



Online Ethics Center
FOR ENGINEERING AND SCIENCE

Recruiting Relatives of a Proband with a Stigmatizing Condition

Author(s)

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Year

2000

Description

A scenario meant to stimulate discussion of the ethical issues that arise in trying to research the genetic factors involved in mental illness.

Body

In 1993, the National Institutes of Health launched its "Molecular Genetics Initiative" by setting out to "collect families" for an analysis of the genetic factors involved in schizophrenia. They intended to begin in the traditional fashion, by identifying probands or index cases amongst patients diagnosed with schizophrenia, and using their medical records to identify family members to recruit.

A psychiatrist on the team cautioned that in contacting the relatives the researchers should take pains not to identify the probands: "This is important," he said, "because the presence or severity of mental disorders may be considered a secret, and subjects may not want relatives to learn of their diagnoses."

- Without reference to the proband's diagnosis, however, how could an investigator, like you, for example, adequately explain to the proband's cousins why you are interested in their participation in a genetic study of this disease?

- If the phenotypic information you are seeking from the relatives (i.e., presence or absence of diagnosed schizophrenia) is already recorded in the proband's medical history, what are the acceptable approaches to using it for research purposes?
- What are the pros and cons of using that information for research purposes without contacting the relatives or obtaining their consent?
- How would you handle this recruitment?

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 Some information in these historical modules may be out-of-date; for instance, there may be a new edition of the professional society's code that is referred to in an item.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

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Case Study / Scenario

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Online Ethics Center