Session 2: Bioethics, Social Responsibility, and Community Engaged Research

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Learning goals

- Describe the four principles of bioethics and apply them to case studies
- Identify shortcomings of the four principle of bioethics
- Identify key stakeholders and conflicts of stakeholdership in community-engaged research
- Understand the benefits of social responsibility and community-engaged research

Taught by
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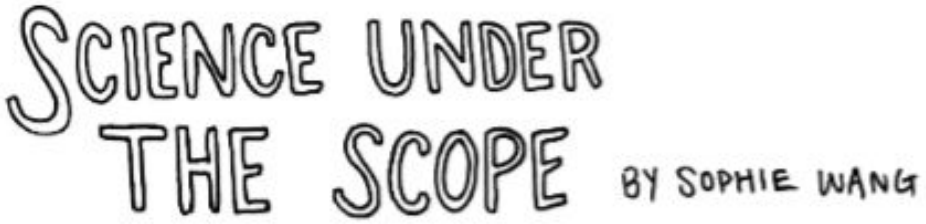
Science and society



lightly adapted from source material at freerads.org

5 min pairs / small groups

1. What part of this reading surprised you?
2. What part of this reading made you uncomfortable?
3. What resonated with you?
4. Where have you seen examples of society influencing science in your field of study?

Introduction to bioethics

Dr. Daphne Martschenko

Activity: Social Responsibility Discussion

Think about these questions from opposing perspectives.

Guiding questions:

1. When do scientists have social responsibility?
2. Is it possible to create an ethical framework that will last over time?

3 min small group/pairs
7 min large group discussion

Stakeholdership

Stakeholdership

- A **stakeholder** is one who is *involved with* or *affected by* a course of action
- To define a stakeholder, we must ask:
  - What is the **course of action**?
  - How is this stakeholder **involved or affected** by the action?
  - What is **at stake** for them?

Challenges of assessing stakeholdership in study design

1. Determine **who the stakeholders are**, and their primary motivations
2. **Solicit input** from stakeholders in ways that are equitable and accessible
3. Prioritize and **balance conflicting perspectives**
4. Appropriate, thoughtful, tailored **communication** with each group

The Havasupai Tribe: Stewardship & Stakeholdership (6min)

https://www.nytimes.com/video/us/1247467672743/blood-journey.html

Activity: Practice identifying stakeholders

Split into **groups of 4-5**

7 mins

In your group reflect on the Havasupai Tribe story from the **perspective of different stakeholders**. The purpose here is not to judge, but reflect and assess.

Guiding questions:

- What is the course of action you are considering?
- Who were the stakeholders and what was at stake for them?
- Where did conflicts arise?
- What are some potential impacts of the outcome?
- Who else might be a stakeholder?

Community-based Participatory Research

Why do community engaged research?

Identify	New intersections through understanding how policy and power operate in the real world
Develop	culturally relevant and useful interventions
Disseminate	Findings and interventions
Reach	key populations

Slide credit: Jen James

Priorities of Community Based Research

- Reciprocal Relationships and True Partnership
  - Requires true power sharing built on mutual respect and benefit
- Co-learning
  - Acknowledges the importance of everyone's contributions and individual expertise
- Transparent and Shared Decision-Making
  - Heightens accountability of researchers and demonstrates impact of community engagement

Slide credit: Daphne Martschenko

Successful community-based research: St. Regis Mohawk Tribe

Context

The reservation is downstream from a superfund site

- General Motors' industrial waste was dumped in the rivers
- PCBs, a carcinogen, was released into environment

Conflict

Polluted waters were affecting the health of community members

- Subsistence living
- Fish intake was leading to dangerous levels of PCB in people
- Affecting breast milk!

Impact

Community-led and initiated study

- Mohawk mothers were participants
- Results published in newspaper and radio
- Research trusted by community members

Activity: Use the priorities of community-based participatory research & design a study on cardiac disease

You will be presented with a community-based research scenario and assigned a stakeholder role. Split into **groups based on your assigned roles.**

10 mins

- Take a minute **on your own** to read and reflect on your assigned role & perspectives
- **In your groups,** try to reach a consensus about the study design, data management, and informed consent policies.

25 mins

- **Group discussion**

Activity: Use the principles of community-based participatory research & design a study on cardiovascular disease

Community background

- **Tight-knit** small town
- **Medically underserved** and most members are do **not have scientific training**
- Have been noticing a **cardiovascular illness** in community members

Disease background

- tends to affect community members **around birth**
- **heart rate and breathing** are affected
- when older, these members **cannot exercise for more than 5 minutes**

Researcher background

- research institution specializing in cardiovascular genetics
- has **never collaborated** with this community before
- needs more **publications** to get more funding through grants

Activity: Use the principles of community-based participatory research & design a study on cardiac disease

- Community members (non-participants)
- Participant community members
- Community leadership (Tribal government, religious leader, community spokesperson, etc)
- Community members that are also researchers
- Lead researchers
- Research team members (trainees, techs, staff, etc)
- Collaborators
- Research institution administrators
- Funding agencies

Activity: Use the principles of community-based participatory research & design a study on cardiac disease

10 minutes in small groups; 25 - 30 minutes in large group

- **Study design**
  - What research questions do we investigate?
  - What data do we collect & generate?
- **Data management**
  - Who owns & manages the data?
  - What restrictions do we put in place on the data?
- **Study consent**
  - What should be included in the consent form?
  - How will data anonymized, esp if sampling from a small group like a Tribal nation?
  - What information will be returned to the community?
    How will interventions be put in place?
  - Can participants opt to withdraw from the study? How?

Final Thoughts

- Scientists should consider their social responsibility when designing, conducting, and disseminating their research
- Existing regulations have done little to ensure or encourage social responsibility, but researchers should think about the downstream implications of their work
- Different stakeholders (researchers, participants, corporations) have different interests in genetic data, which should be balanced when designing a research study
- Equal partnership, co-learning, transparency and shared decision making are important priorities for CBPR

Session 3: Race, Ancestry, Identity, and Genetics Pt 1

Distinguish between race, ethnicity, ancestry, and nationality.

Differentiate between social identity and genetic ancestry, and in particular, understand how social identity is (often) discretized, while genetic ancestry is a continuum.

Discuss the history of eugenics and medical mistrust among racial/ethnic groups through discussions of historical cases/events, such as the case of Henrietta Lacks.

Understand how race/ethnicity becomes biological through the effects of racism and how this is relevant for genetic medicine and research.

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