

Benefit Sharing of Research Participants in Human Genomic Research: Ethical Concerns and Ramifications

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Abstract : The concept of benefit sharing has been a prominent global debate in the world, gaining traction in human research ethics. Despite its prevalence, the concept of benefit sharing is not without controversy over its meaning and justification. This is due to the fact that it lacks a broadly accepted definition and many proponents discuss benefit sharing by arguing for its necessity rather than engaging in critical intellectual engagement with technical issues such as what it implies. What is clear in the literature is that the underlying premise of benefit-sharing is that research involving underprivileged and marginalized people is currently unjust and inequitable because these people are denied access to these gains; thus, benefit-sharing arrangements are required for these research projects to be just and equitable. This paper, therefore, investigates the discourses and justifications behind the concept of benefit sharing to human participants, particularly when dealing with human genomics research. Furthermore, considering that benefit sharing is generally viewed as a transaction between research organizations and research participants, it raises ethical concerns concerning the commodification of human material and undermines the sanctity of the human genome. This is predicated on the idea that research sponsors would be compelled to deliver a minimum set of possible benefits to research participants and communities in exchange for their involvement in the study. There is, therefore, need to protect benefit-sharing practices in international health research by developing a governance legal framework. A legal framework of benefit sharing will also dispel the issue of commodification of human material where human genomic research is done.

Keywords : benefit sharing, human participants, human genomic research, ethical concerns

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