

## State of the Art and Science

### Pathology Image-Sharing on Social Media: Recommendations for Protecting Privacy While Motivating Education

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#### Abstract

There is a rising interest in the use of social media by pathologists. However, the use of pathology images on social media has been debated, particularly gross examination, autopsy, and dermatologic condition photographs. The immediacy of the interactions, increased interest from patients and patient groups, and fewer barriers to public discussion raise additional considerations to ensure patient privacy is protected. Yet these very features all add to the power of social media for educating other physicians and the nonmedical public about disease and for creating better understanding of the important role of pathologists in patient care. The professional and societal benefits are overwhelmingly positive, and we believe the potential for harm is minimal provided common sense and routine patient privacy principles are utilized. We lay out ethical and practical guidelines for pathologists who use social media professionally.

#### Introduction

The interest in using [social media platforms](#) such as Twitter, Facebook, and Instagram among pathologists and other members of the medical profession is increasing dramatically, and the full potential of this medium in medicine is still evolving [1-4]. For example, Twitter has been used to disseminate and discuss findings from society meetings, as strikingly demonstrated by the 2016 United States and Canadian Academy for Pathology (USCAP) meeting in Seattle, which generated over 19,000 tweets and over 28 million impressions [5, 6]. Pathology discussions on social media also concern updates on diagnostic criteria, such as the recent changes in thyroid cancer classification [7, 8]; World Health Organization (WHO) monographs [9]; regulatory frustrations; and research findings. There are numerous subspecialty interest groups, including a nephrology journal club with over 3,000 followers on Twitter [10] and a variety of pathology discussion groups on Facebook (e.g., dermatopathology and bone and soft tissue pathology, which had over 21,000 and 18,000 members, respectively, in April 2016 [11]). These uses have been a powerful force for establishing collaborations and spreading educational updates. What generates some ethical controversy, however, is sharing pathology images [12].

Sharing images on social media has become an increasingly popular way for pathologists to interact not only with each other but also with clinicians in many fields, students, patients, and even the general public. For example, comments posted by pathologists on social media related to cancer diagnosis and treatment, emerging viruses such as Zika, and brain pathology with traumatic injury as featured in the film *Concussion* are all easily accessible to the public through Google and other Internet search engines [13, 14]. Social media's ability to reach a wide audience has tremendous power [15], but it has also given rise to fears about [potential privacy violations](#). In our experience, this fear is most pronounced among nonusers of social media who are usually less familiar with how these platforms are used.

In this article, we aim to respond to these fears by discussing potential risks and benefits of social media use vis-a-vis traditional publishing in pathology and by suggesting [guidelines](#) to help protect patient privacy. Importantly, the posting of de-identified pathology images on social media does *not* violate the Health Insurance Portability and Accountability Act of 1996 (HIPAA) [16]. Social media posts are, in fact, not materially different from traditional medical journal case report publications, so the same ethical standards should apply to each.

### **Social Media Supplants the Case Report?**

Pathologists assume a natural role as teachers within medicine. Correlating the clinical situation with pathology findings at the gross, cellular, and molecular levels is key to improving our understanding of disease mechanisms. Pathologists' teaching roles are seen at tumor boards, medicine-autopsy conferences, and directly at the microscope with visiting clinical teams. Although pathologists have traditionally attempted to share key findings with a broader audience through peer-reviewed [case reports](#), fewer journals are finding these of sufficient impact for publication because the time to publication is often long, and the ability to interact with others can be limited. Social media offers instantaneous sharing of information with more possibilities for interaction among audience members. Table 1 compares some of the potential advantages and disadvantages of publishing images in traditional journal-based case reports versus social media platforms.

