

**Continuing education: Masking sources in Citations - Rick Stoddart**  
**IRB Meeting: January 15<sup>th</sup>, 2013**

**Scenario:**

What are best practices in disguising/masking citation information within a study's bibliography so as not to breach confidentiality of research participants?

For example: if a researcher interviews students in a Corvallis school and also cites specific Corvallis school policy documents, what are strategies to maintain student confidentiality that could be compromised by citing additional materials that may contain identifying information.

**Documents included:**

1. "Types of Risk in Qualitative Research" (2011). *The IRB Member Handbook*. P.134-135
2. "1.11 Rights and Confidentiality of Research Participants" (2010). *Publication Manual of the American Psychological Association*. P.16-17.
3. VandenBos, Gary R. (2000). *Disguising Case Material for Publication*.  
<http://www.apastyle.org/manual/related/vandenbos.pdf>

**Suggested Reference Example:**

**Citing a school's website.**

Elmhurst Community Unit School District 205 (2010). York High School parent/student handbook 2009-10. Retrieved February 6, 2010, from [http://elmhurstcusd205-il.schoolloop.com/cms/page\\_view?d=x&piid=&vpid=1238189827005](http://elmhurstcusd205-il.schoolloop.com/cms/page_view?d=x&piid=&vpid=1238189827005)

Modify to maintain confidentiality:

School Website (2010). Parent/student handbook 2009-10. Retrieved February 6, 2010.

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Example from:

<http://library.elmhurst.edu/files/2010/02/APAguidlines.pdf>

participant observation), questionnaires, surveys, interviewing, or review and analysis of existing data. Because of the potential range of activities involved, qualitative research can present special problems for IRBs, for investigators, and for the subjects themselves.

#### TYPES OF RISK IN QUALITATIVE RESEARCH

##### Breach of Confidentiality

Subjects routinely share the stories of their daily lives with friends and colleagues. But in many forms of qualitative social science research, an investigator collects information with the hope of publishing the results—not necessarily quoting the subjects' comments directly as a reporter might do, but often summarizing the cumulative knowledge gained from the research inquiry. If identities are poorly disguised, whether from others or from the participants themselves, then the subjects may risk embarrassment or more serious harm. Risks are not limited to published data; researchers should separate identifiers from sensitive data as soon as possible.

##### Violation of Privacy

Privacy refers to a state of being free from unsanctioned intrusion. Ordinarily, individuals have a right to privacy—that is, control over the extent, timing, and circumstances of sharing information about themselves with others. Violation of privacy contravenes the Belmont Report's principle of respect for persons.

##### Validation of Bad Behavior

Some research may unintentionally reinforce undesirable characteristics of research subjects. For example, an investigator studying recreational drug use among teens might need to develop a relationship of trust with the subjects, including being able to talk with them without criticizing their drug-taking behavior. A nonjudgmental relationship like this, with a senior university researcher, can have the unfortunate effect of persuading subjects that their behav-

ior is acceptable to wise adults. In cases where study activities may encourage harmful behavior on the part of the subjects, it may be appropriate for the IRB to discuss its concerns with the investigator to help narrow the gap between strict scientific objectivity and responsible social values.

##### Risk of Harm to Others

*Secondary research subjects* are individuals who do not themselves participate in the study but about whom the investigator obtains information via interview or other hearsay means. In December 1999, the Office of Protection from Research Risks (now OHRP) cited failure to obtain informed consent from secondary subjects as a finding in a letter of suspension of IRB authority. Oral historians and genetics researchers, among others, reacted promptly, insisting that extension of this regulatory interpretation would effectively halt much of their research, because they could not possibly obtain informed consent from everybody about whom they indirectly received information. As of this writing, the question is unresolved, but OHRP has not rescinded its interpretation, so IRBs should at least consider whether special consideration should be given to secondary subjects in studies where primary informants provide information about others.

#### INFORMED CONSENT

Although the content may differ, informed consent is no less important in qualitative research than it is in hypothesis-driven studies. However, much qualitative research is exploratory, and the areas of inquiry may not be apparent even to the research team. For this reason it is often impossible to inform subjects of all of the potential research procedures and risks. Ideally, as in all forms of research, the consent process should be sustained throughout the course of a subject's participation. As the researcher refines the study, subjects should be reminded that participation is voluntary, and their understanding of the risks and benefits of participation should be refreshed.



authors are expected to correct the record if they discover errors in their publications; they are also expected to give credit to others for their prior work when it is quoted or paraphrased.

