Patient Privacy, Photographs, and Publication

Cody A. Koch, MD, PhD; Wayne F. Larrabee Jr, MD

As physicians, our most important responsibility lies in protecting patients, which includes a patient’s right to privacy. While patients’ rights are our foremost concern, the advancement of medicine relies on collaboration and the open exchange of ideas and research. The need to collect information about patients in the course of conducting research can present challenges in maintaining patient privacy and anonymity. Never is this more evident than in the practice of facial plastic and reconstructive surgery. Studies of many disease processes rely heavily on laboratory results and/or clinical radiographs; however, the primary form of “data” in facial plastic and reconstructive surgery are often patient photographs. While identifying information can easily be removed from laboratory data, photographs of patients present a unique challenge.

Patient photographs are not easily de-identified. Photographs of an ear, eye, or skin lesion in isolation may not seem revealing. However, the true test of anonymity is not whether the friends, family, or acquaintances of the patient could recognize them from a photograph but rather whether the patient could recognize their own image. One must be cautious that the presence of a birthmark, tattoo, or prominent mole included in a photograph, no matter how small, might unmask the patient’s identity.

In some cases in which the entire face of the patient is included in the photograph, the anonymity of the patient cannot be guaranteed. Historically, attempts at concealing the identity of patients included masking, which consists of placing black bars over the eyes. This practice was abandoned by most journals in the 1980s as it became apparent that patients could still be recognized by others and easily by themselves.

Efforts addressing patient privacy and clinical photographs were included in the US Health Insurance Portability and Accountability Act of 1996 (HIPAA), which requires that full-face patient photographs or similarly identifiable images be completely removed from the medical record for the record to be considered de-identified. Obviously, patient photographs included in publications convey critical information, and their exclusion would undermine the message being communicated. In situations in which patient anonymity cannot be guaranteed, authors must abandon attempts to de-identify clinical photographs and transition to asking permission from the patient to publish their likeness.

Facial plastic and reconstructive surgeons should obtain written informed consent prior to obtaining any patient photographs even if the intent is not to publish the images. Failure to obtain patient permission to be photographed can be considered an invasion of privacy even if the photographs are kept only as a confidential part of the medical record. In addition to the informed consent obtained at the time the patient is photographed, informed consent is necessary for publication. The International Committee of Medical Journal Editors released a position statement in 1995 stating that identifying information, such as photographs, not be published unless the publication is necessary for scientific purposes and the patient has granted informed consent.

Many journals, including JAMA Facial Plastic Surgery, JAMA, and other JAMA Network journals require patients to sign a journal-specific informed consent form prior to publication for any patients who are identifiable in text descriptions or photographs. Some authors have expressed frustration at this requirement, citing the inability to predict which journal a manuscript will be submitted to at the time initial informed consent is obtained. Others have expressed concern about the difficulty of locating and contacting patients to obtain informed consent after the fact. While additional time may be required to obtain journal-specific consent, Hood et al found that 85% of patients could be successfully located and consent obtained.

The rationale behind this requirement lies in the protection of not only the patient but the authors and journal as well. The permission form used by JAMA Facial Plastic Surgery includes all vital aspects of informed consent and has been vetted by the appropriate legal counsel to ensure the appropriate protection of all involved. While many authors have relied on standard structured informed consent forms available from their institutions, the editorial staff of JAMA Facial Plastic Surgery frequently note some common omissions on these standard permission forms. For example, all patients identifiable by their photographs or detailed case descriptions in text of a manuscript submitted for a publication should be given the opportunity to review the manuscript and materials in which they are included or waive their right to do so. In addition, the permission form must include provisions for the publication of the material on the Internet. These provisions are frequently omitted from standard forms, perhaps surprising given the common practice of publishing and displaying journal content online, not just in print.

There may be exceptional cases in which authors have obtained prior written informed consent for the use of a patient’s photographs or detailed case descriptions in publications but are unable to locate the patient to obtain a signature for the JAMA Facial Plastic Surgery permission form. In these unique circumstances, editorial staff and legal counsel representing JAMA Facial Plastic Surgery will review the previously obtained informed consent on an individual basis. If all aspects of informed consent are adequately covered in the author’s informed consent form, an exception to the require-
ment may be made so as not to preclude publication of poten-
tially valuable information.

Whenever questions arise about obtaining informed con-
sent for publication, one should act conservatively and strive
to preserve the patient’s privacy and anonymity. The comple-
tion of a specific informed consent form for patient clinical pho-
tographs to be included in JAMA Facial Plastic Surgery may
seem tedious and unnecessary, but this requirement serves to
protect the interests of all involved. Although an individual-
ized review process exists in the event that a patient cannot
be located to sign the journal-specific form, this should be
viewed as the exception, and all good faith attempts should
be made to follow the established informed consent process
of JAMA Facial Plastic Surgery.

ARTICLE INFORMATION

Author Affiliations: Division of Facial Plastic Surgery, Department of Otolaryngology–Head and
Neck Surgery, University of Washington, Seattle (Koch, Larrabee); Larrabee Center for Facial Plastic
Surgery, Seattle, Washington (Larrabee).

Corresponding Author: Wayne F. Larrabee Jr, MD,
Larrabee Center for Facial Plastic Surgery, 600
Broadway, Ste 280, Seattle, WA 98122 (larrabee
@uw.edu).

Published Online: July 25, 2013.

Conflict of Interest Disclosures: None reported.

REFERENCES


2. Segal J, Sacopulos MJ. Photography consent and
2010;18(2):237-244.

3. International Committee of Medical Journal
Editors. Protection of patients’ rights to privacy. BMJ.

Protecting research participants’ and patients’
rights in scientific publication. In: Iverson C,
Christiansen S, Flanagan A, et al, eds. AMA Manual of
Style: A Guide for Authors and Editors. 10th ed. New

5. Hood CA, Hope T, Dove P. Videos, photographs,
and patient consent. BMJ. 1998;316(7136):1009-
1011.

publication of identifying material in the JAMA
/faci/PatientConsent.pdf. Accessed February 24,
2013.

Opinion Editorial

336 JAMA Facial Plastic Surgery
September/October 2013 Volume 15, Number 5
jamafacialplasticsurgery.com