



Online Ethics Center
FOR ENGINEERING AND SCIENCE

Disclosing Preliminary Results to Research Subjects

Author(s)

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Year

2000

Description

A scenario meant to stimulate discussion about when, if ever, information gained from studying a family's genes should be disclosed to the family.

Body

During a family linkage study in search of a genetic mutation conferring increased risk for breast cancer, one woman subject approaches you and announces that she can no longer endure the uncertainty involved in living with the family's unusually high rate of fatal breast cancer. She has decided to undergo double prophylactic mastectomy, but wants to know what the research team can tell her about her genetic risk status.

Your team has in fact identified some genetic markers that seem to travel through the family with the (still unknown) mutation, but are far from satisfied that the linkage between the markers and the mutation is reliable enough to use for clinical purposes. According to your preliminary analysis using these markers, however, this subject does not appear to carry the family's high risk conferring mutation.

How should you respond to this subject's request for information?

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 Some information in these historical modules may be out-of-date; for instance, there may be a new edition of the professional society's code that is referred to in an item.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

Open-ended scenario

Parent Collection

Scenarios for Ethics Modules in the Responsible Conduct of Research

Topics

Confidentiality

Human Subjects Research

Data Management

Informed Consent

Discipline(s)

Research Ethics

Genetics and Genomics

Life and Environmental Sciences

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