# **Using the Research Registry**



Where is is the Research Registry, and what is it for?

The Research Registry is a space for researchers to register the research projects they are currently working on, browse and search current research projects, and find contact details for projects leads.

If you want to export results out of the Research Environment for publication, you must have an approved research project on the registry.

You can access the Research Registry by logging into the Research Environment and clicking the Research Registry icon on the desktop.

Watch a tutorial video about the Research Registry on our Research Environment Demo Videos page.

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## Why do I need to register a project?

The Research Registry has been designed with the following aims in mind:

- To promote collaboration and to reduce duplication of effort within the Research Environment: Registering a project will allow researchers
  within your domain and throughout all of GeCIP and the Discovery Forum to be aware of the work that is carried out within the Research
  Environment
- 2. To provide a mechanism to assess adherence to the Genomics England Publication Policy: Authorship and co-authorship of any publication or output should be defined in accordance with the guidelines issued by the International Committee of Medical Journal Editors (ICMJE
  - and outlined in the Genomics England Publication Policy. Note that a registered research project should comprise research aimed to result in a publication, such as a journal article, or a piece of work within a student thesis. Hence, multiple projects can be registered within a single domain. For a full definition of a project see here.
- 3. To assess that the proposed research adheres to acceptable uses of data for which the Access Review Committee has granted data access approval: Genomics England will be able to review whether a proposed research project falls within the scope of the detailed research plan submitted by the domain and as such that no additional data access requests need to be considered.
- 4. To allow export of analysis results: The Research Registry provides a page for collaborative development of a manuscript within the Research Environment. Use of this page to prepare a manuscript is not compulsory; manuscripts can be written outside the Research Environment. However, the Airlock Review Team will be reviewing requests for export of analysis results and manuscripts against the Research Registry information, so your project still needs to be registered. Manuscripts and analysis results will be allowed to leave the Research Environment only if they adhere to the criteria outlined above (i.e. if they abide by the Publication Policy, relevant Acceptable Uses of Data and the Publication Moratorium).
- To provide a mechanism to enact the Publication Moratorium: Disease-facing domains have a protected time period for analysis and
  publication on participant data pertaining to their domain in recognition of the efforts of the domain members who have assisted in recruiting
  participants to the project.



You must register your research at least 3 months before submitting an Airlock request to take you results out of the Research Environment. If this is not possible, please contact us on gecip-help@genomicsengland.co.uk.

# What is considered a research project?

A research project is considered to be any set of analyses or investigations that would ordinarily be the subject of a single research article, or piece of work within a student thesis. In some cases this may change during the research period; for example, a project may grow to encompass more than one planned publication. For this reason, you can add more than one publication to a record in the Research Registry. Preliminary searches of the data for the purposes of hypothesis generation or, for example, to generate pilot data for a funding proposal, would not be considered a research project.

The projects submitted to the Research Registry will be reviewed by Genomics England to ensure that they are within the bounds of valid Access Review Committee approval from the research lead's domain. The Research Registry also provides Genomics England with an overview of the research activity being undertaken in the Research Environment; as such, any files moved out through the Airlock must be associated with activities covered by a registered and approved research project.

# Who can register a research project?

A project can be registered by anyone involved in a study that is aimed to result in one or more publications. You do not need to be leading the project to register it but you should discuss it with the project lead if not.

If you have not spoken to your domain lead about the project you are registering, we suggest that you do so before submitting the form.

Outlined below are the most likely scenarios when registering a project:

- A GeCIP member registers a project studying a disease within their domain. For example, a Cardiovascular GeCIP member registers a
  project looking at short QT syndrome. This researcher can take advantage of the moratorium and results can be exported from the Research
  Environment at any time.
- 2. Two project leads from within the same GeCIP domain register two similar projects, studying genomes within their domain. If, during Genomics England review, a project is found to have significant overlap with another, we will notify the relevant project leads and advise them to contact each other about potential areas for collaboration. The project leads can choose one of the following actions:
  - a. choose to collaborate and export a single publication out of the Research Environment for future journal submission.
  - b. choose to compete and work on the analysis and manuscript in parallel. They are both working on genomes within their domain, so do not benefit from any preferential rights to publish on the data. Either group can export their results at any time.
- 3. A GeCIP member registers a project which aims to use genomes protected under another domain's moratorium period.
  - a. The genomes to be used are still under moratorium; ie the affiliated domain has not yet had 9 months to work on them. The project lead will be notified that the data is protected under a moratorium. To carry out the research at this point, the project lead must discuss the proposed research with the relevant GeCIP domain lead. The GeCIP lead may
    - i. grant permission for this project to be carried out.
    - ii. ask that the project is carried out collaboratively with members of both domains.
    - iii. decline; for example, if they wish to carry out a similar analysis. In this case, the project lead will need to wait for the moratorium period for these genomes to expire before being able to export their analysis results. The domain to whom the genomes are assigned benefits from the relative protection of the moratorium period.
  - b. The genomes to be used are no longer under moratorium. The project lead may carry out their analysis and export results at any time. If the project is found to be similar to an existing project, project leads will be informed as in point 2.
- 4. **Project leads from cross-cutting domains want to work on a disease-specific dataset.** If a cross-cutting domains submits a project using genomes that are still under a disease-facing domain's moratorium period, the project lead will be notified and asked to talk to the relevant domain lead: see point 3a. If the genomes are no longer under moratorium, the project lead may proceed and export data at any time, as in point 3b.

