

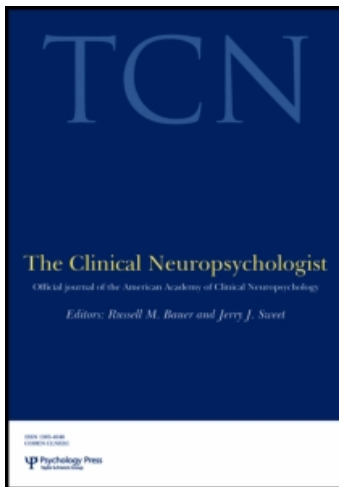
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Disclosure of Neuropsychological Test Data: Official Position of Division 40 (Clinical Neuropsychology) of the American Psychological Association, Association of Postdoctoral Programs in Clinical Neuropsychology, and American Academy of Clinical Neuropsychology

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**DISCLOSURE OF NEUROPSYCHOLOGICAL TEST DATA:
OFFICIAL POSITION OF DIVISION 40 (CLINICAL
NEUROPSYCHOLOGY) OF THE AMERICAN
PSYCHOLOGICAL ASSOCIATION, ASSOCIATION OF
POSTDOCTORAL PROGRAMS IN CLINICAL
NEUROPSYCHOLOGY, AND AMERICAN ACADEMY OF
CLINICAL NEUROPSYCHOLOGY***

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The views expressed in this document are those of Division 40. They have not been approved by the governing body of APA and should not be construed as representing the policy of APA as a whole or of any other division or unit of APA. This statement is not intended to establish a guideline or standard of practice against which clinical practice is to be evaluated. Rather, it is intended to provide a useful summary of considerations and strategies regarding release of test data. It does not provide legal advice, nor is it intended to be or to substitute for the advice of an attorney. Relevant law varies substantially from state to state and context to context. Neuropsychologists are encouraged to consult legal counsel, who can review the pertinent law and facts and provide appropriate legal assistance.

*The order of listing reflects the order in which the organizations became involved with and contributed to this project. The creation of this document was initially as a joint ethics project of American Psychological Association Division 40 (Clinical Neuropsychology) and the Association of Postdoctoral Programs in Clinical Neuropsychology (APPCN).

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American Psychological Association 2002 Ethics Code, 9.04 Release of Test Data

“Pursuant to a client/patient release, psychologists provide test data to the client/patient or other persons identified in the release. . . . In the absence of a client/patient release, psychologists provide test data only as required by law or court order.”

INTRODUCTION

This document is intended to reflect current ethical, legal, and professional practice considerations specifically related to the release of test data. Essential points relevant to test data disclosures, including ethical principles and legal mandates are presented. It is recognized that laws vary from state to state, as do the policies governing various institutions and organizations. Modification and refinement of this information, as the application of ethical and legal guidelines pertaining to test release principles and statutes evolves and becomes more defined, is anticipated. It is strongly recommended that providers seek appropriate consultation and refer to national and state psychological associations, federal and state laws, and institutional or organizational risk management resources. There is no substitute for knowledge of the relevant statutes and ethical guidelines.

WHAT ARE TEST DATA?

Note that Standard 9.04 defines *test data* as:

. . . raw and scaled scores, client/patient responses to test questions or stimuli, and psychologists' notes and recordings concerning client/patient statements and behavior during an examination. Those portions of test materials that include client/patient responses are included in the definition of *test data*.

The 2002 Ethics Code makes a clear distinction between *test data* and *test materials*. The standards support both release of test data AND maintenance of test security. This latter is achieved by protection of *test materials*, in contrast to *test data*. According to standard 9.11:

. . . the term *test materials* refers to manuals, instruments, protocols, and test questions or stimuli and does not include *test data* as defined in Standard 9.04, Release of Test Data. Psychologists make reasonable efforts to maintain the integrity and security of test materials and other assessment techniques consistent with law and contractual obligations, and in a manner that permits adherence to this Ethics Code.

Test data can be released without compromising test materials. Some neuropsychologists provide data in the form of a raw score summary sheet. Others provide the test protocols with test stimuli blocked out, leaving only patient responses, although it is not yet clear whether this latter approach is legally consistent with the patient's right to his/her records under the Health Information Portability and Accountability Act (HIPAA). These methods help to ensure that neuropsychologists do not unwittingly violate copyright restrictions or purchase agreements, or disclose

trade secrets (regarding the latter, see Harcourt Legal Policy, 2004). Importantly, the methods also help to promote instrument validity.

