

What are the ethical issues involved in the case?

Material Transfer Agreement

- In the case all materials and the samples were sent abroad for analysis
- No evidence of a prior agreement about how materials from the study were discussed at any time during the study
- Investigators should ask questions about how materials derived from a research should be handled
- Investigators should seek counsel from their ERC on issues relating MTA when in doubt
- See pages 32-35 of the national code for guidance on MTA

Relationship among equal (unequal?) partners

- Rose's role in the study was not well defined
- Rose's showed her naiveté as a researcher
- Rose did not ask questions on issues relating to analysis of data
- Investigators should ask specific questions about terms of a relationship
- Ask questions for written agreement and scrutinize this agreement and ask questions for terms not clear to you

Dissemination & feedback of research findings

- Investigators have an ethical obligation to give direct feedback of outcome of the research to:
 - Research participants
 - Community
- Investigators have an ethical obligation to disseminate findings to the scientific community through presentations at conferences and publications in journals
- Rose could not give feedback to research participants who were interested in their health condition
- A researcher should not make the condition of a participant worse if it cannot be improved

Who qualifies to be an author?

- An author is someone who:
- Make substantial contributions to the development of concept, implementation of research, and writing of the manuscript
- Can claim responsibility & defend the contents of the paper

Role of Institutions in Protecting Researchers from Exploitation

- Ethics Review Committees can ask questions and offer suggestions on how to deal with MTA, publications issues
- Mentors could offer guidance to young investigators
- Institutions should train investigators about the importance of ethics of research
- Develop policies to guide investigators

Lessons learnt?