**Table 1.** Comparison of potential merits and drawbacks of social media and journal-based pathology case reporting

Factors to consider	Social media presentation	Journal-based case report presentation
Timing	Immediate	Variable, but delayed
Review process	Potential for “crowdsourced” review by ongoing public discussion	Formal expert peer review
Patient details	Typically more limited (particularly on Twitter)	Full history and physical often part of report
Access	Public	Public
Audience	Broad: physicians and health care workers but also more accessible to patients and patient groups	Restricted: physicians and health care workers, often within the specific field
Interaction	Facile, immediate	Variable access to online discussions; could require formal letter to editor or direct contact with author(s)
Use for clinical decisions	Not recommended	Can be cited in diagnostic pathology reports

Social media platforms like Twitter and Facebook circumvent some of the limitations of journal-based case reports, enabling pathologists to share—widely and immediately—not only rare or novel findings but also educational “pearls,” unexplained phenomena, or even just beautiful or playful images.

Although image-sharing on social media has an advantage of immediacy and accessibility, one common criticism is that content on social media is not peer reviewed. It is true that posts are not peer reviewed the way most medical journals’ content is, wherein an editor assigns a manuscript to two or three expert reviewers who then provide anonymous comments about a manuscript and offer recommendations for or against its publication. Yet, in a sense, peer review does actually occur on social media in the form of a “crowdsourced” ongoing public discussion, which can include as many other members of the social network—possibly even qualified professional peers—as

wish to comment on an image or debate a case. Rather than merely passing peer review once, as occurs with many journal-based publications, posts on social media must withstand ongoing, instantaneous, real-time commentary, critique, or review by anyone interested in participating.

### **Image-Sharing in Journal-Based and Social Media Publishing: Same Privacy Protections**

Although the accessibility of social media has raised questions about whether more stringent privacy standards should be implemented and enforced, it is easy to forget that journal-based reports are also publicly available, even if access is fee- or library-based. Both publication venues are governed by HIPAA, and [protected health information](#) (PHI) such as name, date of birth, age older than 89 years, geographic division smaller than a state, and record number should never be included in the text or images [17].

However, some types of information not protected under HIPAA could lead to inadvertent identification of an individual, such as specific details about circumstance or disease type (see table 2). We suggest that sufficient [alteration of patient details](#), although not typically used or required in journal-based case reports, be made when posting images or case descriptions via social media. Examples include rounding a patient's age to the nearest decade, modifying anatomic site, or altering clinical history to retain relevance yet obscure specific details that might facilitate recognition of a patient. None of these alterations are legally required, but, from an ethics perspective, they could help allay anxiety about potential privacy violations while preserving educational value. In addition, the 140-character limit on Twitter further restricts the amount of text material that can be presented compared to a journal-based case report, which often includes lengthy, detailed (even if de-identified) clinical information.

**Table 2.** Guidelines for protecting patient privacy for pathologists using social media

Types of potentially identifying information	Recommendations
Date	Avoid saying, “today I saw a case of rare entity X” or “yesterday I diagnosed entity Y.” Never use dates. Be intentionally vague (“I recently saw an example of...”).
Unusual or newsworthy circumstances	Avoid information disclosure that could allow direct association with a recent crime or accident, such as “I just received this gun-shot bowel and splenectomy from an unfortunate teen.” Consider delay in posting cases that are highly unusual.
Identifying images	Avoid posting full facial images, unique tattoos, or other identifying features without explicit patient permission (ideally, a signed waiver).
Age	Exclude age for patients older than 89 or aggregate ages into a single category of “age 90 or older.” Precise ages with children are also best avoided. Approximate ages are a good idea for all posts even though not legally required.
Geography	Avoid mention of small geographic subdivisions (anything smaller than a state as a general rule) where the patient might have originated.
Anatomic site/patient history	Modifying clinical history is suggested (but not required by HIPAA). Example: if we (the authors) tweet, “left leg mass from 20-year-old woman,” there is a high likelihood that the actual patient’s true sex, age, or anatomic site differs from the information presented in the tweet.

