

THE ETHICAL

Nothing About Me Without Me: The Ethics of Writing About Patients

Speakers:

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The Lancet

New York, New York

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Journal of the Norwegian Medical Association

Oslo, Norway

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Writing about patients today often extends beyond the traditional case study, and patients themselves have increasingly large roles in this process, from simply giving consent to publication to writing articles with their physicians. Some medical journals require that patients give written consent to any publication arising from the relationship between a physician and a patient; others require consent only if it is possible that the patient can be identified from the information given. But is the ability to identify a patient the best criterion for requiring consent? It is often argued that the people being written about and people who know them can deduce who the subject is, whether details traditionally thought to be identifying are included or

not.

To protect patients from being identified in print, the International Committee of Medical Journal Editors (the Vancouver Group) in 1991 published a statement about the protection of patients' anonymity. The 1991 statement stopped short of requiring that patients be shown the

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manuscript to be published. In 1995, the Vancouver Group revised its statement, now called "Protection of Patients' Rights to Privacy", to specify that patients be shown manuscripts before publication if there is any chance that they can be identified.

Participants in this session discussed those issues and others related to publishing about patients, including the following:

- The soon-to-be-enacted US Health Insurance Portability and Accountability Act (HIPPA) and its stance that patients have rights to control their personal

information.

- Lack of uniformity in the practices of institutional review boards.
- Have patients' rights gone too far?
- Who owns the patient's story?
- Can a patient prevent publication of information that might be important to public health?
- Should the patient have editing or veto rights to a document?
- Must consent be sought from a relative if the patient has died?

Especially in light of recent events—for instance, when organs were removed from deceased children in England without their parents' knowledge or consent—the individual rights of patients are an increasingly high-profile issue. Because every case, in theory, can be recognized by someone, many editors advise obtaining "too much" consent to ward off later problems.

Although session participants were unable to arrive at a consensus about all the issues related to writing about patients, they learned that consent is an important consideration for both legal and ethical reasons. As editors and authors, we are becoming more sensitive to the subject, and, as Magne Nylenna stated, "We are on a quite different level of consciousness than we were 10 years ago." 