

# Policy for processing data access requests

This policy describes how the University Health Network Genomics Data Access Committee (DAC) will process requests for datasets stored in the European Genome-phenome Archive (EGA), when those datasets are made available by manuscripts that specifically reference this policy.

## Purpose

1. To ensure that applicants are qualified investigators, affiliated with an academic, non-profit, or government research organization.
2. To ensure that users of the data agree to comply with applicable laws, including requirements as outlined in any governing consent and appropriate ethical approvals, along with any restrictions for the data in question.

## General principles

### Introduction

The DAC will consider applications for access to datasets stored in the EGA when authorized to do so in accordance with this policy. Access to data will be granted to qualified researchers for appropriate use. A qualified researcher refers to a scientist who is employed, or legitimately affiliated with an academic, non-profit, or government research organization.

Access to data will be granted to researchers for appropriate use and will be governed by the provisions and terms contained in the Data Access Agreement and consistent with an informed consent (if applicable).

The DAC is concerned only with access to the data stored within the EGA with this DAC as the designated data access committee. Access is conditional upon availability of data and a signed agreement governing issues related to publication, data use, data storage, data disposal, ethical approval, and confidentiality.

### Application procedure

To request access to data from the EGA, you will be asked to complete a basic application form and to agree to the terms and conditions laid out in the Data Access Agreement (DAA). The DAA must be signed by both a representative with institutional authority to sign on behalf of your organization, and the principal investigator responsible for the research project. You will also be requested to list personnel who will be granted access to the data for the purposes of the research project.

If your application is successful, you will be asked to designate a “registered user”, under the authority of the principal investigator, who will be issued with a username and password by the EGA to enable access to the database.

The DAC will consider applications that include named collaborators, but each institution must sign a separate DAA. Should you wish to share the data with additional collaborators not previously approved, they must make a separate application for access to the data.

You agree to use the data only for the approved purpose and project described in your application; use of the data for a new purpose or new or expanded project will require a new application and approval.

## Assessment criteria

Each application will be assessed to determine if:

- it has been submitted by a qualified researcher or researchers, embedded in a recognized research institution that can provide institutional responsibility for appropriate research governance
- the project described constitutes “biomedical research” in the context of the consent process, and is likely to be understood as such by the sample donors
- it breaches any of the ethical permissions or restrictions in the consent forms for any component cohort or collection

The DAC will use these practices in its assessment:

- The DAC explicitly does NOT attempt to peer review the scientific quality of proposals. However, it does ask for a brief summary of the research to be undertaken, in order to judge whether it falls within the scope of the consents.

## Reporting

The DAC may periodically report publicly on the requests received and their disposition, including reasons for access refusal.

## Acknowledgments

Purpose adapted from the [Blueprint Data Access Committee Terms of Reference](#). General principles adapted from the [Blueprint Data Access Committee General Principles](#).