

Adherence agreement for authorized access to data in the RD-Connect Genome-Phenome Analysis Platform¹

to be used together with **Code of Conduct** for user access to the RD-Connect Genome-Phenome Analysis Platform (GPAP) for health-related information

Effective as of 25 May 2018

Communication to Mats G. Hansson, Centre for Research Ethics & Bioethics at Uppsala University:
mats.hansson@crb.uu.se

[Title, first name, last name]

Acting on behalf of *[department of university/legal entity]*, holding the position *[position]* herewith declares:

1. I have the authority to represent and engage *[department of university/legal entity]* for the purpose of sharing and analysing patient genomic and phenotypic data in the RD-Connect GPAP. For this purpose we ask for access to data in accordance with our research interests as set out in our completed User Verification Form.
2. *[Department of university/legal entity]* agrees to fully endorse and adhere to the Code of Conduct for user access to the RD-Connect Genome-Phenome Analysis Platform for health-related information, version of 25 May 2018. It shall apply to all data processing activities carried out within the GPAP. The General Data Protection Regulation (GDPR) framework is thus in part formalized through this Code.
3. *[Department of university/legal entity]* will ensure the implementation of all measures required by the provisions of this Code.
4. *[Department of university/legal entity]* will ensure compliance with this Code by all staff and personnel working within the project on behalf of *[department of university/legal entity]*.
5. In addition to the rules laid out by the Code, the following project specific rules shall apply:
 - a. There will be no attempt to try to identify or contact data or donor subjects.
 - b. Accessed data will not be redistributed.
 - c. Access codes and user logins are specific to the identified user and are strictly non-transferable.
 - d. Accessed datasets will be destroyed once they are no longer used.
 - e. Publications using any form of data accessed through the RD-Connect GPAP will contain an acknowledgment and a reference of the RD-Connect 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.
 - f. Results of analyses of accessed data and biospecimens will be returned to the platform. Published work will also be sent to RD-Connect.
 - g. In case of misconduct, access to the platform will be withdrawn.
 - h. The GPAP handles personal data of users in compliance with the GDPR. Usernames of users of the GPAP are not published but may be visible to other users of the system.

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

Signature

¹ This Adherence Agreement is based on the General Data Protection Regulation, implying that all personal data is handled in accordance with the national implementations of GDPR provisions.