The key element of this principle is that authors do not present the work of another as if it were their own work. This can extend to ideas as well as written words. If authors model a study after one done by someone else, the originating author should be given credit. If the rationale for a study was suggested in the Discussion section of someone else's article, that person should be given credit. Given the free exchange of ideas, which is very important to the health of intellectual discourse, authors may not know where an idea for a study originated. If authors do know, however, they should acknowledge the source; this includes personal communications. (For additional information on quotations and paraphrasing, see sections 6.03–6.08; for instructions on referencing publications and personal communications, see sections 6.11–6.20.)

**Self-plagiarism.** Just as researchers do not present the work of others as their own (plagiarism), they do not present their own previously published work as new scholarship (self-plagiarism). There are, however, limited circumstances (e.g., describing the details of an instrument or an analytic approach) under which authors may wish to duplicate without attribution (citation) their previously used words, feeling that extensive self-referencing is undesirable or awkward. When the duplicated words are limited in scope, this approach is permissible. When duplication of one's own words is more extensive, citation of the duplicated words should be the norm. What constitutes the maximum acceptable length of duplicated material is difficult to define but must conform to legal notions of fair use. The general view is that the core of the new document must constitute an original contribution to knowledge, and only the amount of previously published material necessary to understand that contribution should be included, primarily in the discussion of theory and methodology. When feasible, all of the author's own words that are cited should be located in a single paragraph or a few paragraphs, with a citation at the end of each. Opening such paragraphs with a phrase like "as I have previously discussed" will also alert readers to the status of the upcoming material.

## Protecting the Rights and Welfare of Research Participants

### 1.11 Rights and Confidentiality of Research Participants

**Certification of standards.** Standards 8.01–8.09 of the APA Ethics Code specify the principles psychologists are to follow in conducting research with humans and animals. Authors, regardless of field, are required to certify that they have followed these standards as a precondition of publishing their articles in APA journals (see <http://www.apa.org/> journals; see also Figure 8.2, pp. 233–234). Authors are also encouraged to include such certifications in the description of participants in the text of the manuscript. Failure to follow these standards can be grounds for rejecting a manuscript for publication or for retraction of a published article.

**Protecting confidentiality.** When researchers use case studies to describe their research, they are prohibited from disclosing "confidential, personally identifiable information concerning their patients, individual or organizational clients, students, research par-

ticipants, or other recipients of Confidential Information. Confidential Information is generally handled as case material, present in its publication from the persons over whom or patients, supervisees, Standard 3.08, Exploitation of the case material (sc employers) are identified altering specific characteristics of obfuscating case details.

Such disguising of details that would lead to being described (Tuckman) is a promising theoretical client-patient's gender omitted only if they are never, should never be adequately disguise identity. For additional information

### 1.12 Conflict of Interest

In all scientific disciplines, objective interpretation of economic and commercial interests may color such objective interpretation. In the presence of a conflict of interest, the researcher should disclose the potentially distorting influence of the conflict on the open course of action if known to others in that any conflict or bias

Whether an interest is not defined by a disclosure is not ordinarily sufficient to justify resulting fees, and personally received royalties on a board of directors may be a part of the payment.

In addition to disclosure, researchers should carefully consider disclosure of service, facility, or personally competing psychological of negative bias against

The previous example of the research. Researchers have potential conflicts of interest with a colleague or collaborator.



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ticipants, or other recipients of their services" (APA Ethics Code Standard 4.07, Use of Confidential Information for Didactic or Other Purposes). Confidentiality in case studies is generally handled by one of two means. One option is to prepare the descriptive case material, present it to the subject of the case report, and obtain written consent for its publication from the subject. In doing so, however, one must be careful not to exploit persons over whom one has supervisory, evaluative, or other authority such as clients, patients, supervisees, employees, or organizational clients (see APA Ethics Code Standard 3.08, Exploitative Relationships). The other option is to disguise some aspects of the case material so that neither the subject nor third parties (e.g., family members, employers) are identifiable. Four main strategies have emerged for achieving this: (a) altering specific characteristics, (b) limiting the description of specific characteristics, (c) obfuscating case detail by adding extraneous material, and (d) using composites.

