

National Institutes of Health (NIH) Genomic Data Sharing (GDS) Governance Structure

Charge to the Central Data Access Committee

Purpose and Function

The NIH Central Data Access Committee (CDAC) is a subcommittee of the Participant Protection and Data Management Committee (PPDM). The CDAC will review and approve or disapprove data access requests (DARs) from the research community for access to General Research Use (GRU) datasets within NIH-designated genomic data repositories, such as the database for Genotypes and Phenotypes (dbGaP). Additional categories of DARs may be reviewed by the CDAC, such as aggregate data requests, as requested by the PPDM. The CDAC's decisions will be based on whether the DAR is consistent with the GWAS/GDS policy and the data use limitations denoted by the submitting institution.

Membership

The CDAC will be comprised of NIH DAC members with appropriate scientific, bioethics, and human subjects' research expertise from at least seven Institutes or Centers. Each member will serve a one-year appointment, with the option to renew. The CDAC will maintain a Chair, chosen from the membership, to serve for a term of one year. Four members of the CDAC shall represent a quorum for conducting business. Consultants, Federal and non-Federal employees with specific expertise, may be asked to participate on an *ad hoc* basis.

Meetings

Meetings will be convened on an as-needed basis.

Administrative Support

GDS policy staff will be responsible for management of the CDAC, including DAR pre- and post-review, DAR distribution to committee members, voting system management, communication with investigators, and maintaining records.

Sunset Provisions

The CDAC charge will undergo periodic review at least every three years. Termination of the Subcommittee requires approval by the PPDM.

GDS Central Data Access Committee

Roster

Chair

Peggy Tucker, M.D.

Director
Human Genetics Program
Division of Cancer Epidemiology and Genetics
National Cancer Institute

Members

Elizabeth Gillanders, Ph.D.

Branch Chief
Host Susceptibility Factors Branch
National Cancer Institute

Emily Harris, Ph.D., M.P.H.

Chief
Translational Genomics Research Branch
National Institute of Dental and Craniofacial Research

Donna Krasnewich, M.D., Ph.D.

Program Director
Division of Genetics and Developmental Biology
National Institute of General Medical Sciences

Thomas Lehner, Ph.D, M.P.H.

Director, Office of Genomics Research Coordination
Chief, Genomics Research Branch,
Division of Neuroscience and Basic Behavioral Science
National Institute of Mental Health

Vivian Ota Wang, Ph.D.

Program Director
National Human Genome Research Institute

Dina Paltoo, Ph.D., M.P.H.

Program Director,
Advanced Technologies and Surgery Branch
National Heart, Lung, and Blood Institute