

Author's Commentary on "PI or Private Investigator"

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With the increased use of computers and innovative technology, access to information is more readily available. This case highlights the ethical issues surrounding the use of this new technology in research to gain access to information and possible infringements on the rights of study subjects. In research involving human subjects, complete data are important. Hence, researchers' ability to reach study participants to verify or gain complete information is crucial. Over the course of time, the potential for losing contact with the participants increases, and the completeness of data becomes jeopardized. Along with greater access to computers, the development of the super highway of information (world wide web) has enabled people who were once lost to research, friends, family, etc., to be located. To help evaluate this case, it is important to consider the Belmont Report, which provides the ethical principles and guidelines that govern research with human subjects research; the Fair Credit Reporting Act of 1970; and the Code of Fair Information Practices (Johnson, 1994).

The first part of the case deals with Bob, a manager for a health study, who is trying to locate some study participants to follow up on incomplete data. Even though the consent form stated that future contact was possible, it did not mention the method(s) that the researchers would use to locate the participants. Further, the protocol for locating subjects after the study's end was never discussed with the IRB. It is quite likely that some study participants would have declined participation if they had known that a credit bureau would be used to contact them. However, this strategy was the last resort, and the number of queries sent to the credit bureau was minimal. The researchers did try to plan for attrition by asking the participants to provide the names, addresses, and phone numbers of friends or relatives who would know how to contact them two or three years later, but some of the participants did not provide this information. Another question is whether the participants who chose not to give a friend's or relative's contact information did not

want to be contacted in the future. In that case, use of the credit bureau to locate these subjects may not have been justified.

It is important to know that the information collected and maintained by the credit bureau is legal, and rights to the information is available to others with a fee. Many banks, department stores, car dealerships, etc. use credit bureaus to verify the financial status of their prospective customers. However, it is important to note that customers give the stores and dealerships permission to check their credit. The research study did not inform the subjects or get their permission to search their credit reports for updated phone numbers or addresses.

The first principle listed in the Belmont Report is respect for persons. This principle refers to deception in research. The subjects were deceived in assuming that future contact would be established using the information they had already provided. It is clear that the researchers did not intend to deceive the subjects, given that the researchers did try to get additional information to help with contacting the subjects in the future.

Bob struggles to locate study subjects using various indirect methods such as directory assistance and the contact information provided by some of the subjects. Despite his efforts, these methods produced little new information. Bob lost sight of the principles listed in the Belmont Report by failing to consider the principles of respect for persons, beneficence and justice. He was so eager to use this new technology that he failed to consider the risks involved. Bob could have jeopardized the trust of the participants if they had found out about the tracing. He should have consulted the IRB, since the use of a credit agency was a change in the study's approved protocol.

In conducting human subjects research, all information collected from the subjects must be kept confidential. The consent form informs the subjects that only the immediate study staff will have access to information about them; that information will be released only be for the purpose of research; and that it will not have any identifying information attached or obtainable. By sending information to the credit bureau, Bob violated the confidentiality rules.

A second risk was to the subjects' credit ratings. The subjects should have been told that a credit bureau would be used to locate them in the event that other methods were not productive. The use of Social Security numbers was not fair, since that

information was not requested from or given by the participants.

This final part of the case highlights the use and misuse of access to information when Bob learned of another credit-reporting company that provides software for independent credit searches. If the use of a credit bureau is ethical for research purposes, Bob should have ordered the software and restricted the use of the computer and software to authorized study personnel. This step would have preserved the confidentiality of the data and protected the subjects from harm. Searching someone's credit, even if only to find a telephone number, could adversely affect an individual's credit rating. Bob should have consulted with the IRB and weighed the pros and cons of using this resource.

Bob should not have tried to remove his company's name from the report because that was dishonest. The Credit Reporting Act of 1970 requires credit agencies to make their records available to subjects and to allow for corrections to credit reports. This Act would have allowed the study participants to remove the research company's name and reduce the risk of an adverse effect on their credit ratings.