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Patient Photographs and Google Images: An AI Ethics Case Study

Abstract:

Over 35% of case reports published in medical journals contain patient photographs. With widespread online academic publishing, there is growing concern about patient photographs that were originally published in medical journals appearing in online image search results. Research has shown that from a random sample of case reports indexed in PubMed, at least one image was found on Google Images for 76.3% of the publications. Inspired by recent examples, this case study explores the ethical implications of patient photographs circulating outside of the original journal website, including attention to patient privacy and informed consent.

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Case Summary

Alex, a first-year medical student, has been grappling with hyperhidrosis, an excessive sweating condition affecting her hands and face. This condition poses challenges for Alex in her interactions with patients and during physical examinations, significantly impacting her confidence. Seeking assistance, Alex consults a specialist to explore potential treatment avenues. During the consultation, the specialist is taken aback by the severity of Alex's symptoms and requests permission to capture images of her hands and face for educational purposes. Alex consents.

Subsequently, due to the unique presentation of Alex's symptoms, the specialist seeks permission to utilize her photographs for educational materials, potentially leading to their publication in academic journals. Alex, believing she is contributing to the medical community, consents and signs a release form. Years later, Alex is alarmed to discover images of her face and hands on Google Images while researching hyperhidrosis. Feeling bewildered and angered by this breach of privacy, she contacts the specialist who initially took her photographs. She demands an explanation as to how her images, intended solely for educational use, found their way onto the internet. The specialist, equally perplexed, clarifies that the images were only utilized for a single publication in a Dermatology journal. Determined to rectify the situation, Alex endeavours to understand how her private medical images became publicly accessible and seeks guidance on their removal from the internet.

Questions and Exercises for Students

Question 1: Describe the core ethics challenges related to the online publication of case reports with medical images.

Question 2: What are the ethics principles that guide your perspective of this case?

Question 3: Do non-identifiable images require informed patient consent? Provide a justification for your response.

Question 4: Is this a breach of patient information? Why or why not?

Question 5: In the case example above, what if the consent form Alex signed mentioned that images would be used in academic publication and that academic publications are likely to be indexed by major search engines? If Alex signed the document but did not understand the full context or implications, do you think Alex's later objection is founded?

Question 6: Who is responsible when the image is available through the public domain (i.e. Google)?

Question 7: Who are the different stakeholders who might have a position on this topic? List at least four groups and include a brief description of what their views might be.

Question 8: To underline the risk of patient identification from the publication of photographs in medical case reports, your friend conducts a search to identify the patient associated with the image in one of the medical case reports below (van Vonderen et al., or Zack et al.). They are able to easily identify the patient's name. What are their next steps?

Question 9: Do you have any concerns about your friend's actions? Identify any recommendations you might have for them.

Question 10: What are the potential solutions from a technical standpoint?



Question 11: If an image for educational purposes was produced through generative AI to reduce the likelihood of identification, does this erode the scientific process?

Exercise 1: The Office of the Privacy Commissioner has learned about this research and convened an expert panel. You have been invited to share your perspective and recommendations. What would you include in your brief to the panel?

Context

Case reports published in academic journals are an important tool for medical, scientific, and educational purposes (Ortega-Loubon 1). Written by practicing clinicians, peer-reviewed case reports provide relevant and timely information that forms the basis of evidence-based medical practice (Carey 77; Ortega-Loubon et al. 1). A large number of case reports are published each year: for example 68,362 case reports were indexed in PubMed in 2023.

Case reports often contain images, including patient photographs (Marshall et al., "Open Availability" 1). With the increasing prevalence of online academic publishing, there is a growing concern about patient photographs appearing in large image repositories such as Google Images. Our research has shown that, from a random sample of case reports indexed in PubMed, at least one image was found on Google Images for 76.3% of the publications (Marshall et al., "Finding Medical" 1). While patients are asked to provide written consent for clinicians to publish images for educational purposes, informed consent documents do not typically mention the possibility of these photographs appearing on online platforms. This circumstance highlights the intersection of privacy and informed consent and raises concerns regarding the limited legal recourse available to patients in such cases.

The risk of patient photographs from medical journals circulating beyond their original intention is not a small-scale problem. Typically, 37% of case reports include patient photographs (Marshall et al., "Open Availability" 1). This means that from the case reports published in 2023, approximately 20,508 included patient photographs. If for 76.3% of these papers at least one image appears on Google Images, then a minimum of 15,648 patients whose images appeared in medical journals in 2023 will be impacted.

While all photographs do not contain identifiable images, some do. This includes facial images, photographs of the eyes and nose or forehead, and full body images. The situation is additionally complicated because the text within the case report normally includes information about patient gender, age, diagnosis, clinician name, and corresponding author address. This means that by connecting a patient image with the information provided in the case report, private health information for patients is more likely to be compromised.

The Personal Information Protection and Electronic Documents Act (PIPEDA) of 1999 is a Canadian federal privacy law that regulates the collection, use, and disclosure of personal information by private sector organizations for commercial activities. A federal court ruling in 2021 found that Google's search engine is subject to privacy protection laws under PIPEDA (Kratz, "Guidance"), meaning that patients in Canada may have the legal right to request the removal of their personal information, including medical photographs, from Google's search results.

