

## AMA Manual of Style

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### Protecting Research Participants' and Patients' Rights in Scientific Publication

Annette Flanagin

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Item type: section

The right of the research subject to safeguard his or her integrity must always be respected. Every precaution should be taken to respect the privacy of the subject and to minimize the impact of the study on the subject's physical and mental integrity and on the personality of the subject. World Medical Association Contemporary rules for protecting the rights of individuals (namely, research participants and patients) in scientific publication have their foundations in doctrines developed during the mid-20th century: the Nuremberg Code, the World Medical Association's Declaration of Geneva, and the World Medical Association's Declaration of Helsinki, as well as the

### Patients' Rights to Privacy and Anonymity

Annette Flanagin

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UPDATE: We will discontinue using quotation marks to identify parts of an article, but retain the capitalization; eg, This is discussed in the Methods section (not the "Methods" section). This change was made February 14, 2013. Privacy is a state or condition of limited access to matters of a personal nature, including but not limited to personal information, as well as an individual's right to control such access. When individuals grant others some form of access to themselves (eg, during a patient-clinician encounter), the individuals are exercising their right to privacy, but they are not waiving this right. Thus, a

### Ethical Review of Studies and Informed Consent

Annette Flanagin

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UPDATE: We will discontinue using quotation marks to identify parts of an article, but retain the capitalization; eg, This is discussed in the Methods section (not the "Methods"

section). This change was made February 14, 2013. To protect the safety and dignity of individuals who participate in research, academic institutions and grant agencies require that any study involving human participants be reviewed and approved by an institutional review board (IRB) or independent ethics review committee. (Note: When referring to individuals who participate in studies, the word participant is preferred to subject [see , Correct and Preferred Usage, Correct and Preferred

## Patients' Rights in Essays and News Reports in Biomedical Journals.

Annette Flanagin

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In essays and news stories in biomedical journals, descriptions and photographs of individuals are often included. However, if these descriptions or photographs depict patients or anyone in an actual patient-clinician encounter who is identifiable, the authors or writers should be asked to “deidentify” those patients. Identifying details may be omitted but may not be altered or falsified. If patients cannot be deidentified, their written informed consent must be obtained. Fictionalized cases and reports generally should not be presented except in rare cases and unless this is made clear to readers (eg, a hypothetical case to explain a clinical scenario or

## Rights in Published Reports of Genetic Studies

Annette Flanagin

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UPDATE: We will discontinue using quotation marks to identify parts of an article, but retain the capitalization; eg, This is discussed in the Methods section (not the “Methods” section). This change was made February 14, 2013. The rules for ethical approval of studies and for obtaining informed consent also apply to genetic studies of family pedigrees and population-based samples. However, obtaining written informed consent from all members of a large pedigree (many of whom may be deceased or unaware of the collection of family data) may be difficult or impossible. Proposals for obtaining some form of group consent and for