



Online Ethics Center  
FOR ENGINEERING AND SCIENCE

# Negotiating Research Practices with Local Communities

## Author(s)

Caroline Whitbeck

## Year

2000

## Description

A scenario meant to stimulate discussion about the ethical issues that arise when a genetic predisposition is found among a certain part of the population.

## Body

As a genetic epidemiologist working with an isolated community of third world people, you have identified an endemic mutation that seems to explain their group's high susceptibility to heart disease at a young age, which had hitherto been attributed to their diet. In meeting with the communities leadership to discuss these results, you encounter two reactions.

On the one hand, the leadership were relieved to learn that their high fat diet was now "proven" not to be the source of their problems. On the other hand, they now insisted that you not link this genetic finding with their community in any publications or reports, because they fear that a known genetic vulnerability would make their daughters less marriageable among neighboring groups.

How should you respond?

## Notes

Caroline Whitbeck introduced methods and modules for discussing numerous issues in responsible conduct of research at a Sigma Xi Forum in 2000. Partial funding for the development of this material came from an NIH grant.

You can find the entire sequence on the OEC at [Scenarios for Ethics Modules in the Responsible Conduct of Research](#). Some information in these historical modules may be out-of-date; for instance, there may be a new edition of the professional society's code that is referred to in an item. If you have suggestions for updates, please contact the OEC.

## Contributor(s)

Caroline Whitbeck

## Rights

Use of Materials on the OEC

## Resource Type

Case Study / Scenario

## Parent Collection

Scenarios for Ethics Modules in the Responsible Conduct of Research

## Topics

Community and Participatory Research

Human Subjects Research

Informed Consent

## Discipline(s)

Immunology and Infectious Diseases

Life and Environmental Sciences

Research Ethics

## Publisher

Online Ethics Center