

Confidentiality Protocol - English version

PROBLEMS:

- 1) Cassettes, transcriptions, discs, without an identity number.
- 2) Cassettes, transcriptions, discs, with the name of the interviewee.
- 3) Confusion last Monday regarding whether or not Mujer Sana, as a project, can receive the names of women who might be interviewed, and/or who might participate in health promotion activities that are carried out by Mujer Sana personnel.

POSSIBLE SOLUTION:

Let's refocus: What does confidentiality in this research project consist of?

Let us remember that the ethical research protocol requires that we maintain in confidence the information that people tell us during an interview. It does not require that we maintain confidential the fact that we have asked someone for permission to interview her. That is to say, we would not be contravening the confidentiality protocol if all the interviewers working for the project know that someone is going to call Mrs. Estable to see if she wants to be interviewed. What we do promise, is that whatever Mrs. Estable says in her interview will remain confidential. That is to say, that nobody will know that, for example, Mrs. Estable has only had one sexual partner in her entire life; or that she does not like to do a breast examination because it tickles. But yes, it will be known that, among the 30 or 40 persons who were interviewed, there were seven who only had a single sexual partner, and one who felt ticklish when she has a breast examination, for example.

How to ensure that the interviewers do not waste time making calls or contacts with people whom others have already interviewed or plan to interview, while at the same time, maintaining confidentiality?

I suggest that two central lists be maintained. One, the list of possible and achieved contacts; the second, a list of persons interviewed, with an ID code.

The list of possible contacts will be generated by the interviewers, and also by the researchers or any other project personnel, who will give the name of the people whom they think could be approached. They can also indicate if they think that the person would prefer to be contacted by the interviewer who gives the name herself, or whether they think the person would not mind receiving a phonecall from another member of the project.

The principal investigator, a co-investigator, or one of the interviewers, would have the task of maintaining this list up to date, receiving information from all the other interviewers, and would verify that there are no duplicate names.

Since all the contacts have not yet been made, and we [the project] will have to find other women beyond those whom everyone already knows, names would be periodically added to the list of possible contacts on an ongoing basis. In that same way, that list can be used to avoid duplication of activities. For example: if someone knows that it is necessary to recruit more participants than those whom she already knows, and she plans to go to an English class to do so, this can be noted on the contacts list, and that way the other interviewers will know that they don't have to go to that same class [to recruit participants]. Once the interviewer returns from the class, and has identified possible participants, she would then pass the names of these possible contacts to the person who is in charge of entering them in the general list of project contacts [as mentioned above, either one of the investigators or an interviewer who has been given this specific co-ordination task].

If we decide to do the above, the general contact list can be considered as research data, and can be destroyed after the period of interviewing (including recruitment and verification) is finished.

Alternatively, however, [and I would propose that we do this alternative] this list also could be used to begin to generate a list of women with whom the project will continue to be involved in its other tasks of health promotion, by inviting them to participate in an activity, sending them a pamphlet, or whatever [emerges after the interview]. If we decide to use the list of contacts for the purposes of ongoing outreach, it would be important to make sure that each woman is asked whether she would agree that the Mujer Sana project can keep her name and telephone number, with the purpose of communicating with her in future. If a woman [who has been interviewed] does not want the project to communicate with her in future, this would be noted in the list, and her name would be erased from the general list of contacts once she has been assigned a confidential identification number to keep track of her information for the research (see what follows).

¿How to ensure the confidentiality of the person who is interviewed?

The interviewer must be extremely careful NEVER to put the name of the person being interviewed on the cassette, on the disc, or on the typed document (printed transcript). She must assign an identity number to each person/interview. She must only use this identity number to refer to this person in any and all written documents.

Once each interview is completed, the interviewer must keep, in a place that is separate from the interview material, perhaps in a different notebook that she would keep confidentially, the name of the person and how to communicate with her, with the number that has been assigned to her. For example:

Identity No:	Name:	Telephone or address:	Interview date:
101	A.Estable	232-1823 (only in the afternoon)	Monday, 1:30

This information is kept by each interviewer only until the time that she can hand this information over to the central co-ordination of the research [investigator]. Once this information has been handed over and confirmed received, the **interviewer must destroy any and all documents that might permit someone to relate or link the identity number with that person.** That is to say, if the interviewer wrote in her notebook the type of information that you see in the previous paragraph, about A. Estable, she must erase this from the notebook, or tear out and destroy that page, and make certain that nobody has seen or can see that information. This is extremely important, since several people will be participating in the analysis, and will be able to read what Mrs. 101 said. It is essential to make sure that nobody, not even other colleagues in the project, should ever know that the specific information contained in interview No. 101 was provided by Mrs. Alma Estable.

The only persons who may know this are the interviewer herself, and the principal or co-investigator, which is what we promise to interviewees in the sheet they sign consenting to be interviewed. The principal investigator always has the obligation to establish systems and protocols that will maintain confidential the identity of all the persons who have been interviewed, and also has the duty to ensure that the interviews are being done correctly, for example, that by mistake the same person is not being interviewed more than one time by several interviewers. Although this may seem difficult to believe, in a long-term project, with multiple interviewers, and with the possibility of a financial incentive for people to participate, this kind of thing could happen.

I suggest the following method to maintain the confidentiality of the person being interviewed, while at the same time, making it possible to supervise the quality of the interviews:

Once the interviewer has handed over her material (cassette, disc, transcript, signed consent forms, field notes), all identified with the same code or id number, the principal investigator keeps this in a file cabinet under key, at a location outside of Centretown CHC. Before putting this away, the consent form is separated from the interview, since, if they were to be kept together, it would be possible to identify the person from her signature on the consent form. The consent forms are kept in a separate file.

The name of the person, and her contact information (telephone or address) are entered next to the identity number, in a notebook, that remains under key, in a separate location from Centretown CHC, during the research period.

Once all the interviews have been completed, this notebook is destroyed, that way no written documentation remains that would ever permit linking the name of a person who has been interviewed, with the number that has been given to her.