**Adherence agreement for authorized access to data and biospecimens in the RD-Connect platform[[1]](#footnote-1)**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 9th November 2015**

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

***[Please amend all italicized sections to reflect your personal details]***

[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 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 the RD-Connect Genome-Phenome Analysis Platform for health-related information and human biological samples, Version1.0of 9th November 2015. 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:
6. There will be no attempt to try to identify or contact data or donor subjects.
7. Accessed data and biospecimens will not be redistributed.
8. Access codes and user logins are specific to the identified user and are strictly non-transferrable.
9. Accessed datasets will be destroyed once they are no longer used.
10. Biospecimens will be handled in accordance with specifications in a Material Transfer Agreement.
11. Publications using any form of data accessed through the RD-Connect platform will contain an acknowledgment and a reference of the RD-Connect Platform 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 for authorship positions in line with standard publication practice.

1. Results of analyses of accessed data and biospecimens will be returned to the platform. Published work will also be sent to RD-Connect.
2. 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]*:

…………………………………………………

Signature

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. [↑](#footnote-ref-1)