

# Participation Agreement FAQs

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## What is the Participation Agreement

The Participation Agreement outlines the key principles that members of each institution must adhere to including our Intellectual Property (IP) and Publication Policy. These policies have been constructed with input from researchers and funders (MRC, Wellcome Trust, NIHR and Cancer Research UK). Each institution will be responsible for ensuring its members are covered by the agreement. The rights and responsibilities of GeCIP Institutions are as set out in the GeCIP Participation Agreement. To ensure we conform to our ethical approval we cannot grant data access to any institution's researchers where there is not institutional approval of the Participation Agreement and its associated documents.

## Where can I get a copy of the Participation Agreement?

You can download the Participation Agreement [here](#).

## Do we need to sign the Participation Agreement or can we just reply via email?

If you agree to the terms and conditions of the agreement we would request that you sign the agreement (either by hand or digitally), and return a scanned copy to the service desk. We will then countersign the document and return a fully executed copy to you.

## Is a digital or a 'wet' signature required?

We will accept both a digital signature and a scanned version of a hand-signed document. Once the document is signed, please return it to the Genomics England Service Desk.

## What do you mean by verification?

Each institution controls who from their institution has access to the data and therefore falls under the signed agreement. We have provided you with a list of those GeCIP researchers who have put down your institution as their affiliation. We ask that you go through each of those researchers and verify that they have an official relationship with the institution (you may interpret that as a contract [or honorary contract] of employment) and that you are happy for them to access the research dataset.

Any researchers that you do not verify will be asked for an alternative affiliation and may still access the dataset under a different institution's agreement.

Should others from your institution apply to access the data after the initial cohort of individuals has been approved, we will contact you again with a reminder of those who have already been approved, and a list of new applicants who require verification. You can request a list of approved researchers from your institution at any time, and may revoke data access for any individual at any time. To be clear, no individual will be given access to the data under your institution's Participation Agreement without clear agreement from the institution. You are obliged to inform Genomics England in a reasonable timeframe should a previously approved individual leave your institution, or are summarily dismissed.

## Some staff hold multiple contracts with different institutions, will they need to get approval from all institutions?

We are aware that researchers may have a number of contracts, honorary or otherwise, with multiple institutions. Pragmatically, we have taken the stance that, for our purposes, their substantive employer is the institution that provides the email address with which they registered when applying to become a member of GeCIP (therefore, the institution that we approach to verify their identity). We consider that the activities they undertake within the Research Environment will be carried out as a member of staff of that institution and therefore any IP generated from those activities will be covered solely by the Participation Agreement entered into between that institution and Genomics England. You should note that any researchers not approved by your institution will be given the opportunity to change the institution they have registered with us (perhaps one at which they have, for example, an honorary contract) if that alternative institution agrees to it. We will not be able to inform you should this occur.

## Is the IP stance detailed in the Participation Agreement negotiable?

No. Under a directive from the United Kingdom's Department of Health, Genomics England cannot enter into negotiations. The IP Policy that has been circulated along with the Participation Agreement contains further details on this arrangement and the allowance we make for licensing of IP.

## Can we make changes to the Participation Agreement?

With over 450 separate institutions represented in GeCIP we are not able to enter into negotiations with individual institutions. However, we are willing to consider amendments to the agreement that would then be applied to all. Please email [gecip-help@genomicsengland.co.uk](mailto:gecip-help@genomicsengland.co.uk) and our legal team will review.

## Can we have a copy of the Participation Agreement in word?

As we cannot enter into negotiations about the Participation Agreement, we cannot provide a copy of it in word.

## Who should sign the Participation Agreement?

The signatory of the Participation Agreement should be someone within your institution that has the appropriate standing to represent it and sign contracts on its behalf. Because of the nature of the agreement we would generally suggest that an individual within the institution's Research and Development (or equivalent) Office would be appropriate.

## We are a charity and don't think it's appropriate/don't need to access the 100,000 Genomes Project data. What should we do?

You can opt out of data access and still remain a part of GeCIP. You should email [gecip-help@genomicsengland.co.uk](mailto:gecip-help@genomicsengland.co.uk) stating that you would like to opt out of data access and do not wish to sign the Participation Agreement.

## Can international institutions sign the Participation Agreement?

Yes – international researchers can join GeCIP and their institution must sign the same Participation Agreement as those based in the UK.

## What does the membership secretary do?

We regularly contact institutions with a list of their GeCIP members. The role of the institutional membership secretary is to verify that the institutional affiliation of the GeCIP members listed is indeed correct and confirm their identity, that the institutional email address they have given is valid and correct, and for their use alone, and that the institution is happy for them to be included under the signed Participation Agreement. Furthermore, we ask that they inform Genomics England in a reasonable time should any of the verified researchers leave the institution or be summarily dismissed.

## Who should be membership secretary?

The identity of the Membership Secretary is the institution's choice, but we advise that they should have access to up-to-date personnel records.

Students are eligible to become members of GeCIP; however, in some institutions the membership secretary does not have access to student records. In these cases, we recommend the institution identify someone who can verify students and we can copy them into communications. The membership secretary would still remain the main point of contact.

## We would like to change our membership secretary. How do we do this?

The identity of the membership secretary is the institution's choice and can be changed at any time. If you would like to change your membership secretary, please let Genomics England know by submitting a ticket to the [Genomics England Service Desk](#) ⚠️.

## Is the participation agreement available in other languages?

No, it is only available in English.

