Privacy and research studies: NetWellness

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By Special to The Plain Dealer

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If I participate in a research study how can I be sure my employer won't find out?

There are several ways to ensure a research volunteer's information remains confidential.

First, in order for the research to be approved, the institutional review board determines that, when appropriate, there are adequate provisions to protect the privacy of subjects and to maintain the confidentiality of data. To learn more, review the IRB Guidebook published by the Office for Human Research Protections, a division of the Department of Health and Human Services.

Privacy can be defined in terms of the volunteer having control over the extent, timing and circumstances of sharing oneself (physically, behaviorally, or intellectually) with others. Privacy is a right and can be violated.

Confidentiality pertains to the expectation that information an individual has disclosed in a relationship of trust will not be shared to others in ways that are inconsistent with the understanding of the original disclosure without permission. Confidentiality is an agreement and can be breached.

As far as your employer finding out you are a part of a research study, the consent process, documented by the consent form, will outline what will be done with the information you share as part of the research. How the information will be kept confidential is part of the research approval process. The ways in which data will be used and made available to others is part of the agreement researchers make with study participants, and those ways must be described during the informed consent process.

While going through the consent process, ask the research team:
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- How will my information be used?
- How will my information be kept confidential?
- How will the information be shared?
- Can the information be collected without using personal identifiers? For example, giving my name, birth date, or other identifiable information, that is information that would link me to the research information shared.
- If identifiers are needed, can codes be created and used during the research study, with identifiers kept separate and secure?
- Can identifiers be destroyed at some stage of the research so my personal identity will not be known?
- If participants were chosen for the study due to sensitive or stigmatizing information, are procedures in place from the beginning to protect identities, such as a waiver of the need to document consent? By forgoing the need to document consent decreases the chances of linking the research participant with the information. Note this waiver of informed consent can only be used when the only thing linking the participant to the data is the consent form and the study poses no more than minimal risk.
- How will the data be protected from careless disclosure? Would using passwords or data encryption be helpful? Would stand-alone computers vs. network computers be best?
- Are the data deidentified enough to protect the research participant information from reidentification?

Some participants want to be protected from unauthorized or inadvertent disclosure. Some want to be identified and quoted. Some agree to have their photographs or audio- or videotapes archived in collections available to the general public.

At the very core of research is the need to keep volunteers safe, and one safety is to protect the volunteer's privacy and confidentiality. By taking steps to ensure a research volunteer's confidentiality, information they have shared as part of their research participation will not be disclosed without their permission.

Bottom line is employers, families, friends -- or anyone else for that matter -- do not find out that someone is taking part in a study unless the volunteer wishes to share that information.

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