
Public/scientist partnerships in the production of biomedical knowledge: the advocates

Mildred Cho*¹

¹Stanford Center for Biomedical Ethics – United States

Abstract

Session: Public/scientist partnerships in the production of biomedical knowledge: the gamers, the advocates and the enablers

Arguably one of the most significant changes to the conduct of biomedical research in the last century has been the rise of patient advocacy groups throughout the entire spectrum of research activities. Patient advocates, often representing specific diseases, now play a major role in funding, recruiting scientists to conduct research projects, obtaining biological samples and research subjects, collecting data, publishing results, and holding patents on inventions from the research.

This shift has begun to influence the infrastructure of science. For example, the Combating Autism Act of 2006 not only appropriated nearly \$1 billion for autism research, it established a novel agency to coordinate autism-related activities across all US agencies, and a grant peer review system that is composed equally of lay members (representing various lay communities and patient advocates) and scientists.

This new paradigm raises a number of ethical issues, largely because the traditional framework of research ethics was built under the assumption of a power imbalance between researchers and the subjects of research. However, this imbalance may be turned upside-down in patient-driven research. The new arrangements potentially create situations in which the patient advocate's interest in the integrity of the research may be in conflict with other interests such as desire for a treatment for their disease, financial interests, or strong prejudice against certain scientific ideas or methods. On the other hand, patients' interests may also be legitimate, even if they are at odds with traditional scientific process.

*Speaker