Patient and Study Participant Rights to Privacy in Journal Publication

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Personal health information is defined as identifiable data related to the past, present, or future health status of an individual. Personal health information has been considered protected health information, which is governed by ethical principles and laws to shield against intrusions into an individual's rights to privacy. However, rapid growth in the volume of electronic health records, access to other health information, and increasing use of personal health data by artificial intelligence, social media, technology, and other companies are threatening the traditional tenets of privacy protections for personal health information. As Gostin and colleagues have warned, “Individuals’ health data are now poorly understood and largely unregulated.” Clearly, new or enhanced legislative privacy safeguards are needed to protect personal health information.

The right to privacy for personal health information also extends to reports in scientific and clinical publications. When patients and study participants grant authors and researchers access to personal information during a patient-clinician or participant-investigator encounter, they allow access to personal information but do not waive all such rights. During and following these encounters, privacy and confidentiality should be maintained, and identifiable personal information should not be made public via publication without consent.

Authors and editors should ensure proper reporting of ethical protections of patients and research participants in scholarly publications. This includes following the principles of ethical review and approval of research and informed consent, or waiver or exemption thereof. This also includes protection of patients and research participants’ rights to privacy in scholarly publication by withholding or removing identifiable personal health information from content submitted to journals unless permission for publication has been provided. Such content includes descriptions in text, demographic data in tables, detailed test results, photographs and other digital images, genetic pedigrees, other detailed data displays, video, and audio.

Identifiability

The threshold for identifiability rests with the individuals who are the focus of the report and not only authors or readers and online viewers of published content. Placing black bars or other objects over the eyes of patients or partially obscuring a face or body part should not be used in manuscripts or videos because these measures do not ensure deidentifiability. Patients can identify themselves, or be identified by others, from detailed descriptions as well as photographs or video with identifiable features, such as body physique, dermatologic presentations, and even clothing worn at the time a photograph was taken or video was recorded. Thus, authors must use care when submitting manuscripts that have detailed descriptions of patients or study participants in text and tables or identifiable depictions in figures and clinical images, video, and audio.

Case Descriptions, Case Reports, Photographs, Video, and Audio

Case descriptions and case reports serve as important contributions to the medical literature and medical education, especially in some specialties. Traditionally, such reports have included specific details about patients. However, only those personal and clinical details essential for understanding and interpreting a specific report should be included. Often, the description can be more general to ensure anonymity, without substantive loss of meaning. Although the degree of specificity needed will depend on the context of what is being reported, specific ages, race/ethnicity, and other sociodemographic details should be presented only if clinically or scientifically relevant and important.

To protect a patient’s right to privacy, nonessential identifying data (eg, sex, age, race/ethnicity, occupation, and location of care or treatment) should be removed from a manuscript, unless clinically or epidemiologically relevant or important. In some cases, cropping clinical images to remove identifiability may suffice. However, omission of some detail may be problematic. For example, omitting a patient’s location from a case report might seem appropriate, but such information may be needed later during an epidemiologic analysis of factors associated with a disease outbreak. More important, changing specific demographic data, such as sex or age, in case descriptions in an attempt to secure anonymity may introduce false or inaccurate data into the medical literature and could be considered falsification.

Patients have recognized descriptions of themselves in medical journal articles without accompanying photographs and even after some details have been removed. In several cases, patients who had not consented to publication of their personal details in medical journals recognized themselves or were recognized by others in specific articles or subsequent news coverage. In several cases, published reports have been retracted and partially or completely removed from publication after patients or family members identified themselves.

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Permission and Consent for Publication of Identifiable Information

The International Committee of Medical Journal Editors (ICMJE),6 the Committee on Publication Ethics (COPE),19 and a number of medical journals, including JAMA and the JAMA Network journals, have recommendations for protecting patients’ rights to privacy and require consent for publication from any potentially identifiable patient.5,10-12,20,21 If detailed descriptions or identifiable data, photographs, video, or audio are included in a manuscript or online supplement, authors should obtain permission from the identifiable patients (or legally authorized representatives) to publish the information. Such consent should include an opportunity for the patient to read the manuscript or review video or audio files before publication or waive the right to do so.5

Although institutions often obtain consent from patients to use information obtained in clinical encounters or during research for educational purposes, such consent does not always adequately address publication in journals or via the internet. Some institutional consent forms permit a revocation of the consent at a later date without qualification and thus may not be acceptable. An example of the patient permission for publication form (https://jamanetwork.com/DocumentLibrary/InstructionsForAuthors/PatientConsent.pdf) used by the JAMA Network journals is available online.22 The JAMA Network journals also have versions of this form translated into multiple languages, which are available on request.

