

Adherence Agreement
for authorised use of the
RD-Connect Genome-Phenome Analysis Platform (RDC-GPAP)
for Public research activities

This document is to be read in conjunction with the Code of Conduct for the use and provision of the RD-Connect Genome-Phenome Analysis Platform (RDC-GPAP). In signing this document, the named party undertakes to abide by the duties set out for the RDC-GPAP user in the Code of Conduct.

Effective as of 8th August 2023

[Legal Entity] a [nationality] company/institution/organization with tax registration number [...], based in [city], [country], [address], represented by [Title, first name, last name of the legal representative of the entity], holding the position of [position], in virtue of [power of attorney/appointment] and [Title, first name, last name of the user of the entity], acting on behalf of [department/unit], holding the position of [position].

Both as signatories of the present agreement herewith declare that:

1. They have the authority to represent and engage *[research group/department/legal entity/other]* for the purpose of submitting and analysing patient genomic and phenotypic data using RDC-GPAP.
2. The interest of *[research group/department/legal entity/other]* in using the RDC-GPAP interface is set out in the completed User Registration Form.
3. They agree to adhere to the **Code of Conduct for the use and provision of the RDC-GPAP**. Code of Conduct shall be available at the RDC-GPAP website <https://platform.rd-connect.eu/> where future modifications shall be published and notified to all Users. It shall apply to all data processing activities carried out within the RDC-GPAP, as well as all duties arising under the General Data Protection Regulation (GDPR) and any further data protection legislation adopted in *[country of university/institute/legal entity]*.
4. Insofar as any staff, students or other people working under *[research group/department/legal entity/other]* direction access RDC-GPAP services, they undertake to ensure that they are informed of the duties of an RDC-GPAP user and adhere to the Code of Conduct.
5. *[research group/department/legal entity/other]* will ensure compliance with the Code of Conduct by any other staff and personnel working within the project on its behalf.
6. *[research group/department/legal entity/other]* will ensure the implementation of all measures required by the provisions of the Code of Conduct.
7. As required by the Code of Conduct, they hereby declare that any data they have submitted to RDC-GPAP, and any data they will submit to RDC-GPAP complies with, at least, one of the following legal bases:
 - a. The **consent** of the data subject in accordance with GDPR Article 6(1)(a) coupled with **explicit consent** for processing sensitive data in accordance with Article 9(2)(a).
 - b. The **legal obligation** of the care providers in accordance with Article 6(1)(c) coupled with the legal basis for processing sensitive data for the **purposes of medical diagnosis** (Article 9(2)(h)).
 - c. The **legal obligation** of the care providers in accordance with Article 6(1)(c) coupled with the legal basis for processing sensitive data for the **purposes of public interest in public health** (Article 9(2) (i)).
 - d. The **legal obligation** of the care providers in accordance with Article 6(1)(c) coupled with the legal basis for processing sensitive data for the **purposes of scientific research** (Article 9(2) (j)).

- e. The **public interest** in accordance with GDPR Article 6(1)(e) coupled with the legal basis for processing sensitive data for the **purposes of medical diagnosis** (Article 9(2)(h)).
 - f. The **public interest** in accordance with GDPR Article 6(1)(e) coupled with the legal basis for processing sensitive data for the **purposes of public interest in public health** (Article 9(2) (i)) .
 - g. The **public interest** in accordance with GDPR Article 6(1)(e) coupled with the legal basis for processing sensitive data for the **purposes scientific research** (Article 9(2) (j)).
 - h. The **legitimate interest** of [university /legal entity] in accordance with GDPR Article 6(1)(f) coupled with the legal basis for processing sensitive data for the **purposes of scientific research** (Article 9(2) (j)).
8. Information about the data use for research has been made available to data subjects, in accordance with GDPR Article 13.
 9. In the case the PI/Group Leader leaves the [*company/institution/organization*], *RD-Connect GPAP must be notified*:
 - a. If the submitted data remains as controlled by the [*company/institution/organization*], a new PI/Group Leader must be assigned to it.
 - b. *If the submitted data remains as controlled by the PI/Group Leader, RD-Connect GPAP must be informed of the new PI/Group Leader’s institution or organization.*
 10. In addition to the rules laid out by the Code of Conduct, the following general rules shall apply:
 - a. There will be no attempt to try to identify or contact data or donor subjects.
 - b. RDC-GPAP data shall not be:
 - I. Copied or downloaded (with the exempt of copying or downloading the data that the same user submitted, or if data is part of a project that specifically allows for it).
 - II. Shared or redistributed (with the exempt of sharing or redistributing the data that the same user submitted, or if data is part of a project that specifically allows for it).
 - III. Sold or in any way commercialized with.
 - c. Access codes and user logins are specific to the identified user and are strictly non-transferable.
 - d. Publications using any form of data accessed through RDC-GPAP will contain an acknowledgment and a reference of RDC-GPAP as appropriate. Where a publication makes use of individual-level datasets and enriched phenotypic data, authors should consider whether the intellectual contribution of the original contributors of the datasets qualifies them for authorship positions in line with standard publication practice. Users must follow the guidelines established in the “RDC-GPAP Publication Policy”. Consorcio para la Explotación del Centro Nacional de Análisis Genómico (Consorcio CNAG) as the provider of RDC-GPAP will be notified of any such publication.
 - e. Results of analyses of accessed data will be returned to the platform.
 - f. In case of misconduct access to the platform will be withdrawn and legal actions might be pursued if necessary.

This form and the personal information it contains will be held by Consorcio CNAG in accordance with GDPR on the legal basis of data necessary for the performance of a contract in accordance with Article 6(1)(b). Usernames of users of the RDC-GPAP are not published but may be visible to other users of the system. The data will be kept for as long as the Adherence Agreement is in force and, after that, until the applicable legal limitation periods. The signatories may exercise at any time their rights of access, rectification, erasure, opposition, limitation and portability, through communication to the other party to (*fill in contact details*) as well as submit a claim to the supervisory authority on Data Protection.

Signed on behalf of *[legal entity]* on *[date]* by *[print name]*:

Title, first name, last name of User: *Title, first name, last name* Legal representative:

Date:

Date:

(Stamp or seal of User
Institution)