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

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Abstract

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

A new kind of public-private partnership is being initiated to advance biomedical research by enabling widespread data-sharing and diverse collaborations between groups within and outside of the scientific community. Although the specific compositions and goals of these partnerships vary, they share a number of important features: all solicit data from diverse groups (i.e., industry, academia, government, disease advocacy organizations and private citizens), all limit intellectual property and patenting rights to facilitate free access to data, all focus on developing common methodological and analytical tools to support a highly distributed network of data usage, all promote the active involvement of project participants at multiple stages of research (from proposing research questions to data analysis and interpretation) and all state that the overarching mission of their partnership is to accelerate the pace and enhance the quality of research with direct benefit to human health. These groups aim to shift biomedical research from an isolated and expert-dependent process to one which relies on expansive networks of individuals from both expert and non-expert communities. These partnerships raise a number of legal, ethical and social issues regarding research participation and researcher conduct. How can informed consent be obtained and privacy protected for projects with a indeterminate number of researchers and research goals? How can expectations and standards of researcher conduct be communicated and enforced? The blurring of traditional research roles in these partnerships requires the reevaluation of traditional approaches to research ethics.

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