**data access agreement - SweGen dataset**

**Between**:

1. Uppsala University, Department of Immunology, Genetics and Pathology, Husargatan 3, 75108 Uppsala, Sweden (the “**Data Provider**”); and
2. [**INSERT INSTITUTION DETAILS**] (the “**Recipient**”).

In response to the Recipient's request for access to the Data (as defined below), Data Provider and the Recipient agree as follows:

1. **Definitions**

“**Data**” shall mean all and any human genetic data obtained from the Data Provider including associated metadata regarding the Data Subjects. Explicitly, Data does not include samples or biological materials;

“**Data Subject**” shall mean the person (irrespective of state of health) to whom Data refers and who has been informed of the purpose for which the Data is held and has given his/her informed consent thereto;

“**Intellectual Property**” means (i) patents, designs, trademarks and trade names (whether registered or unregistered), copyright and related rights, database rights, know-how and confidential information; (ii) all other intellectual property rights and similar or equivalent rights anywhere in the world which currently exist or are recognised in the future; and (iii) applications, extensions and renewals in relation to any such rights;

“**Registered User**” shall mean a Researcher (or an individual conducting Research under the supervision of a Researcher) that is employed by the Recipient and is bound by confidentiality and non-use obligations in respect of Data and who has signed this Agreement and has received acknowledgement of its acceptance. For the avoidance of doubt, “Registered User” may also include students, visiting academics, contractors, subcontractors or independent consultants provided that any such individual is bound by confidentiality and non-use obligations no less onerous than those binding the Recipient’s employees;

“**Research**” shall mean research that is seeking to advance the understanding of influence of genetic factors on human diseases or the distribution of genetic variation in the population.

“**Researcher(s)**” shall mean an individual or individuals carrying out Research who has authored a relevant peer-reviewed article that Data Provider can locate on PubMed and who is still working in the field.

1. **Purpose**

The Recipient agrees to use Data only for the Research, and in accordance with the Swedish Act concerning the Ethical Review of Research Involving Humans (“Lag om etikprövning av forskning som avser människor” – SFS 2003:460).

1. **Confidentiality**

The Recipient agrees to preserve, at all times, the confidentiality of Data pertaining to identifiable Data Subjects. In particular, the Recipient undertakes not to use, or attempt to use the Data to deliberately compromise or otherwise infringe the confidentiality of information on Data Subjects and their right to privacy.

1. **Data Protection**

The Recipient agrees that it, and its Registered Users, are covered by and shall comply with the obligations contained in the *EU General Data Protection Regulation (GDPR)* (Regulation (EU) 2016/679) and any complementary Swedish national legislation as amended from time to time. In particular, the Recipient and its Registered Users understand their duties under such legislation in relation to the handling of Data and the rights of Data Subjects.

The Recipient agrees that it, and its Registered Users, shall not analyse or make any use of the Data in such a way that has the potential to:

1. lead to the identification of any Data Subject; or
2. compromise the anonymity of any Data Subject in any way.
3. **Access and Governance**

The Recipient agrees that it shall take all reasonable security precautions to keep the Data confidential.

The Recipient may not duplicate the data.

The Recipient agrees to that under no circumstances give access to Data to any third party, except to Registered Users (as described below).

The Recipient agrees to only give access to Data, in whole or part, or any identifiable material derived from the Data, to a Registered User. The Recipient agrees that before it gives any Registered User access to Data, it shall first show the Registered User a copy of this Agreement and shall inform the Registered User that he or she must comply with the obligations contained in this Agreement and sign up to the provisions of this Agreement in the form set out at the end of this Agreement. The Recipient shall provide Data Provider with a copy of the Registered User’s acceptance form within thirty (30) days of the date of acceptance by the Registered User.

The Recipient agrees that it shall only give Registered Users that are not Researchers (including but not limited to students or new researchers to the field) access to the Data if they are supervised by a Researcher who will take responsibility for such Registered Users’ use of the Data.

The Data Provider reserves the right to request and inspect data security and management documentation to ensure the adequacy of data protection measures applied by the Recipient.

The Recipient agrees to notify the Data Provider immediately in case a breach of data security.

1. **Errors**

The Recipient agrees to notify the Data Provider of any errors detected in the Data.

1. **Intellectual Property**

The Recipient recognises that nothing in this Agreement shall operate to transfer to the Recipient or its Registered Users any Intellectual Property rights in or relating to the Data.

The Recipient and its Registered Users shall have the right to develop Intellectual Property based on comparisons with their own data, within the given informed consent and implement licensing policies that will not obstruct further research.

1. **Publications**

The Recipient agrees to acknowledge in any work based in whole or part on the Data, the published paper from which the Data derives. The Recipient will also declare in any such work that those who carried out the original analysis and collection of the Data bear no responsibility for the further analysis or interpretation of it by the Recipient.

The Recipient shall endeavour to publish any work derived from the Data in an academic journal or an open access database.

As detailed in 5. , the Recipient shall not publish any part of the Data, but instead refer to the Data Provider.

1. **Termination of Agreement**

This Agreement will terminate immediately upon any breach of the provisions of this Agreement by the Recipient or by the Recipient’s Registered Users.

The Recipient accepts that the changing ethical framework of human genetic research may lead to: (i) alteration to the provisions of this Agreement, in which case the Recipient may accept such alterations or terminate this Agreement; or (ii) the withdrawal of this Agreement in extreme circumstances.

Either party shall have the right to terminate this Agreement with immediate effect upon giving written notice of termination to the other party.

In the event that the recipient will no longer use the Data in their Research this Agreement will terminate.

In the event that this Agreement is terminated in accordance with this Clause 9, the Recipient shall return or destroy all Data at the direction of Data Provider.

1. **Legal statement**

The Recipient acknowledges that Data Provider and all other parties involved in the creation, funding or protection of the Data:

1. make no warranty or representation, express or implied as to the accuracy, quality or comprehensiveness of the Data; and
2. exclude to the fullest extent permitted by law all liability for actions, claims, proceedings, demands, losses (including but not limited to loss of profit), costs, awards damages and payments made by the Recipient that may arise (whether directly or indirectly) in any way whatsoever from the Recipient’s use of the Data, or from the unavailability of, or break in access to the Data for whatever reason.

The Recipient understands that all the Data is protected by copyright and other intellectual property rights, such that duplication or sale of all of or part of the Data on any media is not permitted under any circumstances, except with the prior written consent of Data Provider.

1. **Governing Law**

This Agreement (and any dispute, controversy, proceedings or claim of whatever nature arising out of this Agreement or its formation) shall be construed, interpreted and governed by the laws of Sweden and shall be subject to the exclusive jurisdiction of the Swedish courts.

**AGREED by the parties through their authorised signatories**

**Data Provider**

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| Authorised Signature: |  |
| Name: |  |
| Title: |  |
| Date: |  |

**Recipient:**

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| Address: |  |
| Telephone No: |  |
| Email: |  |
| Authorised Signature: |  |
| Name: |  |
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**Registered Users:**

The Registered Users acknowledge the contents of this Agreement and agree to comply with the obligations herein. For the avoidance of doubt the Registered Users are not a party to this Agreement.

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