

National Institutes of Health Data Science Policy Council (DSPC)

Charge

The NIH Data Science Policy Council (DSPC) is an internal NIH committee consisting of senior NIH leaders and data scientists. The DSPC was created in 2017 as part of a restructuring of NIH programs and governance related to data science, aiming to provide a forum for trans-NIH data science policy development and oversight. The DSPC is intended to address emerging policy challenges and opportunities associated with data science, data sharing, and open data (broadly defined) in biomedical research, thereby promoting maximum public benefit from data utilization in a manner that fulfills the agency's commitment toward responsible stewardship of data. This includes responsibilities to research participants and the public trust with regard to data management, access, and sharing practices.

Roles and Responsibilities

The primary roles and responsibilities of the DSPC are to provide broad trans-NIH leadership in and guidance on data science policies by:

- 1) Addressing emergent and ongoing policy needs related to biomedical data, which include but are not limited to areas such as data management and sharing, data dissemination, and data security, and which are appropriate to address in a trans-NIH manner;
- 2) Providing guidance on the development of policies and procedures in support of 1);
- 3) Providing guidance on policies related to the infrastructure(s) needed to support 1);
- 4) Providing guidance about the interaction of NIH data science activities with those across ICs and outside of NIH (e.g., of other government agencies, the private sector, and other funding agencies – private and public, national and international);
- 5) Overseeing the implementation and ongoing oversight of data sharing policies and related data science activities (e.g., Genomic Data Sharing Policy, Data Management and Sharing Policy, NIH Institute and Center policies);
- 6) Coordinating and promoting harmonization among NIH data sharing policies and processes, including data management, submission, and access practices; and
- 7) Synergizing with the parallel NIH Administrative Data Council (ADC) and Scientific Data Council (SDC).

Composition and Governance

Members of the DSPC will be senior-level staff well-versed in science policy as it relates to data science policies and procedures. DSPC members will include *ex officio* representation from:

- the Office of Science Policy,
- the Office of Extramural Research,
- the Office of Intramural Research,
- the Office of the Chief Information Officer,
- the National Library of Medicine,
- the Tribal Health Research Office,
- the Office of Data Science Strategy, and
- the Office of General Counsel.

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Additional members will include NIH IC directors or other senior NIH personnel responsible for substantial genomic data repositories or other data sharing or stewardship efforts, and senior personnel with responsibilities in health equity. Members will be appointed by the NIH Director for an initial period of two years; membership may be extended beyond two years by the NIH Director.

The DSPC will be co-chaired by the NIH Associate Director for Science Policy (ADSP) and an IC director. To fulfill its roles and responsibilities, the DSPC may designate a charge and membership of working groups for specific tasks and time periods. The DSPC reports to the NIH Steering Committee, which is chaired by the NIH Director.

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