## Is there a deadline for signing up?

No, new institutions are joining GeCIP and signing the Participation Agreement all the time.

## We already signed a data sharing agreement with Genomics England, is this the same thing?

No, the data sharing agreement is between Genomics England and the NHS Genomics Medicine Centres (GMCs) and allows staff at NHS GMCs to access data on their patients for clinical practice. The Participation Agreement covers any institution wishing to access data from the 100,000 Genomes Project for research purposes as part of the Genomics England Clinical Interpretation Partnership (GeCIP).

## We have signed the Participation Agreement. Who should we send it to?

Please send your signed agreement to the [Genomics England Service Desk](#) ⚠️ so that we can countersign it and return a copy to you.

## We have signed the Participation Agreement and verified our researchers, now what happens?

Once the Participation Agreement has been signed and the researchers are verified by you, they are now eligible for data access. They will be given account details once their domain is granted access to the Research Environment ([see here for approved domains](#)). If their domain already has data access, they will be given an account in the next round of account creation, which happens every couple of weeks.

## Do GeCIP members need to apply for approval from HRA?

No, research carried out by GeCIP members on the 100,000 Genomes Project data is covered by our research ethics committee approval (provided the researcher's domain has had their detailed research plan approved by the Genomics England Access Review Committee). There is no need to get separate HRA approval.

## Can we add more researchers to the list of approved persons in our signed Participation Agreement?

Yes, but they must all be members of GeCIP. If they are not already GeCIP members, they can apply through the Genomics England website: <https://www.genomicsengland.co.uk/join-a-gecip-domain/> ⚠️.

Once they are accepted as GeCIP members you can add them to the approved list for your institution. We will email you periodically with a current list of the GeCIP members at your institution for review.

## Do we need to list all people who may be involved with analysing data, or are the laboratory heads/supervisors enough?

Anyone wishing to analyse the data must become a member of GeCIP and you must list all researchers in your signed Participation Agreement or they will not be eligible for data access.

## Will the agreement need to be signed by students who have access to the data or could their primary supervisor sign to cover themselves and the student?

The Participation Agreement is an agreement signed by the institution. The individuals accessing the data will need to sign a separate agreement, the GeCIP rules. Should a student wish to access the data, they will need to be a member of a GeCIP domain and approved by their institution. In short, the process for students accessing the data is exactly the same as for any other researcher. However, if the student is enrolled on a HEE-funded Masters in Genomics Medicine course, this process should be initiated via HEE.

## My institution has requested a list of its GeCIP members. How do I obtain this information?

A list of all registered GeCIP members is included alongside a copy of the participation agreement when Genomics England requests you sign. After an institution has signed, we regularly email the nominated membership secretary an updated list for verification.

We can also provide a list on demand; if you would like to request a list outside these times, please submit a ticket to the [Genomics England Service Desk](#)



## What other institutions have signed the Participation Agreement?

A list of all institutions with registered GeCIP members and whether or not they have signed the agreement can be found here: <https://cnfl.extge.co.uk/pages/viewpage.action?pageId=73711213>

## What data will researchers be given access to and how will they access it?

GeCIP researchers will be given access to the entirety of the de-identified main programme dataset. This dataset contains:


- genomic data for participants who have consented to participate in the Project
- tiering data for participants who have been through the Genomics England interpretation pipeline
  - Office for National Statistics (ONS).
- associated clinical data for all participants who have consented to take part in the Project, including those for whom we do not yet have a sequenced genome
- all secondary data that we hold for participants, including those for whom we do not yet have a sequenced genome:
  - Hospital Episode Statistics (HES), including accident and emergency, admitted patient care, and outpatient care
  - Diagnostic Imaging Dataset (DID), which provides a record of diagnostic tests rather than the images themselves
  - Patient Reported Outcome Measures (PROMs)
  - Mental Health Services Data Set (MHSDS)

Researchers will not be able to download the data. Instead, data will be made available to the researchers via a remote desktop. All of this is provided free of charge to GeCIP researchers.

## Are independent contractors or researchers with honorary contracts covered by the Participation Agreement?

Yes they are.

## What do we do when a GeCIP member leaves our institution?

You should inform Genomics England as agreed in the Participation Agreement. You can do this by emailing [gecip-help@genomicsengland.co.uk](mailto:gecip-help@genomicsengland.co.uk) or submitting a ticket to the [Genomics England Service Desk](#) . You will no longer be responsible for this GeCIP member and we will contact them for their new institution.

## What happens to the Participation Agreement if my institution merges with another institution?

If your institution merges with another, you do not need to sign a new Participation Agreement; the signed agreement remains valid. However, please inform Genomics England about the merger and confirm who the membership secretary will be going forward by submitting a ticket to the [Genomics England Service Desk](#) ⚠️ so that we can update our records.

## My institution hasn't verified me. What do I do?

You should contact the membership secretary at your institution to find out why you haven't been verified.

If you have more than one institution you may wish to change your registered institution and be verified by them instead. You can do this by submitting a ticket to the [Genomics England Service Desk](#) ⚠️.

## I have moved institutions, what do I do?

Let us know via the [Genomics England Service Desk](#) ⚠️ that you have moved institutions, mentioning that you are a member of GeCIP.

You can [check whether your new institution has signed the Participation Agreement](#). If they have, you should contact the membership secretary to ask them to verify your affiliation so that you remain eligible for data access. If they have not, you will need to speak to the relevant parties at your new institution to sign the Participation Agreement.