NIH POLICY FOR SHARING GWAS DATA

Charge to the

Data Access Committees

NIH Data Access Committees (DACs) will review and approve or disapprove all requests from the research community for access to datasets within the NIH GWAS Data Repository, currently the database for Genotypes and Phenotypes (dbGaP). Access decisions will be made based on whether the request conforms to the specifications within the NIH GWAS policy and program specific requirements or procedures (if any). In particular, all data uses proposed for NIH GWAS datasets must be consistent with the data use limitations proscribed for the dataset by the submitting institution and identified on the public website for the NIH GWAS Data Repository. Data Access Committees will also review and approve or disapprove all requests for access to NIH GWAS datasets for programmatic oversight by NIH employees.

Committees will be composed of senior Federal employees with appropriate scientific, bioethics, and human subjects research expertise. Members may be appointed for a specified term as defined by the convening Institute. Consultants with specific expertise may be invited to meetings or to provide written consultation. Consultants may be Federal or non-Federal employees, and are not voting members of the DAC. Timelines for responding to requests for access to GWAS data will vary, but all NIH DACs will strive to provide decisions or feedback to requesting investigators in a timely manner.

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Roster for Data Access Committees

(NIH DACs known to date):

Richard Anderson, NIGMS (NIGMS)

Stephen Chanock, NCI (CGEMS)

Hemin Chin, NEI (NEI)

Valentina Di Francesco, NIAID (NIAID)

Katrina Gwinn, NINDS (NINDS)

Emily Harris, NHGRI (GAIN)

Old, Susan, NHLBI

Brad Ozenberger / Gary Temple, NHGRI (TCGA)

Rebekah Rasooly, NIDDK (NIDDK)

Winnie Rossie, NIA (NIA)

Joni Rutter, NIDA Representative (NIDA)

Susan Shurin, NHLBI (NHLBI)

Lu Wang, NHGRI, (NHGRI)