National Cancer Advisory Board

Ad Hoc Subcommittee on Confidentiality of Patient Data

This subcommittee provides advice and oversight of the proactive NCI efforts to establish best practices to ensure patient confidentiality in cancer research settings The Subcommittee, insofar as is practical and time permits, may recommend and comment upon provisions of draft regulations issued by the Department of Health and Human Services in response to the Health Insurance Portability and Accountability Act of 1966 while they are still in the comment period.

Particular attention shall be given to a recommendations distinguishing the impact of such regulations and practices in patient oriented research settings vs. in settings limited solely to the delivery of care; and the possible adverse impact on the conduct of clinical and epidemiological research and accrual of subjects. The subcommittee may also focus on recommendations that illuminate the impact and consequences of such regulations on participation of community-based health care professionals in research, since maintaining participation of such health care providers is crucial to expanding access of subjects to clinical trials. The subcommittee also shall consider recommendations to balance or mitigate the burden of regulations on research subjects who already have made clear their intent and strong desire to participate in protocols through a valid informed consent.

TERMINATION DATE: 31 August 2008