Protection of Patients’ Right to Privacy in Clinical Photographs, Video, and Detailed Case Descriptions

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Dermatology, one of the most visually oriented fields of medicine, relies on inspection of the skin by a physician trained to perceive and interpret the skin clues to be able to make a diagnosis and demonstrate response to treatment. Clinical photographs are the way records are kept; clinical processes are compared over time, and communication occurs with our colleagues to teach about dermatologic processes and obtain consultations. Such communication needs to be mindful of protecting the patients’ right to privacy. Collecting information about patients in the course of conducting research can present unique concerns about maintaining patient privacy and anonymity. While these concerns about research are usually mitigated by submission of research protocols and amendments to those protocols to the institutional review board with the requirement of deidentification of data, case reports and observations do not come under the purview of the institutional review board; thus, it is important for clinicians to understand how to protect the privacy of their patients when publishing case reports. While identifying information can easily be removed from self-reported surveys, laboratory tests, and pathology data, photographs and videos of patients are not easily deidentified, and often detailed descriptions of patients are needed for reports to be scientifically complete, clinically meaningful, and educational.

Photographs that include an ear, eye, facial hair, or skin lesion may not seem to reveal the person’s identity to the reader, but the test of anonymity is whether the patient could recognize his or her own image. This can be a difficult test to pass. Even a birthmark, tattoo, jewelry, clothing, nail polish, or unique mole included in a photograph might reveal the patient’s identity. The Figure shows 3 examples of images that required patient permission to publish.\(^1\)\(^-\)\(^3\) In the past, attempts at concealing the identity of patients included masking, which consists of placing bars over the eyes or pixelating the areas over the eyes. Masking of facial images was abandoned at least 2 decades ago.\(^4\)\(^-\)\(^6\) Now the standard is careful cropping to remove identifying features while attempting to preserve the elements of the clinical process that is being conveyed. This can prove to be challenging if the image is not properly staged and framed. In situations in which patient anonymity cannot be guaranteed, authors must abandon attempts to deidentify clinical photographs and related text description and ask permission from the patient to publish their likeness and other identifying information. In 1995, the International Committee of Medical Journal Editors released a position paper stating that identifying information, such as photographs, should not be published unless the publication is necessary for scientific purposes and the patient has granted informed consent.\(^7\)

Proper staging and framing of a patient prior to taking a photograph or recording video is key. The physician should have the patient remove identifying and visually distracting jewelry and clothing.\(^8\) If certain articles cannot be easily removed, they may be draped with a solid-colored drape such as a surgical towel, paper drape, or photography bib. Written informed consent needs to be obtained prior to taking any patient photographs, even if the intention is not to publish the images. As part of this consent, the patient should be asked to give permission to have the image published in a medical journal. The permission should give the patient the right to review the manuscript or waive the right to review the manuscript, which should include any photographs or videos. JAMA Dermatology, JAMA, and the other JAMA Network journals require patients to sign a JAMA Network informed consent form prior to publication for any patients who are identifiable in text descriptions or photographs.\(^6\) Since authors may not be able to predict which journal a manuscript will be submitted to at the time the initial informed consent is obtained, the need for patient consent may be perceived as an unnecessary burden. If the author chooses to wait until the manuscript is completed, it may be difficult to locate and contact patients to obtain informed consent after the fact. Furthermore, if the patient dies, then the next of kin will need to be asked to sign the release, which can be difficult for the physician.

While authors may wish to rely on standard institutional informed consent forms, such as those used for surgical procedures, with a few incorporated sentences regarding photographs, the editorial staff of JAMA Dermatology frequently note omissions on these standard permission forms. To summarize the key points, all patients identifiable by their photographs, detailed case descriptions, or pedigrees in a manuscript 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, and this permission must be irrevocable. Obviously, once an article about a patient is published, the identifying information and material cannot be unpublished.

Whenever a physician has a question about the need to obtain informed consent for publication of photographs, video, or descriptive text of a patient, the physician should act conservatively and strive to preserve the patient’s privacy and anonymity. If identifying information is essential to the clinical message or scientific importance of the article, permission from...
the patient (or parents of children) is needed. The completion of a specific informed consent form for patient clinical photographs and other identifying material to be included in *JAMA Dermatology* may seem like a burden, but this requirement serves to protect the interests of all involved. Additional information about this policy is available in the *JAMA Dermatology* Instructions for Authors. The JAMA Network Patient Permission Form granting authors permission to publish patients’ photographs, video, and other identifying information may be obtained from the *JAMA Dermatology* web site at http://files.jamanetwork.com/derm/PatientConsent.pdf. We encourage authors to contact us in advance by sending an email to jamaderm@jamanetwork.org if they have any questions about this policy before submitting their manuscripts.

