



Description

Ethics committees review research proposals involving human participants and their data to ensure that they agree with local and international ethical guidelines. They also monitor studies once they begin and—if necessary—may take part in follow-up actions after the end of the research. Their main responsibility is to protect the subjects involved in the study and also consider the possible risks to the community and the environment. Ethics committees have the authority to approve, reject, modify, or stop studies that do not conform to the accepted standards.

Role of Ethics Committees

Most journals do not publish any results unless they have been approved by an ethics committee and they may withdraw published articles that exhibit any ethical problems. Recently, a study published in the journal *Disability and Society* was retracted after the human research ethics committee at the University of Waikato in New Zealand expressed concerns over the publishing methods used in the study.

The paper described the case of a girl who was born with a brain injury and was treated with hormones to keep her small, making it easier for her parents to take care of her. The procedure—known as the Ashley treatment—is rather controversial but seems to be on the rise. Although the *Disability and Society* study only analyzed a particular case (without actually involving any clinical subjects), the report was apparently inaccurate. The girl's family finally decided to file a complaint against it.

In a similar case, the *European Journal of Cardio-thoracic Surgery* retracted <u>another manuscript about</u> <u>a heart surgery technique</u> after discovering that the researchers did not have ethics approval to perform the procedure on 130 patients. It turned out that the Iranian Cardiac Surgical Society had already asked the authors to stop using the method back in 2004, six years before the study was complete. In the retraction notice, the editor-in-chief also advised other surgeons to refrain from using this technique.





Greater Transparency in Ethics Committees

It is clear that poor regulation can cause severe harm to patients, as demonstrated in the <u>case of Paolo Macchiarini</u>, where a <u>series of irregularities</u> surrounding his recruitment and research activities at the Karolinska Institutet in Stockholm served as a platform for his unacceptable behavior. Thus, independent and reliable committees are essential to ensure high ethical standards in the scientific community.



In a study published recently in the *British Medical Journal*, a group of scientists have called for more transparency in the processes followed by the ethics committee. According to the researchers, any documentation related to the ethical approval of clinical trials should be freely available, allowing ethical decisions to be publicly reviewed and discussed. They believe that this could help researchers to minimize participant harms and maintain public trust.

Members of an Ethics Committee

Most <u>research ethics committees</u> include both individuals with scientific or medical expertise and non-scientists. The reason is that some risks, particularly those related to social, legal, or cultural considerations, may be more easily identified by non-scientific members, whereas the procedures and scientific validity of the study design must be evaluated by experts in the field. Ideally, gender balance and social diversity should also be reflected in the committee's composition. Moreover, the membership should be designed in such a way as to minimize conflicts of interest in the decision-making process.

Good Team Work is Essential

There are several situations where researchers and ethics committees must work together. These include

- Identifying and weighing up the risks and benefits of a study (considering human subjects, animals, the community, and the environment).
- Recognizing any financial or personal interests that may affect the research.
- Evaluating the recruitment process and any incentives that will be given to the participants.
- Assessing the procedures and methods used to ask for participants' informed consent.
- Ensuring that all the research activities are recorded properly and reported in a responsible, honest, and objective way.
- Guaranteeing fairness, confidentiality, and privacy for all the subjects involved in the study—or at least full transparency about data-sharing in cases where absolute confidentiality is not possible.

If the research also includes medical interventions, scientists and ethics committees must make sure that adequate care and treatment will be provided.

Category

- 1. Publishing Research
- 2. Understanding Ethics

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