Case reports and small case series do not meet criteria for research under the Code of Federal Regulations, title 45, part 46, “[Protection of Human Subjects](#),” and thus do not require institutional review board approval [18]. Pathology social media posts are clearly similar and do not by themselves qualify as research. Nonetheless, organizational policies regarding publication of cases vary widely and can be more restrictive than either the law or ethical principles require. Some journals, for example, require patient consent

for publication of case reports and patient images, even if they are de-identified. It should be stressed that this is a policy implemented by individual journals; it is not a requirement of HIPAA. Adoption of this kind of consent policy would not be easy to implement in pathology practice, since direct access to patients is limited. Additionally, it could severely restrict pathology education while providing essentially no benefit for patients' safety. Based on personal experience with publishing and examination of the medical literature, the authors posit that the vast majority of pathology educational images currently available in textbooks, websites, lectures, and case reports, for example, have been published without obtaining consent from patients. This is a widely accepted long-standing practice in pathology, and, provided that privacy is protected, the authors find no major ethical problems with this practice. Indeed, were policies to be implemented to require patient consent retroactively, many pathology education resources would vanish. We argue that the benefits of sharing de-identified pathology images without patient consent greatly outweigh the risks.

It should be noted that organizations and academic institutions might have their own policies or guidelines for posting cases to social media outlets. Unless a user wishes to face disciplinary action from an employer, social media posts should adhere to organizational policies even if they are perceived as Luddite or draconian.

### **Addressing Privacy Concerns for Specific Types of Images**

*Skin conditions.* Skin diseases can alter appearance or create disfigurement in a visible way that can result in patients' feeling socially isolated or rejected. Sharing images of skin disease can thus be more controversial; enhanced caution and sensitivity should be used. That said, sharing these images via social media can present opportunities to educate the public on the nature of these diseases, help improve understanding, and possibly decrease stigma. [Melanoma](#) and other skin cancers are often easily visible to the naked eye; sharing images of these cancers could raise awareness of the importance of self-examination, potentially resulting in earlier diagnosis and better outcomes for some patients. However, images of skin could lead to easier identification of a patient than could gross images of internal organs or microscopic images. One elegant example of this added level of caution is Josette McMichael, a dermatologist and adjunct professor at Emory University who has a special interest in global dermatology and who posts on Twitter and Instagram [19]. Her posts are educational and help raise public awareness about serious medical and social issues abroad, as they show how advanced dermatologic diseases can affect patients in developing countries with limited access to medical care. She shares clinical and pathology images from a variety of sources around the world, including many from countries where cultural or religious views about modesty can generate increased sensitivity about images of patient skin. McMichael has no legal HIPAA obligation to these patients, yet she still takes great caution in carefully maintaining not only patient privacy (e.g., using cropped images to remove background scenery, intentionally altering patient history and country of origin) but also respect for

these overarching cultural and religious views. Compassion, common sense, and great [respect for human rights](#) are excellent antidotes to concerns over patient privacy.

*Facial images.* Posting identifiable facial images should not be done without proper consent from patients [20]; most institutions have standard informed consent forms [21], which could be adapted for images shared on social media. Particularly striking from both the standpoint of the disease process and the boundaries of patient privacy is an image from the *New England Journal of Medicine* of a man with diffuse melanosis cutis holding his driver's license up to his face for comparison [22]. Further highlighting how connected social media and print-based journals are in terms of patient privacy, this image was frequently re-posted on Twitter with acknowledgement to the source.

It is important to remember that although one may delete a post or tweet, there is no guarantee that an image has not already been saved or downloaded by other users who could then share it again at any time. Images to be shared on social media may be watermarked with the name or username of the copyright holder to help ensure that the owner of the image is recognized even if the image becomes detached from the original post in this way. However, from a privacy perspective, a useful mantra to live by online is this: once an image has been released, it is public forever.

### **Conclusion**

There is no significant difference in physicians' obligations regarding patient privacy when pathology images are shared on social media or published in medical journal case reports. Along with following institutional guidelines, pathologists who share images on social media outlets should take due care to protect patients' privacy by using suggested guidelines, common sense, and the principle of *primum non nocere* ("first, do no harm"). With responsible use of social media, the minimal risk to patients is adequately mitigated, and thoughtful efforts have potential not only to increase public understanding of pathologists' roles in diagnosis and patient care but also to advance education among pathologists and other clinicians.

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