Best Practices for Clinical Image Collection and Utilization in Patients With Skin of Color

Kelita A. Waterton, BS; Stephanie Chan, BS; Jane Yoo, MD, MPP; Diane Jackson-Richards, MD; Naiara S. Barbosa, MD

linical images are integral to dermatologic care, research, and education. Studies have highlighted the underrepresentation of images of skin of color (SOC) in educational materials, 1 clinical trials, 2 and research publications.3 Recognition of this disparity has ignited a call to action by dermatologists and dermatologic organizations to address the gap by improving the collection and use of SOC images.4 It is critical to remind dermatologists of the importance of properly obtaining informed consent and ensuring images are not used without a patient's permission, as images in journal articles, conference presentations, and educational materials can be widely distributed and shared. Herein, we summarize current practices of clinical image storage and make general recommendations on how dermatologists can better protect patient privacy. Certain cultural and social factors in patients with SOC should be considered when obtaining informed consent and collecting images.

Clinical Image Acquisition

Consenting procedures are crucial components of proper image usage. However, current consenting practices are inconsistent across various platforms, including academic journals, websites, printed text, social media, and educational presentations.⁵

Current regulations for use of patient health information in the United States are governed by the Health Insurance Portability and Accountability Act (HIPAA)

of 1996. Although this act explicitly prohibits use of "full face photographic images and any comparable images" without consent from the patient or the patient's representative, there is less restriction regarding the use of deidentified images.⁶ Some clinicians or researchers may consider using a black bar or a masking technique over the eyes or face, but this is not always a sufficient method of anonymizing an image.

One study investigating the different requirements listed by the top 20 dermatology journals (as determined by the Google Scholar h5-index) found that while 95% (19/20) of journals stated that written or signed consent or permission was a requirement for use of patient images, only 20% (4/20) instructed authors to inform the patient or the patient's representative that images may become available on the internet.⁵ Once an article is accepted for publication by a medical journal, it eventually may be accessible online; however, patients may not be aware of this factor, which is particularly concerning for those with SOC due to the increased demand for diverse dermatologic resources and images as well as the highly digitalized manner in which we access and share media.

Furthermore, cultural and social factors exist that present challenges to informed decision-making during the consenting process for certain SOC populations such as a lack of trust in the medical and scientific research community, inadequate comprehension of the consent material, health illiteracy, language barriers, or use of

Kelita A. Waterton is from the College of Medicine, SUNY Downstate Health Sciences University, Brooklyn, New York. Stephanie Chan is from the Warren Alpert Medical School, Brown University, Providence, Rhode Island. Dr. Yoo is from the Department of Dermatology, Mount Sinai School of Medicine, New York, New York. Dr. Jackson-Richards is from the Department of Dermatology, Henry Ford Hospital, Detroit, Michigan. Dr. Barbosa is from the Department of Dermatology, Mayo Clinic, Jacksonville, Florida.

The authors report no conflict of interest.

Correspondence: Naiara S. Barbosa, MD, Mayo Clinic, Department of Dermatology, 4500 San Pablo Rd S, Jacksonville, FL 32224 (barbosa.naiara@mayo.edu).

Cutis. 2024 April;113(4):147-149. doi:10.12788/cutis.0989

complex terminology in consent documentation.^{7,8} Studies also have shown that patients in ethnic minority groups have greater barriers to health literacy compared to other patient groups, and patients with limited health literacy are less likely to ask questions during their medical visits.^{9,10} Therefore, when obtaining informed consent for images, it is important that measures are taken to ensure that the patient has full knowledge and understanding of what the consent covers, including the extent to which the images will be used and/or shared and whether the patient's confidentiality and/or anonymity are at risk.

Recommendations—We propose that dermatologists should follow these recommendations:

- 1. Encourage influential dermatology organizations such as the American Academy of Dermatology to establish standardized consenting procedures for image acquisition and use, including requirements to provide (a) written consent for all patient images and (b) specific details as to where and how the image may be used and/or shared.
- 2. Ensure that consent terminology is presented at a sixth-grade reading level or below, minimize the use of medical jargon and complex terms, and provide consent documentation in the patient's preferred language.
- 3. Allow patients to take the consent document home so they can have additional time to comprehensively review the material or have it reviewed by family or friends.
- 4. Employ strategies such as teach-back methods and encourage questions to maximize the level of understanding during the consent process.

Clinical Image Storage

Clinical image storage procedures can have an impact on a patient's health information remaining anonymous and confidential. In a survey evaluating medical photography use among 153 US board-certified dermatologists, 69.1% of respondents reported emailing or texting images between patients and colleagues. Additionally, 30.3% (46/152) reported having patient photographs stored on their personal phone at the time of the survey, and 39.1% (18/46) of those individuals had images that showed identifiable features, such as the patient's face or a tattoo.¹¹

Although most providers state that their devices are password protected, it cannot be guaranteed that the device and consequently the images remain secure and inaccessible to unauthorized individuals. As sharing and viewing images continue to play an essential role in assessing disease state, progression, treatment response, and inclusion in research, we must establish and encourage clear guidelines for the storage and retention of such images.