The HIPAA Privacy Rule is highly relevant to patient privacy protections, and access to health care records and test data if the psychologist is subject to HIPAA and the request for test data is from the patient. HIPAA gives the patient the right to access his/her records, subject to certain exceptions. Patients have no right to access records created in connection with forensic work because of the exception for records "compiled in reasonable anticipation of, or for use in, a civil, criminal or administrative proceeding." (HIPAA, 45CFR Section 164.524(a)). However, HIPAA does not recognize the protection of test materials as a legitimate reason to withhold such records. Some might assert that test instruments, including question booklets and instruction forms are not considered protected health information, and therefore these are not subject to an individual's right of records access under the Privacy Rule. However, recall that standard 9.04 defines *test data* as "raw and scaled scores, client/patient responses to test questions or stimuli, and psychologists' notes and recordings concerning client/patient statements and behavior during an examination." Further, it specifies: "Those portions of test materials that include client/patient responses are included in the definition of *test data*." Therefore, if client/patient responses have been recorded on test protocols, this information cannot be separated from these test materials in the client/patient record (Fisher, 2003). It can be argued that the test protocol becomes a part of the patient record once responses of or notes about a client/patient are recorded on it. Please see further discussion below about addressing conflicting obligations.

HANDLING REQUESTS FOR TEST DATA

First, when in receipt of a request for release of data, the neuropsychologist must determine whether the request carries the force of law (Committee on Legal Issues, American Psychological Association, 2006). It is important to be knowledgeable about the laws governing test data release in your state. These state laws will in large part define how one must proceed in order to handle one's legal obligations when responding to release requests. State laws vary considerably in how test data release is governed in reference to court orders, subpoenas, or client/patient requests. As an illustration, some states mandate release in response only to court orders, while other states do not differentiate between court orders and subpoenas, requiring release in both instances. Also, if the request for data is not directly from the patient but appears to be authorized by the patient, it is advisable to contact the patient and confirm that the authorization indeed reflects the patient's current request for records.

Figure 1 presents a flowchart that is applicable to most situations when data are requested with appropriate written consent. The following variables are relevant: presence of written authorization from the patient or their appropriate designee, authority of state or federal courts, the setting (e.g., medicolegal versus clinical), the necessity or lack thereof to release to another professional, and any substantial harm that can be caused by release. The HIPAA pre-emption doctrine establishes a complicated relationship between state and federal law. In most instances, state law will supersede federal law if it gives the patient greater privacy from third parties or