**REFERENCES**


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Screening for Nodal Metastasis and Its Challenges
Nodal Needles in the SCC Haystack

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Most of us who treat cutaneous squamous cell carcinoma (cSCC) have had patients who develop nodal metastasis. However, such metastases are rare, with risks from single-institution cohorts hovering around 4.0%. For most dermatologists in practice, the number is likely lower. This rarity makes it difficult for physicians to select out the few patients who may need nodal staging from the multitude of patients with cSCC we see daily. If we use the 10% or greater risk generally considered appropriate for melanoma, the challenge of identifying who is in that 10% group remains because there is little firm prognostic data available for cSCC. Assuming we could accurately identify which patients have that 10% risk, we are still not sure how best to evaluate lymph node basins because there are no controlled studies of nodal staging modalities in cSCC. A survey study of Mohs surgeons reported that there is no consensus as to the best way to radiologically stage nodal basins and that more than 20% of respondents did not perform any nodal staging of patients they thought had a 10% risk of nodal metastasis. Thus, the only thing that is clear is that we are presently unclear. Schmitt and colleagues are therefore to be congratulated for their study in this issue of JAMA Dermatology because it is the first to use a systematic approach to begin to shed some light on this very gray area.

The current variation in nodal staging practices among physicians’ likely stems from lack of data on whom to stage and lack of confidence that subclinical nodal disease can be detected radiologically. Studies of radiologic imaging (computed tomography and positron emission tomography/computed tomography) have shown relatively low sensitivity in picking up subclinical nodal disease in many cancers, including cSCC. Ultrasonography fares better, with a sensitivity of 80% for vulvar tumors and 89% for head and neck tumors, but it is not widely available for nodal screening. Sentinel lymph node biopsy (SLNB) is more sensitive and specific than radiologic imaging, with few false-negative results (even in head and neck tumors) and low morbidity. Yet the utility of SLNB in cSCC is markedly understudied. Unlike melanoma where multiple large studies have sought to define which patients are suitable for SLNB, data are limited for cSCC. This is likely because most patients with cSCC do well, and the small yet real subgroup at risk for metastasis has not been well defined. Tumor staging systems attempt to stratify patients based on their risk of developing adverse outcomes, particularly metastasis and death. Identification of such patients is critical in defining a high-risk cSCC group in which nodal staging including SLNB could be considered.

The study by Schmitt et al4 is the first to apply tumor staging criteria to cSCC cases that have undergone SLNB. They were able to assign tumor stage to 130 cases via the American Joint Committee on Cancer (AJCC) staging system and to 117 via the alternative staging system. As the authors acknowledge, the cases studied were garnered from previously published data, and thus there were no uniform inclusion criteria for SLNB eligibility. Though this is a limitation, it is also a reflection of the real-life lack of precision clinicians are faced with in making treatment decisions for patients with high-risk cSCC. The study found no cases of positive SLNs in tumors smaller than 2 cm in diameter. The majority (13 of 18 [72%]) of the positive SLN cases were AJCC stage T2 tumors. However, most cases in the study (109 of 130 [92%]) were AJCC stage T2, so it stands to reason that most of the positive SLNs would be in this group. Only 5 cases (4%) in the study were in the upper AJCC stages (T3/T4), precluding meaningful evaluation of risk of SLN positivity in these stages. In the alternative staging system, only 20% (23 of 117) of cases were in the upper stages (T2b/T3), yet a slim majority (8 of 14 [57%]) of the positive SLNs occurred in these upper stages. We agree these data indicate that T2b tumors may comprise a group worthy of further study of SLNB utility. The risk of SLN positivity was nearly 30% in this group, which warrants careful consideration of SLNB if this figure holds up in larger studies with uniform inclusion criteria.

However, these data also point out some important limitations in our current understanding of high-risk cSCC and subsequently which patients require nodal staging. Some of the patients undergoing SLNB had T1 tumors according to AJCC or alternative staging (16 of 130 and 9 of 117, respectively). These tumors were all smaller than 2 cm in diameter. In the case of the 9 alternative stage T1 tumors, they were also confined to the dermis or subcutaneous fat, were well or moderately differentiated, and had no perineural invasion. It is unclear why these tumors were considered high risk enough to warrant SLNB. They may have had other risk factors that made clini-