

Adherence agreement for authorized access to data and biospecimens in the RD-Connect platform¹ to be used together with Code of practice for integrated user access to RD-Connect platform for health-related information and human biological samples.

Effective as of 9 November 2015.

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

Mr./Ms. [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 the project [short description of project]. For this project we ask for access to data and biospecimens in accordance with the detailed description in Appendix 1.
2. [Department of University/legal entity] agrees to fully endorse and adhere to the *Code of practice for integrated user access to RD-Connect platform for health-related information and human biological samples*, Version [Version] of [Date]. It shall apply to all data and biospecimen processing activities carried out within the project [project name]. The personal data protection 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 and biospecimens will not be redistributed.
 - c. Access codes and user logins are specific to the identified user and are strictly non-transferrable.
 - d. Accessed datasets will be destroyed once they are no longer used.
 - e. Biospecimens will be handled in accordance with specifications in a Material Transfer Agreement..

¹ This adherence agreement is based on the Personal Data Directive, Directive95/46/EC, implying that all personal data shall be handled in accordance with Secrecy law.

- f. Publications using accessed data and biospecimens will comply with the RD-Connect publication policy [insert link]. In particular the following provisions will apply:
- Publications using any form of data accessed through the RD-Connect platform will contain an acknowledgment of the RD-Connect Platform.
 - 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 for authorship positions in line with standard publication practice.
- g. Results of analyses of accessed data and biospecimens will be returned to the platform. Published work will also be sent to RD-Connect.
- h. In case of misconduct access to the platform will be withdrawn.

Signed on behalf of [Department of University/legal entity] on [Date] by [print name]:

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Signature