This case provides an opportunity to explore the ethical complexity of what happens when patient photographs are found in massive online image repositories. By identifying potential stakeholders and considering the risks and benefits from each standpoint, trainees will have an opportunity to identify key challenges and potential points of intervention to improve future AI systems.



Recommend Readings

Background Knowledge Required to Understand Consent, Especially with Regards to Patient Data

- Roguljić, Marija, et al. "What Patients, Students and Doctors Think About Permission to Publish Patient Photographs in Academic Journals: A Cross-Sectional Survey in Croatia." Science and Engineering Ethics, vol. 26, no. 3, 2020, pp. 1229–1247, https://doi.org/10.1007/s11948-019-00134-y.
- 2. Roguljić, Marija, et al. "Publishing Identifiable Patient Photographs in Scientific Journals: Scoping Review of Policies and Practices." *Journal of Medical Internet Research*, vol. 24, no. 8, 2022, pp. e37594. https://doi.org/10.2196/37594.

Background Reading Related to Privacy and Issues Related to PIPEDA

1. Bhattacharjee, Maushumi et al. "Patient Photographs on Google Images: A Commentary on Informed Consent, Copyright, and Privacy Laws." *Law, Innovation and Technology*, vol. 15, no. 2, 2023, pp. 536–557. https://doi.org/10.1080/17579961.2023.2245684.

Research Directly Related to the Case Study

- 1. Edwards, Benj. "Artist Finds Private Medical Records Photos in Popular AI Training Data Set." Ars Technica, 21 Sept. 2022, https://arstechnica.com/information-technology/2022/09/artist-finds-private-medical-record-photos-in-popular-ai-training-data-set/.
- 2. Han, Andrew. "BMJ Journal Pulls Case Report After UK Tabloids Publish Graphic Photos." Retraction Watch, 18 Feb. 2018, https://retractionwatch.com/2018/02/22/bmj-journal-pulls-case-report-after-uk-tabloids-publish-graphic-photos/.
- 3. Marshall, Zack et al. "Open Availability of Patient Medical Photographs in Google Images Search Results: Cross-Sectional Study of Transgender Research." Journal of Medical Internet Research, vol. 20, no. 2, 2018, pp. e70. https://doi.org/10.2196/jmir.8787.
- 4. Marshall, Zack et al. "Finding Medical Photographs of Patients Online: Randomized, Cross-Sectional Study." Journal of Medical Internet Research, vol. 26, no. 2, 2024, pp. e55352. https://doi.org/10.2196/55352.
- 5. van Vonderen, Jeroen et al. "Herpes Simplex Transmission to Chest and Face Through Autoinoculation in an Infant." BMJ Case Reports, 2017, pp. bcr-2017-220447. https://doi.org/10.1136/bcr-2017-220447.
- 6. Zack, Fred et al. "Unusual head injury by a forklift vehicle." Journal of Forensic and Legal Medicine, vol. 56, 2018, pp. 9–11. https://doi.org/10.1016/j.jflm.2018.02.024.

Key Concepts

Privacy of Patient Health Information

Clinical photographs of patients play an important role in healthcare. They support accurate diagnosis and treatment plans, contribute to comprehensive records, and facilitate medical education. Often medical



photographs are published in clinical texts and case reports. They are a tool to help explain clinical findings, procedural steps, and postoperative results. While clinicians may consider patient photographs an information component like many others, they can hold different meanings for patients. These perspectives are influenced by age, gender, ethnicity, and culture. Thus, patient photographs must be handled with care to ensure that they are not used in a way that violates patient privacy or causes harm. It is crucial to ensure that patients are fully aware of how their photographs are being used and who has access to them.

Informed Consent

When a patient's personal information is intended for use in publications, it is necessary to obtain their consent. To obtain informed consent, healthcare providers are typically required to: provide information, answer questions, ensure the decision is voluntary, assess for capacity, and obtain documentation through a signed consent form. In the case of medical photographs, it is recommended that clinicians inform patients about the online availability of journal publications. There are mixed opinions across medical specialties and between healthcare providers about whether informed consent is required in all cases. For example, if the photograph is not identifiable, some feel that informed consent is optional. Others feel that if efforts have been made to de-identify the photograph, informed consent is not necessary. However, this highlights another area of contention: whether it is ever possible to de-identify a photograph, especially when the written text describing the patient and their health condition accompanies a clinical photograph in a case report.

References

- Carey, John C. "The Importance of Case Reports in Advancing Scientific Knowledge of Rare Diseases." Rare Diseases Epidemiology, edited by Manuel Posada de la Paz, Springer, 2010, pp. 77-86. https://doi.org/10.1007/978-90-481-9485-8 5
- Kratz, Martin. "Guidance on Application of PIPEDA to Google Search." Slaw, 5 Aug. 2021, http://www.slaw.ca/2021/08/05/guidance-on-application-of-pipeda-to-google-search/
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