Recommendations—We propose that dermatologists should follow these recommendations:

- 1. Store clinical images exclusively on password-protected devices and in password-protected files.
- 2. Use work-related cameras or electronic devices rather than personal devices, unless the personal device is being used to upload directly into the patient's medical record. In such cases, use a HIPAA-compliant electronic

medical record mobile application that does not store images on the application or the device itself.

3. Avoid using text-messaging systems or unencrypted email to share identifying images without clear patient consent.

Clinical Image Use

Once a thorough consenting process has been completed, it is crucial that the use and distribution of the clinical image are in accordance with the terms specified in the original consent. With the current state of technologic advancement, widespread social media usage, and constant sharing of information, adherence to these terms can be challenging. For example, an image initially intended for use in an educational presentation at a professional conference can be shared on social media if an audience member captures a photo of it. In another example, a patient may consent to their image being shown on a dermatologic website but that image can be duplicated and shared on other unauthorized sites and locations. This situation can be particularly distressing to patients whose image may include all or most of their face, an intimate area, or other physical features that they did not wish to share widely.

Individuals identifying as Black/African American, Latino/Hispanic, or Asian have been shown to express less comfort with providing permission for images of a nonidentifiable sensitive area to be taken (or obtained) or for use for teaching irrespective of identifiability compared to their White counterparts, 12 which may be due to the aforementioned lack of trust in medical providers and the health care system in general, both of which may contribute to concerns with how a clinical image is used and/or shared. Although consent from a patient or the patient's representative can be granted, we must ensure that the use of these images adheres to the patient's initial agreement. Ultimately, medical providers, researchers, and other parties involved in acquiring or sharing patient images have both an ethical and legal responsibility to ensure that anonymity, privacy, and confidentiality are preserved to the greatest extent possible.

Recommendations—We propose that dermatologists should follow these recommendations:

- 1. Display a message on websites containing patient images stating that the sharing of the images outside the established guidelines and intended use is prohibited.
- 2. Place a watermark on images to discourage unauthorized duplication.
- 3. Issue explicit instructions to audiences prohibiting the copying or reproducing of any patient images during teaching events or presentations.

Final Thoughts

The use of clinical images is an essential component of dermatologic care, education, and research. Due to the higher demand for diverse and representative images and the dearth of images in the medical literature, many SOC images have been widely disseminated and utilized by dermatologists, raising concerns of the adequacy of informed consent for the storage and use of such material. Therefore, dermatologists should implement streamlined guidelines and consent procedures to ensure a patient's informed consent is provided with full knowledge of how and where their images might be used and shared. Additional efforts should be made to protect patients' privacy and unauthorized use of their images. Furthermore, we encourage our leading dermatology organizations to develop expert consensus on best practices for appropriate clinical image consent, storage, and use.

REFERENCES

- Alvarado SM, Feng H. Representation of dark skin images of common dermatologic conditions in educational resources: a cross-sectional analysis [published online June 18, 2020]. J Am Acad Dermatol. 2021;84:1427-1431. doi:10.1016/j.jaad.2020.06.041
- Charrow A, Xia FD, Joyce C, et al. Diversity in dermatology clinical trials: a systematic review. JAMA Dermatol. 2017;153:193-198. doi:10.1001/jamadermatol.2016.4129
- Marroquin NA, Carboni A, Zueger M, et al. Skin of color representation trends in JAAD case reports 2015-2021: content analysis. *JMIR Dermatol*. 2023;6:e40816. doi:10.2196/40816

- Kim Y, Miller JJ, Hollins LC. Skin of color matters: a call to action. J Am Acad Dermatol. 2021;84:E273-E274. doi:10.1016/j.jaad.2020.11.026
- Nanda JK, Marchetti MA. Consent and deidentification of patient images in dermatology journals: observational study. *JMIR Dermatol*. 2022;5:E37398. doi:10.2196/37398
- US Department of Health and Human Services. Summary of the HIPAA privacy rule. Updated October 19, 2022. Accessed March 15, 2024. https://www.hhs.gov/hipaa/for-professionals/privacy/laws-regulations/index.html
- Quinn SC, Garza MA, Butler J, et al. Improving informed consent with minority participants: results from researcher and community surveys. *J Empir Res Hum Res Ethics*. 2012;7:44-55. doi:10.1525/jer.2012.7.5.44
- Hadden KB, Prince LY, Moore TD, et al. Improving readability of informed consents for research at an academic medical institution. J Clin Transl Sci. 2017;1:361-365. doi:10.1017/cts.2017.312
- Muvuka B, Combs RM, Ayangeakaa SD, et al. Health literacy in African-American communities: barriers and strategies. *Health Lit Res Pract*. 2020;4:E138-E143. doi:10.3928/24748307-20200617-01
- Menendez ME, van Hoorn BT, Mackert M, et al. Patients with limited health literacy ask fewer questions during office visits with hand surgeons. Clin Orthop Relat Res. 2017;475:1291-1297. doi:10.1007/s11999-016-5140-5
- Milam EC, Leger MC. Use of medical photography among dermatologists: a nationwide online survey study. J Eur Acad Dermatol Venereol. 2018;32:1804-1809. doi:10.1111/jdv.14839
- Leger MC, Wu T, Haimovic A, et al. Patient perspectives on medical photography in dermatology. *Dermatol Surg*. 2014;40:1028-1037. doi:10.1097/01.DSS.0000452632.22081.79

