# GeCIP and your access to data

# How do I get access to data?

In order to protect Project participants' data, 100,000 Genomes Project data can only be accessed through a secure Research Environment. To access the data for research, you must be a member of the Genomics England Clinical Interpretation Partnership (GeCIP), the research community set up to analyse the Project data. You can apply to join the GeCIP on our website.

To be eligible for data access, you must meet these requirements:

- 1. Your application to a GeCIP domain has been accepted.
- 2. Your institution has signed the GeCIP Participation Agreement, which outlines the key principles that members of each institution must adhere to, including our Intellectual Property and Publication Policy. As of 2019, your institution must have signed the agreement before you can apply to GeCIP. See if your institution has signed here.
- 3. Your institution has verified you are affiliated with that institution. We contact institutions regularly to ask them to review their current list of affiliated GeCIP members, so no action is required on your part. This step is necessary to make sure we know who is accessing the data, in line with the consent that Project participants have given.
- 4. Your domain has submitted a Detailed Research Plan and it has been approved by the Genomics England Access Review Committee. The majority of domains meet this requirement. See the status of your domain's detailed research plan here.

Certain other individuals have access to some of the Project data. For example, students on the MSc Genomic Medicine have in the past been given access to a small subset of data for teaching purposes, approved individuals from certain commercial companies have access to some data for research, and individuals involved in the pilot phase of the programme have access to pilot data.

# How long will it take to get access to data after I apply to GeCIP?

After you apply to join GeCIP, the following steps need to take place:

- Your application is sent to the relevant domain lead(s).
- Your application is reviewed by the domain lead(s): this can take up to 10 working days).
- Your details are sent to your institution so they can verify your affiliation: this can be immediate (if the institution has agreed to "auto-verify" those
  with affiliated email addresses), but can often take weeks or even months. We cannot guarantee a timeframe for these step to be completed
  because it depends on your institution.
- Your details are sent for account creation: this occurs in batches every 10 working days, and accounts may be created a few days after details
  are sent.

A system is being built to automate this process, but currently it requires a lot of manual steps and input from different parties, meaning it is not generally feasible to "fast-track" applicants through the process. **Please apply well before you require data access.** 

# Why don't all GeCIP members have access to the data yet?

As above, each GeCIP member needs to be registered under an institution that has signed the GeCIP Participation Agreement, and verified their affiliation with that institution.

All domains that have had their Detailed Research Plan approved have been given access to the data. As of December 2019, 38 GeCIP domains have been granted access to the data, guided by the order of approval of their detailed research plans. These are:

#### Rare disease

- Neurology
- Endocrine and metabolism
- Hearing and sight
- Inherited cancer predisposition
- Renal
- Cardiovascular
- Immune disorders
- Non-malignant haematological and haemostasis disorders
- Musculoskeletal
- Respiratory
- Paediatrics
- Skin

#### Cancer

- Colorectal cancer
- Breast cancer
- Lung cancer
- Ovarian cancer
- Prostate cancerCancer of unknown
- primaryGlioma
- Haematological malignancy
- Melanoma
- Pan-cancer
- Renal cell carcinoma
- Sarcoma
- Testicular cancer
- Upper gastrointestinal cancer
- Neuroendocrine tumours
- Head and neck cancer
- Childhood solid cancers

### **Cross-cutting**

- Quantitative methods, machine learning and functional genomics
- Electronic health records
- Stratified medicine
- Population genomics
- Functional effects
- Health economics
- Integrated Pathogens and Mobile Elements
- Enhanced interpretation
- Ethics and social science

# When happens when I get access to the data?

You will be sent an email containing a link to complete Information Governance training. This training is a requirement for you to access the data. After you have completed the training, you will need to wait for your access to the Research Environment to be granted. This will generally take up to one working day. You will then receive an email letting you know your account has been given access to the environment, and instructions for logging in.

If you already have a Research Environment account for other reasons, your account will be updated to give you access to the Main Programme data within the Research Environment, and you will receive an email informing you of this.

# I can see the data even though some of my domains don't have access. Can I start work?

You may be a member of multiple GeCIP domains. If at least one of these domains has been given access and you meet the requirements above, you will have been given an account to access the data.

Although all domains can see all Project data (although their access to domain-specific shared folders differs), you should not start work on domain-specific analysis until your domain has been given access. Please see above for the domains who have access to data.

## I think I should have access to the data. What should I do?

If you are a GeCIP member, your domain has been granted access, and your institution has signed the Participation Agreement and verified your affiliation, you should have had an account created to access the data. Accounts are created in batches every 2-3 weeks rather than individually, so please allow up to a few weeks after verification to receive your details. If you still haven't received account details, please submit a ticket to the Genomics England Service Desk 1. (You will need to register for the Service Desk portal if it is your first time using it).

If your institution or email address changes, please let us know by submitting a ticket as above, so that your details are sent to the right place.