Please note, you can use genomes protected under another domain's moratorium as controls or to investigate a disease unrelated to the domain they fall within.

## How to register your project

Navigate to the Research Registry Project Submission Form page. Log into the Research Environment. Click "Research Registry" then the subpage "Research Registry Project Submission Form" on the side menu.

- Date
- Project title
- Project lead
  - You can search for and add a project lead. You will only be able to find profiles for GeCIP members who have accounts and have completed their Information Governance training. Those who haven't can be added as external contributors below.
- Co-researchers
  - You should include all researchers who are expected to be authors on any publication resulting from this project as co-researchers. For GeCIP members who have received account details for the Research Environment, you will be able to add them by searching for their name.
  - o If anyone working on the project does not have an account for the Research Environment (yet), or hasn't completed their Information Governance training, you will not be able to find them by searching for their name. Instead you can add them as 'external contributors' on the page after you have selected co-researchers; you will need their full name and email address in order to do this.
- · External collaborators
  - blocked URLYou should include all researchers who are expected to be authors on any publication resulting from this project as co-researchers. For GeCIP members who have received account details for the Research Environment, you will be able to add them by searching for their name. If anyone working on the project does not have an account for the Research Environment (yet), you can add them as 'external contributors' on the page after you have selected co-researchers; you will need their full name and email address in order to do this.
- Project contact email
  - $^{\circ}$  Please provide the email any queries about the project or requests to join should be sent to
- Project Type
  - Please provide whether you are registering a project as a GeCIP member, Discovery Forum member or member of staff at Genomics England. You may wish to select multiple Project Types if you are working on a collaboration between these.
- Research area
- Rare disease group (if applicable)
- Rare disease subgroup (if applicable)
- Cancer type (if applicable)
- · Cancer subtype (if applicable)
- Funding
- Name of funder
  - If you are applying for funding or have received funding for your project, you should state this here. This will be used to determine who
    owns the intellectual property for your project.
- Abstract and lay summary

- You must provide an abstract and lay summary of your project. These will be visible to anyone looking at the Research Registry. The lay summary may be used to describe your project on the Genomics England public website, if permission is granted by the project lead, and should be understandable by patients and the general public
- GeCIP domains (you can select multiple domains)
  - O Please list the domains you are interested in researching data from.
  - o You will need to select the GeCIP domain(s) that the project pertains to. You should be a member of this domain.
  - If your project is part of more than one domain, you can add addition domains in the 'Other GeCIP Domain(s)' section. You can select
    multiple domains by holding CTRL/CMD and clicking the domain name.
- Related project
  - o If any related projects have been submitted to the Research Registry, please provide their Registry ID
- Are any of the genomes that you want to use currently under moratorium?
  - You should check in the 'domain\_assignment' table in LabKey to see which genomes are under moratorium

Check the box to accept that Genomics England reserves the right to refuse this project.

When you are ready, click "Register".

The status of your project will be 'blank'.

A member of the GeCIP team at Genomics England will review your project, and change the status to "UNDER REVIEW", and ensure the project is in line with your domain or company's ARC-approved research plan. You will receive a notification when it has been approved by Genomics England and the status of your project will change to 'APPROVED'.

If you have any queries, or if you want to edit or change the status of your project (e.g. to "publication under review"), please contact geciphelp@genomicsengland.co.uk.

## How do I review the status of a project?

A list of all current and completed research projects is available within the Research Registry and can be reviewed by all researchers accessing the Research Environment. To view the Research Registry, log in to the Research Environment and click the icon "Research Registry". Please note that because the Research Registry is inside the Research Environment, one needs to be a researcher with an active Research Environment account to be able to view it.

You will be able to view all projects that have been registered and their status:

- Under review being reviewed by Genomics England, not yet approved.
- Approved project has been approved by Genomics England and can begin work.
- Not Approved project has not been approved by Genomics England. Where this happens, we will contact the project lead.
- Publication under review project has been completed and is waiting export via 'Airlock'.
- Published project has been published in a journal.

## Collaborating on a Project

Any researcher can request to join a project listed in the Research Registry by using the contact email provided for the project to get in touch with the lead researcher. If they are happy to collaborate, the lead can email gecip-help@genomicsengland.co.uk and we will add any co-researchers or external contributors to the project. While each project lead is encouraged to positively consider applications to join a research project, the decision on whether to accept or reject an application is entirely theirs. If you are accepted to collaborate on a project outside your domain you will be collaborating with that domain and not be restricted by the moratorium period.

You can request a **Research Space** within the **Research Environment** for your project by emailing gecip-help@genomicsengland.co.uk. This is a JIRA page where researchers can share notes and updates on their projects. These pages are only accessible from within the Research Environment and you will be able to edit who has permissions to view and edit the page by clicking the **3 dots menu** in the top right hand corner. Then navigating to "**Restrictions**"

# **Creating Publications**

There is the option to use Confluence to prepare your publication draft. Although it may not have all the formatting options available in word processors, Confluence has some useful features for collaborating on text and will allow you to:

- Have complete version control: to view the history of a page click on the 3 dots menu in the top right and select Page History
- Add comments to a page or inline: add a comment at the bottom of the page, or select some text and click on the comment icon above it.
- Link to articles: Pubmed has been whitelisted in the Research Environment, so links to any pages on http://www.ncbi.nlm.nih.gov/pubmed/ will be accessible from Confluence.