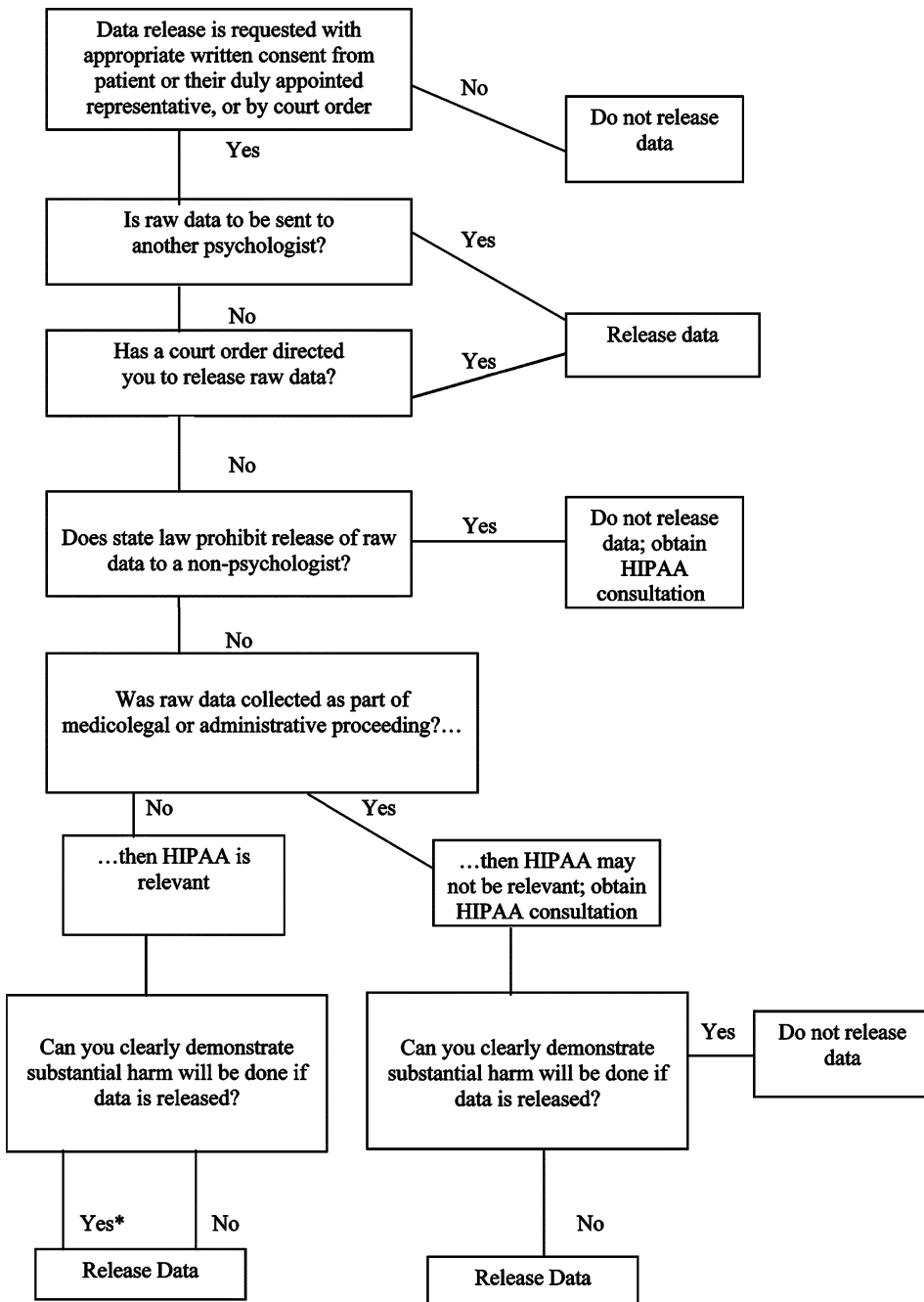


Figure 1 Release of test data. *Even if one can demonstrate that substantial harm may be done if data are provided, release may still be mandated under HIPAA and state regulations. Note that this exception to test release in Standard 9.04 is discretionary rather than mandatory. Again, there is no substitute for knowledge of the relevant statutes and ethical guidelines, and efforts can be made to resolve conflicting obligations while complying with data requests as outlined. Figure 1 reproduced and modified from Grote (2005) and used with permission of publisher.

gives the patient greater access to his/her records. In addition, a number of states incorporate APA Ethics standards into their regulatory scheme. Appropriate consultation in making determinations about resolution of conflicts between state and federal laws and ethical guidelines is recommended. If providers undertake due diligence in becoming educated about the relevant state and federal regulations and relevant ethical principles, and they make good faith efforts to meet obligations while resolving potential conflicts, few impasses are likely to result.

In general, most neuropsychology practitioners would consider test protocols to be *test material*, and would want to maintain test security, not violate copyright, and protect test item novelty and validity. However, because test protocols may become *test data* once client/patient responses are recorded on them, practitioners must be aware that they may be compelled to release such data by valid subpoena, court order, in response to a patient response under HIPAA, or other appropriate legal authority.

In attempting to resolve conflicting obligations in a responsible manner, neuro-psychologists may elect to offer the following alternatives to releasing test data that are also considered test material: (1) release data summary sheet alone; (2) release data with protocol stimuli blocked out; (3) release data to another neuropsychologist; or (4) release data set into a sealed record, or request a protective order of the test materials which would limit their release to the case. If a patient seeks test data and HIPAA applies, it is advisable to let the patient know of his/her legal right to the actual test data when offering these alternatives. In most situations, conflicts can be reconciled with such alternatives. Discussing conflicting obligations with the persons who request the data may be beneficial. The neuropsychology practitioner can also appeal to the court directly (if a court is involved) to negotiate suitable arrangements that maximize compliance with the Ethics Code. Specific requests or legal procedures might also be considered, such as asking the courts to determine through in camera proceedings whether the use of client records or test data is relevant, or filing a motion to quash subpoenas or filing protective orders (Committee on Legal Issues, American Psychological Association, 2006). When release of data includes test protocols, it is recommended that the neuropsychologist explicitly request that such data be handled in a manner that promotes the longevity of test stimuli, reduces the chances of coaching, and is in keeping with copyright law.

