Avoiding Group Harms - International Research Perspectives

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Introduction

In some cases, when individuals who belong to vulnerable populations are involved in research, harm may come not necessarily to the individual subjects but to the group as a whole - including those who did not actually take part in the research. Most formal policies and regulations on the protection of human research subjects include this risk as an adjunct to the principles of beneficence (minimizing risks of harm) and justice (equitable selection of subjects), and attribute group harms to the misuse and misinterpretation of research findings.

For example, the Council for International Organizations of Medical Sciences (CIOMS 2016) guidelines state, "results could indicate – rightly or wrongly – that a group has a higher than average prevalence of alcoholism, mental illness or sexually transmitted disease, or that it is particularly susceptible to certain genetic disorders." CIOMS (2016) further identifies epidemiological, genetic, and sociological research as areas of high risk for this possibility, and say "plans to conduct such research should be sensitive to these considerations and minimize risks to groups, notably by maintaining confidentiality during and after the study and publishing the resulting data in a manner that is respectful of the interests of all concerned."

We believe that minimizing group harms is an important consideration in the conduct of research. The dangers of not considering this issue before conducting research are first, that actual and irremediable harm may come to the larger group or community and second, that members of the group may refuse to take part in valuable and useful research in the future. In this module, we will discuss the issue of group harms resulting from research.

Learning Objectives

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

- Describe some distinct groups or communities of people who might be vulnerable to group harms.
- Identify examples of research that have caused harm to groups.
- Identify strategies that researchers can take to reduce the risk of group harms.

What do we mean by "groups?"

Researchers use the terms "populations," "groups," and "communities" in a variety of ways. People belong to groups or subgroups because they share some common feature or characteristic of birth, behavior, or belief. Examples include ethnic or racial groups (such as, African-American, Hispanic, White or Asian), or religious groups (such as, Islamic, Taoist, or Christian Scientist). People may belong to groups described by geo-political location (such as, Brazilians, New Yorkers, or Parisians), or by occupation (such as, agricultural workers, physicians, or teachers). Other groups may be defined by age, gender, by physical condition (such as, diabetic, sight-impaired, or cancer patient), or by behavior (such as smokers, men who have sex with other men, or marathon runners). Groups or populations often contain sub-groups. Individual people usually belong to many different groups and subgroups. People may choose to describe themselves as members of groups, or others may assign membership to them.

What do we mean by "harms"?

A harm is an adverse outcome, that may be physical, psychological, socio-economic, or political. Although it is not possible to conduct research that is totally risk-free, researchers agree that they must minimize risk or harms to the greatest extent possible. Some groups, because of their vulnerable position in society, may be at especially high risk of suffering harm if individual members take part in research. Generally, these groups include those who:

- have suffered and continue to suffer discrimination (such as the Gujjar of India, Americans of African descent, and the Quechuas of South America),
- have less access to education, social services, and health care (such as rural or low-income populations), or
- are socially stigmatized (such as commercial sex workers, injection drug users, or members of religious cults).

Group harms result when group members, **including those who did not participate in the research itself,** suffer negative consequences due to the research findings. Harms that can result from research findings include:

- economic: loss or denial of access to economic services, employment
- political: disenfranchisement, imprisonment or detention, loss of citizenship
- social: stigmatization, stereotyping, or discrimination in social arenas
- educational: identification as less educable or not worthy of education
- genetic determinism: assumption that having certain genes predicts disease or behavior that may be viewed negatively by the larger society; and
- cultural: violation of group norms and values cause internal discord and damage to cultural identity.

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, we believe that makes it even more important that researchers pay attention to the possibility that they 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. Furthermore, 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 follows are examples of studies that have had negative impacts on groups of people who were not necessarily study subjects.

- Publication of results of research 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).
- Dignitary harms to the Yanomami of South America resulted from ethnographic and genetic research conducted using inadequate informed consent (American Anthropological Association 2002).
- Publication of the results from a study purporting to show high rates of alcoholism among Alaska Native residents of Barrow, Alaska had an unexpected negative economic impact on all Barrow residents because it resulted in a negative economic rating for city-issued bonds that made it more difficult for the city to borrow money (Klausner and Foulks 1982).
- A number of studies purporting to study the intelligence of African Americans vs. whites and Asians resulted in characterizations of African Americans as less educable (Herrnstein and Murray 1994; Hochschild 1996, 69-73).
- Relations between the Chilean and U.S. governments were strained after the Chilean press uncovered a politically sensitive study (Project CAMELOT) of the processes of social change and counterinsurgency conducted by the U.S. Army (McFate 2005). Conducted in Chile, the U.S. government cancelled the project after the Chilean government filed a complaint.

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 participants are members?
2. Are there any possible unintended consequences of my research such as stigmatization or discrimination?
3. If I were a member of this group, how would I feel about the research findings - positive and negative - being made public?
4. Do the potential benefits of my research outweigh the potential harms to the participants and to the population?
5. Can I predict how others (such as insurance companies, employers, the media or government) could use the results of my research findings?

Asking and answering 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, that the researcher understands and has taken steps to minimize the risk of the harms that might result, and that the group understands the potential effects of the harms on both individuals and the group.
- **Collaborative 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 on-going consultation:** Researchers should work with the group to make sure that they provide group leaders with accurate information about the research as it progresses and changes. The group must have an opportunity to monitor the research and its effects. Researchers should anticipate that their research might have to change or even stop in order to minimize potential group harms. Note: It may be wise to have a plan for termination of the project, should this become necessary.
- **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 develop a plan for disclosing the research results and to anticipate 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. Note: the publication of results without the consent of all parties may constitute research misconduct in some jurisdictions.
- **Make benefits available to groups:** Researchers must consider how their studies might benefit the communities involved both during the study period and thereafter. In this sense, "benefits" should not be narrowly restricted to material

gains such as goods and services, but could include building human capacity and social capital within the community - for example by training community members to collect and interpret data, to participate in the ethical review process, to use research findings to advocate on behalf of the community, etc. These benefits may be negotiated with the group in advance of the research.

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

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Dr. Singh has residual blood samples and clinical data from prior research he conducted five years ago on the prevalence of thyroid disease in Tibet. He now proposes to use the samples to explore possible genetic risk factors for Kashin-Beck disease, a chronic bone disease that mainly affects children. Given the prevalence of this disease in the Tibetan population, Dr. Singh believes that the subjects would be agreeable to the use of their specimens and data for this research. However, due to the passage of time, Dr. Singh is concerned that he will not be able to locate the subjects to describe the new research and ask their consent. Dr. Singh has approached you, as IRB Chair, for guidance.

- What guidance might the IRB Chair provide Dr. Singh about obtaining informed consent?

  The IRB Chair might explain that the people of Tibet have been subjected to political, cultural, and religious persecution. The revelation of a genetic basis for Kashin-Beck disease could lead to further stigmatization and discrimination. The benefits of the research would, at best, be delayed until further research could be done to identify any possible cures or treatments.

  She also might note that consulting with the community in advance and adhering to the local ethics review process would be consistent with the ethical principle, respect for persons, and inform whether or not the research should proceed and how.

The IRB chair explains that one might argue that the research is eligible for a waiver of the consent process on the basis that obtaining consent is impracticable and the rights and welfare of the individual subjects would not be jeopardized if appropriate steps were taken to protect the confidentiality of their information and specimens. However, she notes that taking such an approach without consulting with the community and having a local ethics review would be insensitive to the community at large and could lead to a situation of group harm in a population that has already suffered.

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