Cases of Group Harm in Biorepository Research

An overview of notable cases of group harm

Harm to communities through biorepository research usually grows from many small choices. This reading shares examples of how choices made during different parts of a study can cause group harm.

Planning: Choosing Research Questions

Sometimes, researchers design studies that do not match the needs or priorities of the people whose data they use.

In 2012, Kim and colleagues[1] used samples from the multiethnic cohort study (MEC).[2] This repository includes samples from Japanese American, Native Hawaiian, African American, Latino, and White people. The MEC was created mainly to study cancer.[3] Kim's team combined some of that data with samples from another repository called the Human Genome Diversity Project (HGDP).[4] They did this to study the "genetic origins" of Native Hawaiians.[1]

Studies about human origins are common. However, Native Hawaiian scholars say this topic is **not a priority** for their communities. Native Hawaiians have told researchers that they want their samples to be used for research on health issues that impact their community, like heart disease and diabetes.[5]

Stretching Consent

The MEC and HGDP biobanks present their goals as relating to medical and health research. The participants donate samples with this understanding. Thus, some wonder if genetic origin and similar studies actually **stretch participant consent.**

For example, “racial hereditarian researchers” use biomedical data to publish papers based on their beliefs. These "researchers" make claims about intelligence in Black and White Americans. People then use these studies to spread racist ideas.[6]

People joining a repository often give consent for broad use of their samples. This can make it unclear exactly which kinds of studies should be allowed.

It is important for researchers to listen to what communities want. When studies do not match community priorities, they are more likely to lead to harm.

Study Execution and Analysis: How Data Choices Shape Meaning

How researchers label, group, and analyze data affects how their results are understood. Poor labeling or categorization can reinforce harmful ideas or impact the accuracy of research. In 2002, Rosenberg and colleagues published a study[7] using data from the HGDP.[8] The study tried to describe human genetic differences by grouping people who were genetically similar. Rosenberg’s team found six genetic “clusters” of people that lined up with major world regions.[7] This finding became famous. This paper has been cited thousands of times. Many people–including researchers–interpreted these clusters as evidence for biological races.[9]

The authors later said that was not their goal. Another important finding they presented is that most genetic variation (93–95%) exists **within** their proposed clusters, not **between** them.[7] However, their study design and presentation encouraged misinterpretation.

Scientific racism scholar Dorothy Roberts said, "There is nothing in the team's findings to suggest that six clusters represent human population structure better than ten, or fifteen, or twenty."[10] Scholars have suggested that choosing to divide people into six clusters encouraged others to misuse the study.[9]

Dissemination: Sharing Research with Context

Even the most well-designed studies can cause harm if results are shared without context. Missing context allows findings to be easily misunderstood or misused. This often has real consequences. Research shapes how individuals and governments understand groups. Faulty research can lead to harms like increased discrimination and inequitable policies. Social and cultural background helps readers understand what findings really mean.

The "Warrior Gene" and Māori Communities

At a 2006 conference in Australia, researchers Hall, Green, Chambers and Lea presented findings about the Maori people. Maori are the indigenous people of New Zealand. The researchers shared that the Māori people in their sample had higher rates of a certain gene variant connected to tobacco and alcohol use. The gene was nicknamed the **"warrior gene,"** linking it to aggression.[11–14]

The researchers even told the press that "historically Māori were fearless warriors." They related this to supposed violence in Maori people. The research team later walked back these statements, but the harm was already done.[14]

These claims reflect **genetic essentialism**—the false idea that genes alone explain behavior.[15] The researchers ignored the history of oppression that still impacts Māori communities today.

Weaponization of Transgender Health Research

A 2011 study by Dhejne and colleagues is another example of missing context. The researchers wanted to study the effects of gender-affirming surgery on death rates, mental health, and social integration among transgender people in Sweden. They compared transgender people who had gender-affirming surgery with cisgender people. The study showed higher rates of death and suicide among the transgender group.[16]

Experts say the study should have compared transgender people who had surgery with transgender people who had not, not cisgender people. This would have made the results more accurate.[17]

Dhejne and colleagues' study has been used in politics and media to argue against gender-affirming care. Dhejne has spoken out against how her work has been misused, but this has not stopped it from happening.[18] It is good that she is pushing back, but Dhejne and colleagues could have done more to put their findings in context from the start.

Final Thoughts

Group harm in research is not caused by any one part of the research process. It can arise from any number of choices—from what questions researchers ask, to how they handle data, to how they share results. The CHIRON materials help researchers recognize these choices.

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