The JAMA Network journals ask authors to indicate that permission for publication from identifiable patients or study participants has been obtained in the Acknowledgment section at the end of the manuscript as shown in these examples:

Additional Contributions: The authors thank the study participants for participating in this study and enabling this discovery to be made and the parents and adult children of the families in Figure 1 for providing permission to publish this information.

Additional Contributions: We are grateful to the patients who provided permission after reviewing the manuscript to publish this information.

Some authors have expressed concern that obtaining consent from identifiable patients is burdensome.21,23-26 Others have expressed concern that the process of obtaining consent for publication may be offensive to the patient or the patient’s family members.23 However, subsequent discovery of unauthorized publication of a patient’s information that results in identification or unwanted publicity could be even more disturbing9,16-18 and may result in legal claims related to incursion of privacy16,27 or may contravene national privacy laws, such as the US Health Insurance Portability and Accountability Act (HIPAA)28,29 or those of other countries.30-32

Generally, JAMA Network journal editors have found that authors usually report that patients are willing to share their information in journal articles. The requirements for patient permission or deidentification apply to all types of manuscripts, including case reports and case series as well as genetic analyses, other types of studies, opinion pieces, and narrative essays. If authors are unable to obtain permission for publication and the patients cannot be deidentified, JAMA Network journal editors will not publish the articles.

Genetic Pedigrees

The rules for obtaining consent to publish identifiable information also apply to genetic studies of family pedigrees and population-based samples.5,14 However, obtaining written consent for publication of identifiable information from all members of a large pedigree or populations-based sample may be difficult or impossible. Recommendations for obtaining group consent and for avoiding the publication of information about identifiable family members who cannot give their permission have been proposed.33 All such studies must be reviewed by an ethics committee or review board (or granted a formal waiver or exemption from such review), and if individual participants are considered to be human research participants and are considered to be identifiable, informed consent may be required.34,35 If individuals are to be identified in a subsequent publication, consent for publication could be addressed as part of the informed consent process.14 The Methods section of all reports of genetic studies should include statements about ethical review and approval or waiver and informed consent procedures or waivers; this section may include consent for publication of identifiable information.

As with reports of other types of studies, nonessential identifying information should be removed from or made anonymous in reports of genetic studies. However, data should not be altered or modified in an attempt to disguise the identities of individuals or family members, although relevant information may be masked.14,33 For example, in figures displaying pedigrees and family relationships, diamonds or sex-neutral symbols can be used instead of circles and squares if the sex of family members is not essential to the report (eg, if the disease is known not to be sex linked), or sections of pedigrees may be excluded from pedigree charts or not described in detail if appropriate consent for publication cannot be obtained as long as such omissions are noted.

If identifiable personal information about the participants in genetic pedigree studies is required for scientific or clinical interpretation, consent for publication should be obtained. For example, a recent genetic analysis that identified a novel homozygous duplication of the gene RYR2 among young Amish individuals with exertion-related sudden death and sudden cardiac arrest was published in JAMA Cardiology.36 The report includes identifiable family members and children in the text and in a genetic pedigree published as a figure, and the authors obtained permission for publication of the index cases and identifiable family members. The Acknowledgment section in the article indicates:

Additional Contributions: The authors thank the study participants for participating in this study and enabling this discovery to be made and the parents and adult children of the families in Figure 1 for providing permission to publish this information.
Narrative Essays

Descriptions of individuals are often included in narrative essays in journals. However, authors should not include identifiable personal information of patients in such essays without their permission or should ensure that any such descriptions are anonymized.2, 20 As with other types of articles, identifying details may be omitted, but deidentification should not include altering data or facts or presenting composites of multiple patients as an actual single case. If patients cannot be deidentified, their written consent for publication must be obtained. Permission for publication is also required if narrative essays are accompanied by identifiable photographs, video, or audio of patients. These requirements apply to patients of any age, to those who are unable to provide consent, and to those who are deceased, in which case an authorized legal representative or family member may provide permission for publication. Fictionalized cases generally should not be presented unless this is made clear to readers (eg, a hypothetical case to explain a clinical scenario or a fictional essay in which it is made clear to the readers that it is fictional).

Social Media

Posts in journal-related social media and online discussion groups are subject to the same principles with regard to patient privacy.3 Content should be anonymized or permission should be obtained from patients and research participants whose identifiable information will be featured in social media posts. Clinicians should understand the rights of patients to privacy when posting summaries of patient encounters, photographs, video, or audio on social media.

Conclusions

The rights to privacy of patients, study participants, and others extend to manuscripts and multimedia that are submitted to and published in scientific and clinical journals. In general, identifiable detail can be removed from descriptions, but such deidentification may not be possible with photographs, video, or audio. If identifying information about a patient or study participant is required for scientific or clinical presentation and interpretation of content submitted to a journal, consent for publication should be obtained.

REFERENCES

5. Flanagin A. Protecting research participants' and patients' rights in Scientific Publication, in the AMA Manual of Style.5

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