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## Case reports and ethics: Focus on consent, privacy and authorship

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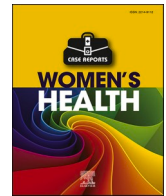
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## Editorial

## Case reports and ethics: Focus on consent, privacy and authorship



## ARTICLE INFO

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Case reports represent a timely way for advancing medical scientific knowledge of rare medical conditions [1]. Publication in reputable international journals allows the dissemination of information to the widest audience. Although an efficient method of medical advancement, publishing case reports is not without its issues and problems. From an ethical and legal perspective, 3 key areas – consent, patient privacy and authorship – need to be considered by researchers and writers of case reports before they undertake their research and submit their article for publication.

These three possible areas of concern, consent, privacy and authorship, will be discussed in turn.

## Consent

Consent is a fundamental aspect of the therapeutic relationship between the patient and the healthcare professional. It is the interrelationship between the ethical principle of autonomy and the legal recognition that a person has a right to self-determination [2].

The need for consent to be provided by a patient in order for medical treatment to be provided to them is established within healthcare. Yet, it is unfortunately true to say that consent is not always obtained from patients for research to be undertaken with them or for information about them to be published, possibly because there is confusion about what the patient has actually consented to. Consent for treatment does not cover consent for research purposes or for publication. To be clear, to undertake research with a patient or to publish details about a patient requires explicit consent from the patient for that specific action.

When receiving consent from a patient for treatment purposes, traditional best practice has advised that written consent with records being kept by the patient and by the institution is the preferred method. The record should include the reasons for the procedure/treatment, the details of the treatment and the information provided to the patient, along with copies of any documentation given to the patient. This is because it allows the records to be checked if there is ever any concern about whether the consent was actually provided by the patient for the

specific treatment that was provided.

Provision needs to be made where a patient has the mental capacity to consent but is unable to provide written consent, for instance because they have a physical impairment and are unable to sign their names or have literacy issues. Alternative methods of providing and documenting consent include the use of fingerprints instead of a signature, or the patient verbally providing consent and this being audio or video recorded. Whatever method is used to provide consent, it needs to be witnessed, with the process complying with the relevant legal requirements of the particular jurisdiction in which the patient is located.

Where the patient lacks the mental capacity to consent for themselves or is under the legal age of capacity, local legal requirements need to be followed. This will usually include the use of legal representatives to make a decision on behalf of the patient. Legal representatives must be approved substitute decision makers or should hold power of attorney for the patient. For those under the legal age of capacity, parents or those with parental responsibility can provide consent.

As already stated, having consent from a patient for a treatment option does not mean that consent has been obtained for research or publication purposes. Explicit consent from the patient or an approved legal representative for publication of a case report and associated images in a medical journal or book is an essential requirement.

If the patient has the capacity to consent, it is their decision whether to consent to publication or not. Legal representatives may provide consent only if patients lack mental capacity, are under the legal age to do so, or are deceased. In cases where the patient's [1–5] condition and its treatment transiently affect mental capacity, such as ventilation for COVID-19, patient consent should be obtained once capacity has been restored, so that their wishes are respected [3].

Where patients are untraceable, deceased or there is no legal representative and publication of the case report is in the public interest, approval should be provided in accordance with local legislation. This may involve institutional authorities such as a hospital board, its legal services and an ethics committee. If consent is not provided by the patient, this needs to be documented, with reasons given.

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Consent for publication should be obtained by a person involved in the patient's care, and they must be suitably qualified and trained to obtain consent. It is important that the consent process is not rushed or missed during the initial research or the publication stage. Failure to obtain consent can result in the non-publication of research.

### Patient privacy

Patients share personal information with healthcare professionals so that they can receive the most appropriate care and treatment according to their needs [2]. The provision of information by patients is undertaken with the expectation that the healthcare professional will protect that information and use it only for the purpose for which it was provided, namely the patient's healthcare needs.

If patients believe that their personal information is to be shared widely without permission, it may make them less forthcoming to share it, which could adversely affect their care and treatment.

Personal information is anything that can identify an individual, and anything that the patient would not want to be freely divulged, such as their condition, treatment, past medical history and so on.

When discussing patient participation in research and publication of patient care and treatment, one aspect of that discussion needs to encompass patient information and how it will be treated and used. This is because the patient has provided their information for one purpose, their healthcare needs, and to use it for another, publication of a case report, would not be covered by the original consent.

It is important that patient privacy is respected and any personal identifiers, such as name, date of birth, identification numbers, locations and dates of treatment are removed from the case report. These are detailed in the 2017 revision of the CARE guidelines for case reports [4]. However, by their unique nature, patient anonymity cannot be guaranteed even when identifiers are removed from the report and associated images. This is particularly important for open-access publishing, where articles are readily publicly available worldwide. Therefore, any discussion with the patient and/or their representative needs to acknowledge the possibility that despite efforts to maintain the patient's privacy and anonymity, it may be possible to identify the patient from the information in the case report.

### Authorship

The Guide for Authors for *Case Reports in Women's Health* [5] states that 'At least one author of case reports/case series should have been involved in patient care. Individuals only involved in patient care who have not contributed to the writing of the article should be listed in the acknowledgements.'

This means that the authors listed on a case report should be the individuals who contributed to its concept, development, and final version. The inclusion of an individual in the list of authors is not a 'gift' to be given or a right to be demanded.

If someone was not involved in the article they should not be included as an author but, as the guidance notes, could have their contribution recognised in the acknowledgment list.

Having your name listed on an article that you were not involved with could be seen as fraud and brings into question the ethical validity of other aspects of the article.

### In conclusion

Researchers and writers of case reports must be vigilant and ensure that: consent for publication has been obtained in accordance with local legislation and obtained by a person involved in the patient's care who is suitably qualified and trained to obtain consent; that information that could identify a person directly is removed; and that only those who have contributed to the case report are listed as authors.

The case report should note that the patient(s) featured have provided their consent for their information to be included and that they are aware that their anonymity cannot be guaranteed even though all steps have been taken to protect their privacy.

### Contributors

Marc Cornock is the sole author.

### Conflict of interest

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### Provenance and peer review

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