

NIH POLICY FOR SHARING GWAS DATA

Charge to the **Senior Oversight Committee (SOC)**

Purpose

The NIH Genome-Wide Association Studies (GWAS) Senior Oversight Committee (SOC) advises the NIH Director of the policies, procedures, and issues regarding the on-going implementation and monitoring of the GWAS Data Sharing Policy. The SOC serves as the principal trans-NIH committee that oversees and manages the development, implementation, and evaluation of GWAS policies and procedures across the NIH Institutes and Centers (ICs).

Function

The SOC remit encompasses a broad range of activities, including all matters related to the on-going development, evaluation, and modification of the NIH GWAS policy and the procedures necessary to promote their robust and consistent implementation across the NIH. The SOC will be informed in its activities by the Technical Standards Steering Committee (TSC) and the Participant Protection and Data Management (PPDM) Steering Committee. The SOC shall provide analyses and make recommendations to the NIH Director on policy or technical issues related to the NIH GWAS Policy. Recommendations may be based on analyses or recommendations received from the Steering Committees or based on internal activities. The SOC will work with the Advisory Committee to the Director Working Group for GWAS Participant and Data Protection to consider GWAS data use practices, as well as to discuss issues or concerns regarding the effectiveness of or vulnerabilities within the GWAS Policy.

As needed, SOC special working groups or subcommittees may be appointed by the chair(s) for specific tasks and time periods. An SOC member will generally serve as the chair of each special workgroup, which may include only SOC members or other NIH staff. Broad representation by IC staff on these working groups or subcommittees will be strongly encouraged as appropriate in order to facilitate discussion from various perspectives as well as to promote consensus in decision making.

Membership

Members of the SOC will include senior NIH leaders representing the ICs and the appropriate divisions within the NIH Office of the Director. The initial constitution of the committee will include the following representation:

- Four Institutes and Center Directors (NCI, NHGRI, NHLBI, and NIMH)
- Office of Extramural Research (OER)
- Office of Intramural Research (OIR)
- Office of Science Policy (OSP)
- Office of General Counsel (OGC) (*Ex-officio*)

The NIH Director will select the SOC chair(s) from among the IC Directors and rotate this responsibility as appropriate. The SOC chair(s) will provide staff to serve as the Executive Secretary for the committee. Five members of the SOC shall represent a quorum for conducting business.

Meetings

Regular meetings of the SOC will be held at least quarterly, or as otherwise determined to be necessary. Special meetings may be called by the SOC chair(s) with sufficient notice to the members. The Executive Secretary will be responsible for facilitating the preparation of meeting minutes for approval by the chair(s) and distribution to the SOC members. When necessary, special “action” memoranda will be distributed to members that indicate needs for more timely responses or other actions outside the conduct of a regular meeting.

Sunset Provisions

The Charter for the SOC exists in perpetuity. A periodic review of the charter will occur with current members every three years. Any amendments or termination of the SOC shall require the approval of the NIH Director.

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Roster for **Senior Oversight Committee (SOC)**

Francis S. Collins, M.D., Ph.D. (Co-Chair)
Director
NHGRI

Elizabeth G. Nabel, M.D. (Co-Chair)
Director
NHLBI

Michael M. Gottesman, M.D.
Deputy Director for Intramural Research
NIH
*Chair, Research Participant Protection and
Data Management Steering Committee
(PPDM)*

Thomas R. Insel, M.D.
Director
NIMH

Jack F. Jones, Jr., Ph.D.
Chief Information Technology Architect
NIH
*Co-chair, Technical Standards Steering
Committee*

Barbara M. McGarey, J.D.
Office of the General Council
HHS
Ex-Officio Member

John E. Niederhuber, M.D.
Director
NCI

Norka D. Ruiz Bravo, Ph.D.
Deputy Director for Extramural Research
NIH

Lana R. Skirboll, Ph.D.
Associate Director for Policy
NIH
*Provides Staff Management for the Advisory
Committee to the Director Working Group*