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Policy Title. Data Access Committee Review Standards (DACReS)

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Executive Summary. The [Regulatory and Ethics Work Stream](#) (REWS), in association with [Data Use and Research Identities Work Stream](#) (DURI), propose to develop procedural standards for data access committees that facilitate consistency, effectiveness, and robustness of reviews for data access requests to genomic and health-related data.

Background

Both inappropriately restrictive and overly permissive policies governing access to genomic and associated clinical data challenge underlying principles of research ethics. Whereas the former prevents authorized persons from accessing data needed to advance genomic research, the latter places research participants at increased privacy risk given the inherent identifiability and sensitivity of genomic data. Data access committees (DAC) represent one institutional safeguard charged with applying rules meant to ensure an ethically permissible balance between data protection and utility in the research context. There are no standard review criteria, however, for how to operationalize these procedures across DACs. Moreover, access processes can differ where commercially valuable data or intellectual property is at stake, where data privacy laws impose jurisdiction-specific obligations, or where the data requested involve indigenous peoples. Lack of procedural standards and guidance can therefore invite inconsistencies in DAC reviews, compromising their quality and effectiveness at ensuring adequate research data protections.

Policy Objectives. The DACReS team proposes to fill this unmet policy need by developing procedural standards for DACs and carrying out the following specific aims:

Aim 1. Review current policies, processes and practices for reviewing access requests among publicly funded genomic-phenotypic research datasets e.g., those held by NIH dbGap and EGA

Aim 2. Identify sector-specific issues in reviewing data access requests, including where health and genomic data collected for clinical purposes are repurposed for research and where data are proprietary or have commercial value.

Aim 3. Outline best practices/processes that mediate access of researchers to secure computing environments and datasets by applying a model-to-data approach.

Related GA4GH policies

- [Ethics Review Recognition Policy](#)
- [Consent Policy](#)

Request of DACReS members. Commit ~5-10 hours/month to review documents, collaborate with other Work Streams, attend one monthly teleconference to discuss project details/progress, attend REWS meetings to update membership on progress, participate in policy revision and approval process.

Projected Timeline. June 2020-July 2021



Appendix A. DACReS working group collaborators

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