

Privacy Issues in Biomedical and Clinical Research (Compass Series)



After discussions with the National Cancer Institute and the Department of Energy the Board on Biology of the National Research Council agreed to run a workshop under the auspices of its Forum on Biotechnology entitled Privacy Issues in Biomedical and Clinical Research on November 1, 1997. The organizers want to stress the forum was not intended to cover the full gauntlet of issues concerning Genomics and the Privacy of Medical Records. The emphasis of this forum was to look at pending legislation in Congress (Fall, 1997) and consider, if enacted as written, how this would affect genetic research. The broad language of this legislation written to protect the individual could inadvertently restrict research intended to help these same individuals. Scientific progress requires the sharing of information for the validation of results and the dissemination of gained knowledge to be effective. Other issues which were touched upon in this forum but not fully explored include; the trust of individuals involved in genetic studies in the manner their genetic information could be used, the practice of the generalized linking of particular ethnic groups with specific genetic traits, and the potential for positive and negative impact on the quality of life by having knowledge of ones genetic potential. These and other issues which have come upon us in the age of genomics require separate, focused efforts to explore their potential effect on society.

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