

Confidentiality in Research

TIPS AND RESOURCES FOR RESEARCHERS

Confidentiality in Research at the Vanderbilt Kennedy Center (VKC)

The people who make up the VKC interact with individuals and families through research, clinical services, information and referral, and community involvement activities. Throughout these many forms of interaction, sharing of personal and private information is inevitable. In recognition of the many disciplines within the VKC and our relationships with community members, we have developed these tips and resources for our researchers, faculty, trainees, and staff on how to maintain confidentiality.



What is the difference between confidentiality and privacy?

- **Privacy** is the right to be left alone; the right of an individual to withhold himself and his property from public scrutiny. Privacy derives from the concepts of individual freedom and autonomy and involves the ability of an individual to control the release or dissemination of information that relates to himself or herself (Sacks, 1997).

From the HIPPA perspective, privacy refers to the person—consider where you will speak with the person, consider what you will say, how you will address their concerns.

- **Confidentiality** is the right to rely on the trust or discretion of another; the right of an individual to control access to and disclosure of private information entrusted to another. Confidentiality derives from a relationship when an individual gives private information to another, on the condition or with the understanding that the other will not disclose it, or will disclose it to the extent that the individual directs (Sacks, 1997).

From the HIPPA perspective, confidentiality refers to the data of the person—how you will keep it secure, who will have access to it or who you may share it with, what you will do with it once the project is complete.

Guidelines for maintaining confidentiality

- At the beginning of a relationship or a conversation with a community member, establish the expectations of confidentiality.
“Know that, unless someone’s safety is in question or I am legally required to divulge information, what you tell me will remain confidential.”
- Re-establish boundaries at the end of the conversation.
“Thank you for sharing with me. Nothing you’ve said will go any further.” OR *“Thank you for telling me about your situation. To get some answers for you, I may need to tell some colleagues these aspects of the situation [list].”*

- Before pursuing consequent contacts, ask about confidentiality considerations.
“Do you feel more comfortable with us discussing this issue on the phone or by email?” *Is it okay to leave a message on your voice mail or with other family members?”*
- Confidentiality must be protected in all forms of communication: written, spoken, and electronic. Pay attention to person, place, and time when personal information is involved.
“Does this person need this information?”
“Who else is within sight or sound?”
“Is this the right public or private space to have this conversation, to look at this email, or to store/fax/leave this written information?”
- Secure the environment in which confidential information is kept.
Use furniture and desk arrangements that prevent accidental exposure. Engage locks. Use covers for posted/common use information. Comply with password security procedures. Keep sensitive information on controlled-access, password-protected servers, and not on portable devices. Explore encryption options as they become available.
- Determine “need to know” before you share information.
“You won’t believe what she told me!” *The information the family member volunteered may be enlightening/interesting/gossip-worthy, but who needs to know?*
- Equate email confidentiality with that of a postcard.
Speak in person about participant or family information. Develop files on controlled-access password-protected servers for scheduling and eligibility criteria discussions. Explore encryption options as they become available.
- If projects have arrangements to cooperate on recruitment, share contact and assessment information as you have permission from the IRB and the individual/family.
Do not share information about family members’ personality, habits, attitudes, actions, time management, or competence.

Please see reverse.



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RESOURCES

- In research, case studies, or teaching situations, confidentiality extends beyond use of names.

Use vague references to place of residence, activities and habits, family constellation, resources used, and experiences and training of the family members to disguise the family more effectively in small, close-knit communities.

- Coworkers and colleagues deserve confidentiality as well, unless they have chosen to share in a group situation.

What is a valid consent for release of confidential information?

Consent is to give assent or approval, to agree. Informed consent is to agree after achieving an understanding of what is involved. (*Merriam-Webster OnLine*). A valid consent for release of confidential information would include:

- A person's name and identifying information
- Address of the entity directed to release the information
- Description of the information to be released
- Identity of the party to be furnished the information
- Language authorizing release of information
- Signature of person or authorized individual
- Time period for which release remains valid

What to do if you face an ethical dilemma or have concerns

An ethical dilemma is a conflict that involves determining appropriate conduct when an individual faces conflicting professional values and responsibilities.

If you have concerns about a person's safety or well-being or face an ethical dilemma, discuss it in hypothetical terms with a supervisor or with Vanderbilt Kennedy Center Social Worker, Carol Rabideau, (615) 936-5122. Formulate a plan for response. Communicate identifiable information only in the course of your plan.

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Resources

- **Collaborative Institutional Training Initiative (CITI).** A web-based training program in human research subjects protections. [www.citiprogram.org/citidocuments/forms/Human%20Subjects%20Research%20\(HSR\)%20Catalog.pdf](http://www.citiprogram.org/citidocuments/forms/Human%20Subjects%20Research%20(HSR)%20Catalog.pdf)
- **Health Insurance Portability and Accountability Act (HIPAA).** Medical Privacy - National Standards to Protect the Privacy of Personal Health Information www.hhs.gov/ocr/privacy/

References

- Sacks, Herbert S. (1997, October 3). Men of Zeal: Snoops and Paparazzi. *Psychiatric News*. Retrieved on September 12, 2008, from psychnews.org/pnews/97-10-03/pres.html
- Merriam-Webster OnLine. Retrieved on September 12, 2008, from www.merriam-webster.com

Who We Are and Who We Serve

The **Vanderbilt Kennedy Center (VKC)** works with and for people with disabilities and their family members, service providers and advocates, researchers and policy makers. It is among only a few centers nationwide to be a University Center for Excellence in Developmental Disabilities, a *Eunice Kennedy Shriver* Intellectual and Developmental Disabilities Research Center, and a Leadership Education in Neurodevelopmental and Related Disabilities Training Program. The following are some of the ways the Center's programs and staff can assist families, educators, and other service providers.

Two Easy Ways to Take Part in Research

The VKC serves families through research studies. **StudyFinder** is a searchable database that lists current VKC studies, including ASD research. Studies seek people of all ages with and without developmental disabilities. See kc.vanderbilt.edu/studyfinder, (615) 936-0448. **Research Match** is a secure place for volunteers and researchers to connect. Once you sign up and get added to the registry, a researcher will contact you if you're a possible match for the research study. See www.researchmatch.org.

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