WHEN DOES ONE CONSIDER NOT RELEASING TEST DATA?

According to standard 9.04 of the Ethics Code, "Psychologists may refrain from releasing test data to protect a client/patient or others from substantial harm or misuse or misrepresentation of the data or the test, recognizing that in many instances release of confidential information under these circumstances is regulated by law." Also related, standard 9.09 requires that "Psychologists retain responsibility for the appropriate application, interpretation, and use of assessment instruments." Grounds for opposing or limiting production of test data should be considered carefully. Relevant consideration might include the jurisdiction of the court over the psychologist or test data, the scope of the request in reference to the relevance of obtained data to the issues before the court, or the potential impact

on both the public and profession of psychology of loss of valuable assessment tools (Committee on Legal Issues, American Psychological Association, 2006).

The previous 1992 Ethics Code mandated refraining from release of test results to “persons, other than to patients or clients as appropriate, who were not qualified to use such information.” Providers would often request that data be released to another psychologist or neuropsychologist to adhere to the standard. However, the 2002 Ethics Code does not include this mandate. While some professional organizations may have official statements that direct members to release test data only to qualified persons, providers must beware that such statements may not be current with existing national and state laws or ethical guidelines. Nonetheless, release to another psychologist or neuropsychologist may be the most effective way of reducing the likelihood of “misuse or misrepresentation of the data” (9.04) and of promoting the “appropriate . . . use of assessment instruments” (9.09). Therefore, neuropsychology providers may still reasonably request release of records directly to another psychologist or neuropsychologist, but they must be aware that law or professional ethics may mandate release of test data to non-psychologists.

Protecting a client/patient or others from substantial harm is one of the primary reasons to refrain from releasing data and can only be judged on a case by case basis. While the ethics code does not define *substantial harm*, it should be recognized that under HIPAA, access to designated record sets can only be denied if the psychologist has determined “in the exercise of professional judgment, that the access requested is reasonably likely to endanger the life or physical safety of the [patient] or another person” (HIPAA, 45CFR Section 164.524(a)). Minor discomfort will not be recognized by either the Ethics Code or HIPAA as a legitimate reason to deny access.

Many problems can be avoided with careful, thorough informed consent procedures. This is where the process of test release truly begins. During consent for testing, it could be specified that data recorded on protocol sheets will not be released, and that requests for information will be limited to provision of a report and a data summary sheet. The reasons for testing, intended use of and possible consequences of testing, and what testing information will be released to whom should be explicit (Committee on Psychological Tests and Assessment, American Psychological Association, 1996). Note that consent procedures, however, will not negate the need to meet obligations set by legal regulatory or ethical standards. Furthermore, providers are encouraged to write their reports taking into consideration the relative ease with which this information can also now be accessed.

ADDRESSING CONFLICTING OBLIGATIONS

It has long been recognized that there are times when two or more of the principles and standards of the Ethics Code can conflict, and times when the Ethics Code may conflict with other professional guidelines or state or federal law. The 2002 Ethics Code addresses this in its Introduction:

In the process of making decisions regarding their professional behavior, psychologists must consider this Ethics Code in addition to applicable laws and psychology board regulations. In applying the Ethics Code to their professional work, psychologists may consider other materials and guidelines that have been

adopted or endorsed by scientific and professional psychological organizations and the dictates of their own conscience, as well as consult with others within the field. If this Ethics Code establishes a higher standard of conduct than is required by law, psychologists must meet the higher ethical standard.

Standard 1.02 explicitly states:

If psychologists' ethical responsibilities conflict with law, regulations, or other governing legal authority, psychologists make known their commitment to the Ethics Code and take steps to resolve the conflict. If the conflict is unresolvable via such means, psychologists may adhere to the requirements of the law, regulations, or other governing legal authority.

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