Ethics in action: Approving and improving medical research with human subjects

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In this thesis, Jean Philippe de Jong presents a new understanding of ethical oversight on medical research with human subjects and proposes that there are two philosophies for ethical oversight: ‘(dis)approving’ and ‘improving’. Systems for ethical oversight on medical research have been in place for many years, with Research Ethics Committees as their cornerstone. Although these oversight systems aim to ensure that the ethical quality of research is in order, they have been criticized for impeding the progress of science and failing to provide adequate protection for research subjects. In reality however, little is known about the practice of ethical oversight: it is a ‘black box’. This thesis opens up this black box and studies different aspects of ethical oversight in practice. It deals, amongst others, with ethical review of research proposals, oversight on the actual conduct of research, (non-)publication of research and justice in distributing the benefits of research results. The author suggests there are two philosophies for doing good in ethical oversight: (1) ‘(dis)approving’ which aims to ensure that research is ethical and works towards (dis)approval, is carried out within relationships based on authority and focuses on documentation; and (2) ‘improving’ which aims to improve the ethical quality of research by giving advice, is carried out within relationships based on equality and focuses on the actual research practice. The author concludes that although (dis)approving is closer to what people expect from Research Ethics Committees and is the dominant approach to ethical oversight, improving is a valuable alternative for supporting scientific progress and guarding the interests of research subjects.