

ORCA - Online Research @ Cardiff

This is an Open Access document downloaded from ORCA, Cardiff University's institutional repository:https://orca.cardiff.ac.uk/id/eprint/135148/

This is the author's version of a work that was submitted to / accepted for publication.

Citation for final published version:

Ahmed, S., Shipman, A., Millington, G., Langan, E. A. and Ingram, J. R. 2020. Consent for publication: why it matters now more than ever. British Journal of Dermatology 183 (3), pp. 409-410. 10.1111/bjd.19320

Publishers page: http://dx.doi.org/10.1111/bjd.19320

Please note:

Changes made as a result of publishing processes such as copy-editing, formatting and page numbers may not be reflected in this version. For the definitive version of this publication, please refer to the published source. You are advised to consult the publisher's version if you wish to cite this paper.

This version is being made available in accordance with publisher policies. See http://orca.cf.ac.uk/policies.html for usage policies. Copyright and moral rights for publications made available in ORCA are retained by the copyright holders.



Consent for publication: why it matters now more than ever

We live in an age where almost everything we do is in the 'public eye' and machine learning is constantly collecting data and images from the internet. While big data will help unlock some answers, it poses challenges for patient privacy and confidentiality.¹ In keeping with all medical journals, it is our responsibility to ensure that the articles we publish have patient consent for publication, especially for clinical images or case reports.

Earning and retaining the trust of the public and patients is an important principle.² Article 9 in the General Data Protection Regulation (GDPR) specifically discusses patient confidentiality and how information gathered for research must be handled.³ The Confidentiality code of practice by the Department of Health in the UK clearly articulates that consent must be taken and recorded when a patient's identifiable information is used outside the context of care.⁴

Dermatology is one of the most visual medical specialties and photographs are an integral part of research publications. However, there has always been a grey area around identifiable and nonidentifiable photos. For example, a person's foot may not be identifiable but if a distinctive tattoo is included in the image then it could be identifiable. Before social media, the patient may never have come across their image in medical literature. In today's publishing world, their image may be viewed and recognised in a social media post by family or friends, with loss of anonymity. Sometimes the rarer the disease, the easier it is to piece together some information and so patients featured in case reports may be identifiable even though the researchers believe this to be unlikely. Chances are slim but nevertheless possible.

Open Access articles allow anyone to view or reuse the images, which can pose a problem if a patient has given consent for treatment but not for publication or sharing on social media. In the past, photos were used only within the context of the article and read or viewed by only the research community or subscribers, but it is a more open world now.⁵ A patient who views their image out of the original context for which they gave consent may feel that their privacy has been invaded.⁶ It is our duty as custodians of patients' photos and data, to protect it in line with governance laws.^{3,7}

To address the evolving nature of medical publishing, including social media considerations, we have revised our journal policies and now require authors to obtain written consent from their patients for all case reports and all clinical images, whether or not they are identifiable. In line with recommendations from the Committee for Publication Ethics (COPE) and following discussions with our editorial board members, we have clarified our instructions to authors as follows:

- 1. All authors who submit to the journal will need to confirm during the submission process that they have consent for publication of any clinical images (including those that may not be identifiable) and that they have consent for publication on social media.
- The British Association of Dermatologists (BAD) consent form is available online <>, for use in any of our journals: the British Journal of Dermatology BJD, Clinical and Experimental Dermatology (CED) and Skin Health and Disease (SHD). In order to protect patient privacy, we do not require completed consent forms to be submitted; however, authors should securely store the consent form themselves.
- 3. Researchers can use their own institutional consent forms so long as these include consent for publication of the patient's images or case report on the internet as well as for social media. We require submission of a blank consent form to demonstrate compliance.

We realise that our revised patient consent policy asks a bit more from authors, but as part of being an ethical and responsible publisher, we are taking this extra step to protect patient privacy and to ensure that trust in medical research continues. Fully informed patient consent for publication in BJD is a key part of our mission statement to improve patient outcomes in skin disease worldwide and we thank our authors for ensuring that we continue to put patients first in all of our publishing endeavours.

References

- 1. Price WN, Cohen IG. Privacy in the age of medical big data. Nat Med. 2019 Jan;25(1):37-43. doi: 10.1038/s41591-018-0272-7. Epub 2019 Jan 7.
- Resnik DB. Scientific Research and the Public Trust. Sci Eng Ethics. 2011 Sep; 17(3): 399–409. Published online 2010 Aug 29. doi: 10.1007/s11948-010-9210-x
- 3. EU. GDPR. <u>https://gdpr.eu/tag/gdpr/</u> (Last accessed on 06 May 2020)
- NHS confidentiality code of practice. November 2003. Available on <u>https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment</u> <u>data/file/200146/Confidentiality - NHS_Code_of_Practice.pdf</u> (last accessed on 7 May 2020).
- 5. Creative commons. <u>https://creativecommons.org/licenses/</u> (last accessed on 07 May 2020)
- Roguljić M and Wager E. Consent for publishing patient photographs. Case Rep Womens Health. 2020 Apr; 26: e00194. Published online 2020 Mar 27. doi: 10.1016/j.crwh.2020.e00194
- 7. UKRI GDPR and Research An Overview for Researchers. What is GDPR? <u>https://www.ukri.org/files/about/policy/ukri-gdpr-faqs-pdf/</u> (last accessed 06 May 2020)
- 8. COPE. Journals' Best Practices for ensuring consent for publishing medical case reports: guidance from COPE. <u>https://publicationethics.org/resources/guidelines/journals'-best-</u> <u>practices-ensuring-consent-publishing-medical-case-reports</u> (last accessed on 7 May 2020).