Such disguising of cases is a delicate issue because it is essential not to change variables that would lead the reader to draw false conclusions related to the phenomena being described (Tuckett, 2000). For example, altering the subject's gender in a case illustrating a promising therapy for rape trauma might compromise its educative value if the client-patient's gender played a significant role in the treatment. Subject details should be omitted only if they are not essential to the phenomenon described. Subject privacy, however, should never be sacrificed for clinical or scientific accuracy. Cases that cannot adequately disguise identifiable subject information should not be submitted for publication. For additional information on the presentation of case material, see VandenBos (2001).

## 1.12 Conflict of Interest

In all scientific disciplines, professional communications are presumed to be based on objective interpretations of evidence and unbiased interpretation of fact. An author's economic and commercial interests in products or services used or discussed in a paper may color such objectivity. Although such relations do not necessarily constitute a conflict of interest, the integrity of the field requires disclosure of the possibilities of such potentially distorting influences where they may exist. In general, the safest and most open course of action is to disclose in an author note activities and relationships that if known to others might be viewed as a conflict of interest, even if you do not believe that any conflict or bias exists.

Whether an interest is significant will depend on individual circumstances and cannot be defined by a dollar amount. Holdings in a company through a mutual fund are not ordinarily sufficient to warrant disclosure, whereas salaries, research grants, consulting fees, and personal stock holdings would be. Being the copyright holder of and/or recipient of royalties from a psychological test might be another example. Participation on a board of directors or any other relationship with an entity or person that is in some way part of the paper should also be carefully considered for possible disclosure.

In addition to disclosure of possible sources of positive bias, authors should also carefully consider disclosure when circumstances could suggest bias against a product, service, facility, or person. For example, having a copyright or royalty interest in a competing psychological test or assessment protocol might be seen as a possible source of negative bias against another test instrument.

The previous examples refer to possible conflicts of interest of a researcher in the conduct of the research. It is important to recognize that reviewers of research reports also have potential conflicts of interest. In general, one should not review a manuscript from a colleague or collaborator, a close personal friend, or a recent student. Typically, the action

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**Draft, September 29, 2000**

**Disguising Case Material for Publication**

Gary R. VandenBos

American Psychological Association

The APA Publications office regularly receives about one request per month for "guidelines" on disguising clinical case material for publication. These requests come from authors as well as from editors of other journals asking APA to provide some suggestions on how to most appropriately disguise published clinical case material without altering critical elements of the case itself. Thus far, we have been unable to give them any guidelines because we have not found any information on typical practices in disguising clinical case material in the psychology database. The unavailability of this vital element in APA publishing guidelines has prompted the APA Publications and Communication Board and the APA Chief Editorial Advisor to consider the inclusion of a brief guideline statement on disguising clinical case material for publication in the next revision of the APA Publication Manual.

**APA Survey of Disguising Practices in Clinical Case Studies**

In support of this plan, we conducted a brief survey to get a sense of "typical practice" around disguising clinical case material. In August 2000, we examined all published issues of 6 APA journals from 1996 through 2000 and selected the names of all senior authors whose articles in these journals included an individual case description. The APA journals examined were Professional Psychology: Research and Practice, Psychotherapy, Counseling Psychology, Psychology of Addictive Behavior, Psychoanalytic Psychology, and Family Psychology. We found a total of 153 senior

authors. On September 1, 000, we mailed out a cover letter and accompanying one-page questionnaire to all 153 senior authors. The survey questionnaire included a list of 24 variables that are typically included in each clinical case history. We asked these authors which of these 24 variables they had ever changed, and they were also asked which ones they felt should never be changed. In addition, respondents were also asked to list other case features, if any, which they changed in writing case material for publication. Within three weeks we received 67 completed questionnaires, a response rate of 44%.

### **Survey Results**

The first question asked, in an open-ended way, was "How does the respondent disguise the facts of the case in order to protect the subject's privacy?" Three main strategies emerged: (1) altering specific characteristics, (2) limiting the descriptions of specific characteristics, and (3) obfuscating case detail by adding extraneous material. The most frequently used approach was to alter specific details, with changing demographic characteristics being by far the most frequent factor mentioned (although altering family background and identifying features came in almost tied for a close second). When a "limiting" description approach was used, the most frequently mentioned methods were deleting truly unique information that would identify the individual and severely limiting the number of case related variables described; these approaches were far less frequent than altering specific characteristics. In terms of the obfuscation approach, the primary strategy was to create a composite illustrative case that was in fact based on several cases.

