the potential impact of the results of the research.

References

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