Blueprint Data Access Committee

1. General principles:

The Blueprint Data Access Committee will consider applications for access to data sets stored in the European Genome-phenome Archive (EGA) when authorised to do so by the Blueprint consortium and the holders of the original consent documents. Access to data will be granted to qualified researchers for appropriate use. A qualified researcher refers to a scientist who is employed, or a student enrolled at, or legitimately affiliated with an academic, non-profit or government institution, or a commercial company.

Access to data will be granted to researchers for appropriate use and will be governed by the provisions laid out in the associated informed consent for each cohort or collection, and the terms contained in the Data Access Agreement.

The Blueprint Data Access Committee is concerned only with access to the data stored within the EGA from the Blueprint Consortium. Access is conditional upon availability of samples and/or data and signed agreement by the researcher(s) and the responsible employing Institution to abide by policies related to publication, data disposal, ethical approval and confidentiality.

2. Application procedure:

Applicants requesting access to data from the EGA for which the Blueprint DAC has responsibility will be asked to complete a basic application form and to agree to the terms and conditions laid out in the Blueprint Data Access Agreement (DAA). The DAA must be signed by both the applicant and the relevant Head of Department, Head of Institute, or equivalent.

Successful applicants who have access to data will be designated "Registered Users" and will be issued with a username and password by the EGA to enable access to the database.

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

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

3. Membership of Blueprint Data Access Committee:

Lucia Altucci, Second Universtiy of Naples (SUNAP)
Elias Campo, Institut d'Investigacions Biomèdique August Pi i Sunyer (IDIBAPS)
Paul Flicek, European Bioinformatics Institute (EMBL-EBI)
Ralf Küppers, Universitaetsklinikum Essen (UKE)
Willem Ouwehand, University of Cambridge (UCAM)
Reiner Siebert, Christian Albrechts University of Kiel (CAU)
Edo Vellenga, University Medical Centre Groningen (UMCG)

4. Assessment Criteria:

Each application will be assessed to determine if:

- it has been submitted by a qualified researcher or researchers, embedded in a recognised 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
- it has the potential to produce information that will enable identification of individual participants
- that PhD students include details of their research supervisors
- the research breaches the Fort Lauderdale Agreement or Toronto Statement terms of data sharing for "Community Resource Projects", when the data in question is associated with such a project.

In considering applications, the Blueprint DAC have clarified their policies in regard to specific data access requests. The Committee has agreed that:

- it 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. It also considers that grossly inadequate research is ethically questionable, and reserves the right to refer back for clarification those requests that do not appear to attain even a minimal standard of competence
- unless specifically restricted in the consent documents for a particular collection or cohort, the use of data by commercial companies for commercial purposes is permissible.
- research in the genetics of learning ability has been considered "biomedical research"
- use of anonymised data in teaching is permissible, with the proviso that datasets for specific disease collections are not identified by name of disease, and that the data must not be removed from the teaching laboratory, in order to protect the confidentiality of the participants

5. Data Available

Please visit http://www.blueprint-epigenome.eu to view the datasets available. The exact nature of the data varies by study and is described for each dataset.

6. Meetings and time lines

It is anticipated that most requests for data access will be handled virtually, by email or teleconference. In-person meetings will be held at least twice per year and virtual meetings as necessary for access decisions. The goal of the Blueprint DAC will be to return a decision to the applicant with 15 working days of the completion of the application.

7. Reporting

The Blueprint DAC will produce semi-annual activity reports for the Blueprint Governing Board with summary of all activity.