We provided respondents with a list of 24 case variables, which could be altered in order to disguise the individual's identity. In addition, respondents were asked to give additional elements, if any, that were changed in order to disguise the case. We also

asked respondents which of the 24 variables should never be changed in the "disguising" process. These data are presented in Table 1. Overall, respondents reported an average of 6.12 variables ever changed across one or more case study descriptions. Respondents also checked an average of 1.67 variables that should never be altered in clinical case descriptions (but it should be noted that 64% of respondents said that none of the items should ever be altered). The most frequently changed aspects of clinical cases were the individual's occupation (77.6%) and employment status (59.7%). These were followed by age (58.2%), location in the country (55.2%), number of children (43.3%), sex of the patient (35.8%), information on the patient's parents (35.8%), ethnicity (34.3%), education (28.4%), religion (25.4%), and marital status (23.9%). The only two variables where respondents gave somewhat frequent "never alter" comments were for sex of subject (13.4%) and ethnicity (8.9%). Actual clinical material such as precipitating events, clinical background, presenting problem, reported thoughts, feelings, and behaviors were rarely altered and were the most frequently identified variables which should never be altered.

In a separate question, we asked the respondents to estimate the number of features typically altered in the process of disguising a clinical case. Of the 37 respondents who provided a specific number, the average number of variables that respondents reported they changed was 3.69.

We asked whether or not the respondent provided the individual being described with a copy of the clinical case description prior to publication and obtained the individual's written permission to publish it. Forty-five respondents (67.2%) answered "No." Fifteen respondents said, "Yes;" 7 respondents gave such responses as "Sometimes," "Obtained permission (mostly verbal) only, but did not show the client the material," or gave no answer.

We asked whether, at the beginning of treatment, respondents informed their patients that they sometimes wrote clinical case descriptions for publication and described procedures that might be later used to secure their permission to publish the case material. Only five respondents (7.5%) reported routinely doing this at the beginning of treatment.

We also asked whether or not after writing a clinical case description, they had either the patient or a colleague read the description and decide whether the patient's identity could be guessed. Twenty-eight respondents (41.8%) said "No." Thirty-five respondents (52.2%) reported that they went through the process of checking on how effective they were in disguising the clinical case material. Four respondents fell under the "Sometimes" and "No answer" categories.

### **Conclusion**

On average respondents reported that they changed an average of 3.69 elements about a specific clinical case in the process of preparing a clinical case description for publication. Overall, out of 24 possible clinical case variables considered, respondents reported 6.12 variables that they had changed in a case study at some point in their publication careers. A majority of respondents reported having changed four variables in one or more case study reports; these were occupation, employment, age, and geographic location in the country. In addition, between 25% and 49% of respondents reported having altered seven additional background variables. These variables were, in descending order, number of children, sex, own parent information, ethnicity, education, religion, and marital status. Core clinical information was rarely reported as being changed, and this material was high on the list of variables that respondents said should never be altered.



Table 1. Elements of case descriptions that respondents have altered or believe should never be altered

Case elements	Have altered		Should never alter	
	No.	Percent	No.	Percent
Occupation	52	77.6	0	0.0
Employment setting	40	59.7	0	0.0
Age	39	58.2	3	4.5
Geographical location	37	55.2	1	1.5
No. of children	29	43.3	2	3.0
Sex	24	35.8	9	13.4
Parental information	24	35.8	4	6.0
Ethnicity	23	34.3	6	9.0
Education	19	28.4	2	3.0
Religion	17	25.4	2	3.0
Marital status	16	23.9	3	4.5
Precipitating events	11	16.4	5	7.5
Clinical background	10	14.9	6	9.0
Presenting problem	9	13.4	9	13.4
Secondary symptoms	9	13.4	5	7.5
Others' involvement	9	13.4	4	6.0
Reported behavior	8	11.9	8	11.9
Others' statements	8	11.9	3	4.5
Others' behavior	7	10.4	3	4.5
Reported thoughts	5	7.5	10	14.9
Reported feelings	4	6.0	10	14.9
Psychological test data	4	6.0	9	13.4
Drug or alcohol use	3	4.5	4	6.0
Criminal behavior	3	4.5	4	6.0
Total cases	67		67	