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; the editor of the journal that did publish the case study explains why he did so; and two members of the BMJ’s ethics committee explain why they recommended not to publish it (p 610). 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 (p 589).

**Gaining consent for publication in difficult cases involving children**

We recently wrote a case study on the treatment and care of an infant with spinal muscular atrophy type 1, an inherited disorder causing progressive muscle weakness without apparent intellectual impairment leading to complete paralysis and, without intervention, to death in infancy from respiratory failure. Our discussion focused on the fact that the parents wished their child to be kept alive by mechanical ventilation. Continuing ventilation was contrary to usual current Australian practice but consistent with a 2006 English High Court judgment relating to a child with the same disease.

We had varied views about the harms and benefits of continuing invasive ventilation for children with spinal muscular atrophy type 1, but we all thought that it was not in the best interests of this particular child. We submitted an article for publication to inform our colleagues’ thought about the very difficult questions raised in the treatment and care of children with this fatal disease. Our aim was to stimulate reflection and debate about how paediatricians should best manage similar situations in future.

We understood and accepted that publication of cases involving children normally requires parental consent to publication. However, the child’s primary responsible clinician, who was one of the original authors, felt that approaching the parents for consent ran the risk of impairing his relationship with them, including the ongoing discussions about the merits of continued ventilation. We decided, therefore, to anonymise the case by changing potentially identifying details. We made this clear to the BMJ when we submitted the manuscript for publication, and included a clarifying statement in the manuscript. We assessed the risk that the parents would never become aware of the publication as remote, and were confident that if they did become aware they were unlikely to be offended by our discussion. We felt there were considerable potential benefits to future children with this or similar conditions if the resultant debate led to improved management. So we were disappointed when the BMJ decided not to publish our case study, and we decided to submit the same article to another journal, which published it.

Could we have achieved our goal without reference to an actual case? We believe 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. Whether or not we were right in this case, there is a discussion to be had about the kinds of cases that might justify waiving the normal requirement for parental consent. For instance, the original descriptions of child physical abuse and of Munchausen syndrome by proxy could never have been published if parental consent had been a prerequisite for publication. It might be difficult also to publish case reports involving the death of a child, situations involving conflict between professional staff treating a child and the child’s parents, and new variations on instances of physical, sexual, or emotional abuse of children.

At the time we submitted our paper, the International Committee of Medical Journal Editors said: “Identifying details should be omitted if they are not essential. Complete anonymity is difficult to achieve, however, and informed consent should be obtained if there is any doubt.” The BMJ’s policy at the time also allowed for some exceptions to a strict requirement always to obtain consent, but subsequent changes in attitude and legal status seem to have eliminated this flexibility.

More widely, journals’ attitudes to consent vary. The UK Archives of Diseases in Childhood (produced by the BMJ Publishing Group) requires consent for every case report, whereas the US journal Pediatrics requires consent for reports which could potentially reveal the identity of a patient and the US Journal of Pediatrics has no specific consent requirements.

A requirement without exception for consent from parents of children for publication will stifle at least some of the discussions we need to have about the limits of medical treatment for very sick children.
The rigid exclusion of all contributions where parental consent has not been obtained would compromise the ability of the journal to undertake its central task of disseminating knowledge in conditions where “publication without the consent of the patient will be permitted.” These include that the risk of identification is minimised by measures to prevent recognition of the patient and that the case holds a worthwhile clinical or other lesson.\(^1\)

There is inevitably a tension faced by journal editors in establishing their policy between ensuring “the protection of patient confidentiality while at the same time seeking to facilitate the serious communication of medical information.”\(^3\)

A range of opinions exist about how best to balance these often opposing points of view. These opinions are often strongly held and compellingly articulated. With regard to the case study by Isaacs and colleagues\(^4\) the *Journal of Paediatrics and Child Health* decided to publish without parental consent because we felt that the article raised important issues that needed to be aired and deserved to be debated. The journal policy on informed consent states that submitted papers “in general … should be accompanied by the written consent of the subject (or parents/guardian)”\(^5\) but also states that, “While the editors recognise that it might not always be possible or appropriate to seek such consent, the onus will be on the authors to demonstrate that this exception applies in their case.”\(^6\)

In this instance we accepted the argument that seeking parental permission would have further compromised a difficult relationship with the child’s parents, making it even less likely to achieve an appropriate resolution to a challenging clinical and ethical situation. In addition to the specific clinical and ethical issues generated by the management of this case, the case study also raised important ethical issues about allocation of scarce resources, the use of modern technology to keep children alive, differing perceptions about quality of life, and how to balance what clinicians feel is in the best interests of a child with the wishes of the parents.

The cornerstone of any journal’s policy should be to protect the privacy and dignity of patients. But we would also argue for a degree of flexibility. The rigid exclusion of all contributions where parental consent has not been obtained would compromise the ability of the journal to undertake its central task of disseminating knowledge. As one editor was quoted as saying in a discussion about obtaining consent, “It remains a subjective process but it is useful to have rules to guide our subjectivity.”\(^7\)
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. Yet consideration must be given to the way in which clinical case studies are used, particularly in relation to respecting patient confidentiality.

In the case described by Isaacs and colleagues, 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. 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.” 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.

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.

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 parent.

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. The difficulty is trying to come to an agreement about the threshold at which this public interest should over-ride 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?

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