Rule-of-Thumb #4 for an AAHRPP Interview:

Know the policies!

AAHRPP interviewers will want you to demonstrate that you are aware of University of Kentucky policies, UK IRB/ORI policies, and whether your conduct of research is consistent with University of Kentucky policies.

The Office of Research Integrity (ORI) provides a variety of guidance/policy/educational documents on the ORI web site: http://www.research.uky.edu/ori/human/guidance.htm. To supplement the documents on that page, ORI also has a web page for UK IRB/ORI Standard Operating Procedures and Policies: http://www.research.uky.edu/ori/human/SOPs_&_Policies.htm. In addition, the ORI web site provides links to the University of Kentucky Administrative Regulations applicable to the conduct of human research: http://www.research.uky.edu/ori/human/guidance.htm#AR.

Case Study #4:

Privacy vs. Confidentiality

You are preparing a proposal for research which involves pregnant women. You remember there is a well-known pregnancy counseling center in town that should be a good resource for recruiting your target subject population. You have scheduled time for in-the-field recruitment, and you think it would be easiest to ask women if they want to participate in your research as they approach the counseling center. But, you take into consideration the women may want to remain anonymous during the identification and initial contact stage, so you develop alternate strategies for recruitment from this facility with that in mind. Are you addressing confidentiality or privacy issues in this part of your proposal?


ANSWER:

You are addressing privacy issues in this part of your proposal when developing strategies for recruitment which take into consideration an individual’s desire to control the access of others to themselves. Privacy concerns people, whereas confidentiality concerns data.

In developing strategies for the protection of subjects’ privacy, consideration should be given to:

• The methods used to identify and contact potential participants.
• The settings in which an individual will be interacting with an investigator.
• The appropriateness of all personnel present for research activities.
• The methods used to obtain information about participants and the nature of the requested information.
• Information that is obtained about individuals other than the “target participants,” and whether such individuals meet the regulatory definition of “human participant” (e.g., a subject provides information about a family member for a survey).
• Privacy guidelines developed by relevant professional associations and scholarly disciplines (e.g., oral history, anthropology, psychology).
• How to access the minimum amount of information necessary to complete the study.
Confidentiality refers to the researcher’s agreement with the participant about how the participant’s identifiable private information will be handled, managed, and disseminated. To address confidentiality in a research proposal, you should outline strategies to maintain confidentiality of identifiable data, including controls on storage, handling, and sharing of data.

See the Research Description (“Form B”) of the IRB Application to see how to provide the information the IRB needs for reviewing privacy and confidentiality issues in human research:
Medical “Form B” - http://www.research.uky.edu/ori/MedicalFullReviewApplication.htm#Core;

For information on how the Health Insurance Portability and Accountability Act (HIPAA) applies to confidentiality of individually identifiable health information that may be collected in the course of the research (aka “protected health information” (PHI)), see the ORI web site: HIPAA in Human Research [http://www.research.uky.edu/ori/HIPAA/main%20page.htm]