Protecting Confidentiality Rights:
An Ethical Practice Model

(Adapted for Use in Research Settings)

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I. PREPARE

A. Understand Subjects' Rights and Your Ethical Responsibilities in Behalf of Those Rights
B. Learn the Laws that Can Affect Your Ability to Protect Confidentiality of Research Subjects
C. Clarify Your Personal Ethical Position About Confidentiality and its Legal Limits in Research
D. Decide When/How You Will Limit Confidentiality Voluntarily
E. Develop Plan for Ethical Response to Laws That Require You to Disclose "Involuntarily"
F. Choose Reliable Ethics Consultants and Legal Consultants and Use as Needed
G. Devise Informed Consent Forms that Reflect Your Real Intentions
H. Prepare to Discuss Confidentiality and Its Limits in Understandable Language

II. TELL PROSPECTIVE RESEARCH SUBJECTS THE TRUTH (Inform Their Consent)

A. Inform Prospective Subjects About Limits of Confidentiality
B. Inform Prospective Subjects & Obtain Permission Before Recording Voices or Images
C. Inform About Foreseeable Uses of the Information to be Gathered
D. Inform about Factors That Might Influence Willingness to Participate (e.g., Risks/Benefits)
E. Inform About Right to Decline to Participate or to Withdraw Once Participation Begins
F. Inform About Consequences of Declining/Withdrawing
G. Explain Any Roles or Potential Conflicts of Interest That Might Affect Confidentiality
H. Obtain Informed Subject's Consent to Participate, Understand These Conditions

III. OBTAIN INFORMED CONSENT BEFORE DISCLOSING ANYTHING VOLUNTARILY

A. Respect the Rule**:** Disclose Without Subject's Consent Only if Legally Unavoidable
B. Inform Subject Adequately About Content and Implications of the Potential Disclosure
C. Obtain and Document the Subject's Consent Before Disclosing

IV. RESPOND ETHICALLY TO LEGALLY-IMPOSED DISCLOSURE SITUATIONS

A. Notify Subject of Pending Legal Demand for a Disclosure Without Subject's Consent
B. Respond According to Plan (from Step 1,E above)
C. Limit Disclosure of Confidential Information to the Extent Legally Possible

V. AVOID THE "AVOIDABLE" BREACHES OF CONFIDENTIALITY

A. Avoid Making Unethical Exceptions to the Confidentiality Rule
B. Establish and Maintain Protective Policies and Procedures;
C. Monitor Note Taking and Record Keeping Practices
D. Train Staff in Policies for Protecting Privacy and Confidentiality
E. Anticipate Legal Demands [*see over]*
F. Protect Subject Identity in Presentations, Research, Consultations

VI. TALK ABOUT CONFIDENTIALITY

A. Model Ethical Research Practices; Confront Others' Unethical Practices
B. Provide Peer Consultation About Confidentiality Ethics in Research
C. Teach Ethical Practices to Students, Supervisees, Employees, Agency, Institution

(Adapted from the Model first introduced in the article, "Protecting Confidentiality Rights: The Need for an Ethical Practice Model" (Fisher, 2008), and elaborated in the Oxford University Press book, The Ethics of Conditional Confidentiality (Fisher, 2013) and further elaborated in the APA book, Confidentiality Limits in Psychotherapy (Fisher, 2016).

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Articles Related to Federal Certificate of Confidentiality

in Research Settings

Haggerty, L.A. & Hawkins, J. (2000). Informed consent and the limits of confidentiality. *Western Journal of Nursing Research, 22,* 508-514. doi: 10.1177/01939450022044557

Melton, G. B. (1990). Certificates of confidentiality under the Public Health Service Act: Strong protection but not enough. *Violence and Victims, 5,* 67-71.

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"C. Obtain Federal Confidentiality Protection, If Available: In the area of public health, federal law offers two sources of confidentiality protection. First, there are federal statutory provisions that limit the disclosure and use of information obtained in the course of research supported or conducted by the Public Health Service. For example, one provision protects information obtained through activities carried out or supported by the Agency for Health Care Policy and Research . . .

"Second, some public officials have the authority to grant confidentiality protection under certain circumstances. For instance, one such provision gives the Secretary of Health discretion to grant federal confidentiality certificates for a range of both publicly and privately funded research projects. . .

"These two statutory provisions do overlap to some extent. While logically one might assume that confidentiality protection is enhanced when these provisions are used in combination, this is not the case. According to federal authorities, a confidentiality certificate will weaken the protection that qualifying projects receive under the self-executing statutory grant of confidentiality.[20] There are two explanations for this result: First, federal confidentiality certificates give the researcher discretion to disclose the protected data. In contrast, under a statutory grant of confidentiality, the researcher may disclose the protected data only if the research subject contents after notice. Second, a federal confidentiality certificate only protects the names or other identifying characteristics of the research subjects. In contrast, a statutory grant of confidentiality protects all data obtained in the course of activities falling under the scope of the statute.[21] It is important for researchers to have knowledge of these differences so they may determine what information is protected, and when they may legally disclose protected information.

"These public health statutes illustrate the variety of federal confidentiality protections which may be available to resourceful researchers. Thus, they are well-advised to investigate possible sources of statutory protection before resorting to home-spun confidentiality assurances."

From: Traynor, M. (1997). Countering the excessive subpoena for scholarly research. Retrieved from http://library.findlaw.com/1997/Oct/14/126469.html