

# **Australasian Association of Bioethics and Health Law (AABHL) Guidelines on Case Discussion, Presentation and Publication<sup>1</sup>**

## **1. Preamble**

Individuals' stories, narratives or experiences are often important for ethical learning and reflection. Cases can provide particularity, context, meaning, authenticity and unique insights into a lives and experiences. There are, therefore, important reasons why cases should be told, discussed, published, and read.

Historically, case reports have been published and presented without the involvement or consent of the individual concerned. This was because of concerns that they would not allow their story to be told or would disagree with the ethicist's interpretation of their story. It was also thought that there was no risk or ethical obligation to seek consent.<sup>4,5</sup> Views have changed and it is now widely accepted that scientific and intellectual interest in individuals' stories must be balanced against ethical obligations to respect their autonomy, privacy and confidentiality.<sup>6</sup> These ethical obligations suggest that there is good reason to seek individuals' consent before discussing, presenting or publishing their stories and for making them a 'partner' in such work.<sup>7,8</sup>

In response, the Committee on Publication Ethics<sup>9</sup>, International Committee of Medical Journal Editors<sup>10</sup> and the Case Report (CARE) group (comprising clinicians, researchers and journal editors)<sup>11,12</sup> have issued guidelines on the publication of case reports, all of which state that, with limited exceptions, consent should be obtained prior to publication of a case report. Since this time, numerous relevant academic journals, including the BMJ, BMJ Case Reports, Journal of Medical Ethics, Journal of Medical Case Reports, and Oxford Medical Case Reports, have implemented these recommendations and introduced mechanisms for documenting consent.<sup>13,14,15</sup>

Importantly, there is an expectation that, as much as possible, cases should be deidentified/anonymized by removing as much potentially identifiable demographic or health information as possible to reduce the risk of the individual being identified.<sup>16</sup> While deidentification offers additional protection, it may create a practical and epistemological challenge because the value of the case report may lie in its integrity, authenticity, and particularity. The task for presenters and authors, therefore, is to be mindful of the need to ensure that de-identification does not distort or negate the meaning and educational value of the case report.<sup>17</sup>

## **2. Purpose**

---

<sup>1</sup> Adapted with permission from the policy of the Clinical Ethics Society of Australia (CESA)

The purpose of this guideline is to assist members of AABHL to understand the ethical obligations associated with the discussion, presentation, and publication of case reports.

### **3. Scope**

This guideline applies to the discussion and presentation of cases at AABHL events and at events supported by AABHL. It also applies to the publication of case reports presented at AABHL events.

### **4. Consent requirements**

- Presenters and authors must ensure that they adhere to all relevant guidelines and policies, including institutional guidelines, when reporting or publishing case reports.
- Consent should be obtained from everyone whose personal information is disclosed.
- If a person lacks capacity, consent should be sought from their legal guardian.
- Where the case is about a child, consent should be obtained from their parent or guardian. However, if the child is old enough to understand the situation, the child's assent to use of their information should also be sought even if they are unable to give legal consent.
- If the person is deceased, consent should be obtained from the person's closest relative/next-of-kin.
- In situations where the person and/or their relatives are uncontactable despite best efforts then the presenter/author should provide a clear explanation for why support has not been obtained. (Where publication is sought in an academic journal - decisions regarding the ethical acceptability of publication will be made by the journal editors).
- Responsibility for obtaining consent lies with the presenter, senior author, or a patient's primary (health) carer.
- In presentations a statement regarding consent should be included in declarations associated with the oral or written presentation.
- In publications:
  - a statement regarding consent should be included in the text of the manuscript;
  - authors should always comply with journal author guidelines and supply consent forms as required; and
  - unless ethically inappropriate, those whose information is being used should be provided an opportunity for the to read drafts of the manuscript and view any images accompanying it.
- Consent should make clear to the individuals whose information is being used:
  - that presentation or publication will result in their case being in the public domain;
  - that despite every effort at anonymisation there exists a possibility that they may be identified; and that,
  - that consent is irrevocable after (but not before) presentation and publication.

## **5. Anonymisation, deidentification and sensitivity**

- In all situations, including where a person has consented to the presentation and/or publication of their case, presenters and authors should try to reduce the risk of a person being identified by removing potentially identifiable demographic or health information, such as name, age, birth, death, admission and discharge dates, and so forth.
- A number of other strategies should be considered where cases/stories are presented or discussed – even where a person has provided their consent for their case/story to be used in a presentation/discussion or publications. These include:
  - Employing pseudonyms (names and places)
  - Generalising demographic data
  - Not including information about identifying factors, such as ethnicity and occupation, unless relevant
  - Excluding specific ages and instead using ranges such as “early”/”mid”/”late” “20s”, “30s”, “40s” and so forth
  - Using descriptive terms to describe ages eg: preterm neonatal, term neonatal (birth – 27 days), infancy (28 days – 12 months), toddler (13 months – 2 years), early childhood (2 – 5 years), middle childhood (6 – 11 years), early adolescence (12 – 18 years), late adolescence (19 – 21 years), adult (18-65), older adult (>65-70), elderly (>75) and very elderly (>85).
  - Using relationship categories rather than explicit relationships to describe others related to the focus of the case report e.g. use “first degree relative” instead of parents or siblings, or “second degree relative” for grandparents or cousins
  - Creating composite stories
  - Asking the person to approve particular quotes (especially for publication and where quotes concern highly sensitive issues)
  - Negotiating with the person the degree to which they would like to be identified or deidentified.

