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## Analysis

# Commentary: Consent and confidentiality in publishing—the view of the *BMJ*'s ethics committee

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Two years ago four paediatricians and an ethicist submitted to the *BMJ* a case study as an ethical debate which the *BMJ* decided not to publish because the authors had not obtained the consent of the patient's parents for publication. The authors submitted it elsewhere, and the article was published last year.

Here the authors explain why they think the *BMJ* should have published despite the lack of consent (doi: [10.1136/bmj.a1231](http://dx.doi.org.proxy2.library.usyd.edu.au/10.1136/bmj.a1231)); the editor of the journal that did publish the case study explains why he did so (doi: [10.1136/bmj.a1233](http://dx.doi.org.proxy2.library.usyd.edu.au/10.1136/bmj.a1233)); and two members of the *BMJ*'s ethics committee explain why they recommended not to publish it. An accompanying editorial explains why English law would now not allow the *BMJ* to publish it without consent, even if we thought it reasonable to do so.

We explain here the response of the *BMJ*'s ethics committee to the case study submitted by Isaacs and colleagues and make some broader points about the need for patient consent to publish case studies. We conclude that the “public interest” criterion for publication justifiably has a high threshold, which was not met by this paper. Yet we recognise that policy formation in this contested area can be difficult and that further debate is required.

The publication of case studies in medical journals provides a rich narrative of clinical practice with valuable lessons for other practitioners and has extended ethical debates, suggested policy changes, and led to changes in clinical practice.<sup>1</sup> Yet consideration must be given to the way in which clinical case studies are used, particularly in relation to respecting patient confidentiality.<sup>2</sup>

In the case described by Isaacs and colleagues<sup>3</sup> the authors believed the case would make a valuable contribution to the literature but were reluctant to obtain consent from the family for publication. The case is also complex because a decision to publish affected not just the infant involved, but the parents as well.

As patients, we recognise that information relevant to our care may be shared among health professionals to ensure good standards and continuity of care. We do not, however, expect this information to enter the public domain without our knowledge or consent. Respecting the confidentiality of medical information and seeking consent to additional uses are underpinned by two main considerations—autonomy and trust. At the heart of autonomy is our right to control the way our personal information is used.<sup>4</sup> If we lack trust that our health information will be kept confidential, we are less likely to disclose full information, possibly damaging the therapeutic relationship. There is therefore both a personal and a public interest in respecting confidentiality.

Publishing case studies is no exception. For example, the General Medical Council's (GMC) policy on confidentiality states: "It is very difficult to anonymise case studies fully, especially if they are of interest because they deal with a rare condition ... For this reason you must obtain express consent from patients before publishing personal information about them as individuals in media to which the public has access, for example in journals or text books, whether or not you believe the patient can be identified."<sup>5</sup> This policy is in line with the UK's data protection legislation in relation to publishing medical information about an individual.

Confidentiality is not an absolute value, and both the common law and the GMC recognise that it can be breached without consent when the public interest is sufficiently engaged. There is, however, a high threshold for such disclosures—such as prevention of serious harm to an individual. Although there is clearly a degree of public interest in the issues raised by Isaacs and colleagues' case study, it is difficult to see how they begin to reach such a threshold.

At the time the case study was submitted it had been *BMJ* policy for more than 10 years that consent should be obtained for all descriptions of individual cases, with limited exceptions—that the patient was untraceable and that it was impossible or unreasonable to expect consent to be obtained. These requirements were not met, given that the patient and family were still connected with the hospital. The *BMJ*'s policy and stance on anonymisation are consistent with those of other medical journals.

Isaacs and colleagues argue that their case study should have been published because the case had been appropriately anonymised, the "critical relationship" between the child's doctors and parents would be impaired if consent was sought, and there was considerable public interest in publishing the case.<sup>3</sup>

Anonymisation of case studies is always difficult. In this case the *BMJ*'s ethics committee felt that such an unusual case would be identifiable to the family themselves or to others in their community, even if not immediately. Moreover, electronic publication means that material remains easily available in the public domain. The large lay readership of medical literature increases the possibility of recognition. Encountering an identifiable case report can come as an unwelcome shock.<sup>6</sup>

Isaacs and colleagues' second defence is that the child's primary physician thought that approaching the parents for consent might have impaired the critical relationship between the child's doctors and the parents.<sup>3</sup> This is not a sound reason for removing parents' rights to make decisions about the handling of sensitive information relating to their child. In some countries it could also be contrary to law. Publication should simply not go ahead if discussing it would harm the interests of the patient or the family, particularly as the child involved was still on the ward. Although approaching the issue of consent to publication can clearly be difficult and uncomfortable, it does not need to impair clinical relationships if properly handled. The process of obtaining consent could actually improve communication with patients and their families.

Grating against these two responses is the notion of public interest. The public has an interest in knowing what kind of ethical dilemmas arise in medicine, and in having medical practitioners properly trained in managing ethical dilemmas.<sup>7</sup> The difficulty is trying to come to an agreement about the threshold at which this public interest should override an individual's right to confidentiality. We would advocate a conservative approach, but in this case the threshold is irrelevant: had consent been sought and gained, the public interest test need never have been invoked. It is only where consent cannot be sought that consideration should be given to the public interest.

Towards the end of their present article, Isaacs and colleagues argue that "the narrative of a real case, in all its complexity, has a compelling authenticity and humanity that constructed cases or theoretical arguments rarely capture." They are right, but should these factors, which are presumably aesthetic, be held in the balance against individuals' rights to protect highly sensitive information about themselves or their children?

## Notes

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## Footnotes

- We thank the members of the *BMJ's* ethics committee for their careful consideration of this issue, which has informed the scope of this article.
- Competing interest: JS and AJN are current members of the *BMJ's* ethics committee.

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