## **6. Situations where consent and/or anonymisation/deidentification is not required for case discussion, presentation or publication**

Where cases are in the public domain (sometimes also referred to as the ‘public sphere’ or ‘commons’) they may be discussed, presented, or published without the need either for deidentification/anonymisation or consent from the person involved.

From a legal perspective, the ‘public domain’ is an ‘umbrella term’ that refers not to material that is publicly available (most online material, for example, is subject to copyright), but to a space where no intellectual property exists and works may be used (copied, distributed, displayed, performed, or modified) without any copyright or other legal restriction and even without attribution. Works enter into the public domain where their copyright has expired (such as is the case with the Bible or the works of Beethoven), where authors have voluntarily waived their

copyright to enable free public access (such as is the case with images licensed under the Creative Commons designation), or where copyright simply does not apply (such as is the case with ideas, principles or concepts; laws, legal cases, statutes or judicial decisions; government reports; and news media reports).

In regard to the discussion, presentation or publication of case reports this means that consent is not legally required where:

- cases have been the subject of case law, or legal reports, and where
- the facts of cases have been reported in the media.

Even where consent/anonymization is not legally required, however,

- all sources (including case law, legal reports and articles reporting the facts of the case) should still be appropriately referenced, and
- consideration should still be given to whether there is an ethical argument to support anonymization/deidentification and/or consent.

## **7. Guideline review**

This Guideline shall be reviewed every three years by the AABHL Committee to ensure its effectiveness and relevance. Amendments may be made as necessary to reflect changes in AABHL's operations or regulatory requirements.

## **8. Contacts**

For questions about this policy, contact the AABHL Committee via [secretary@aabhl.org](mailto:secretary@aabhl.org)

## **References**

1. Vandenbroucke JP. In defense of case reports and case series. *Ann Intern Med* 2001;134:330.
2. Nissen T, Wynn R. The history of the case report: a selective review. *JRSM Open*. 2014;5(4) doi: 10.1177/2054270414523410. 2054270414523410.
3. McLean SF. Case-based learning and its application in medical and health-care fields: a review of worldwide literature. *J Med Educ Curric Dev*. 2016;3 doi: 10.4137/JMECD.S20377. JMECD.S20377.
4. Levine SB, Stagno JS. Informed consent for case reports: The ethical dilemma of right to privacy versus pedagogical freedom. *J Psychother Pract Res*. 2001;10:193–201.
5. Healy D, Wilkinson G, Fahy T, Russell G, et al., editors. Case reports and confidentiality: Opinion is sought, medical and legal. *Br J Psychiatry*. 1995;166:555–8.
6. Herring J. *Medical Law and Ethics*. Oxford, UK: Oxford University Press, 2018.

7. Geppert C. The Balance of Truth-Telling and Respect for Confidentiality: The Ethics of Case Reports. *Fed Pract.* 2022;39(2):60-61. doi: 10.12788/fp.0233.
8. Rosoff PM. Can the case report withstand ethical scrutiny? *Hastings Cent Rep.* 2019;49(6):17–21. doi: 10.1002/hast.1065.
9. Riley DS, Barber MS, Kienle GS, et al. CARE guidelines for case reports: explanation and elaboration document. *J Clin Epidemiol.* 2017;89:218–235. doi: 10.1016/j.jclinepi.2017.04.026.
10. International Committee of Medical Journal Editors Recommendations. 2019. <http://www.icmje.org/recommendations/>.
11. Gagnier JJ, Kienle G, Altman DG, et al. The CARE guidelines: consensus-based clinical case reporting guideline development. *BMJ Case Rep.* 2013;2013 doi: 10.1136/bcr-2013-201554. bcr2013201554.
12. CARE Statement. <https://www.care-statement.org/>
13. <https://authors.bmj.com/policies/patient-consent-and-confidentiality/>) (BMJ Case Reports - Instructions for Authors.
14. n.d. <https://casereports.bmj.com/pages/authors/#consent>.
15. Oxford Medical Case Reports - Instructions for Authors. n.d. <https://academic.oup.com/omcr/pages/Policies>.
16. Thomson RJ, Camm CF. The importance of consent in case reports. *Eur Heart J Case Rep.* 2021;5(2):ytaa560. Doi:10.1093/ehjcr/ytaa560.
17. International Committee of Medical Journal Editors. Recommendations for the conduct, reporting, editing, and publication of scholarly work in medical journals. [[http://www.icmje.org/news-and-editorials/new\\_journal\\_dec2021.html](http://www.icmje.org/news-and-editorials/new_journal_dec2021.html).]