

# DATA ACCESS AGREEMENT

authorized by The First Korean Stroke Genetics Association Research (The FirstKSGAR) Consortium

These terms and conditions govern access to the managed access datasets (details of which are set out in Appendix I) to which the User Institution has requested access. The User Institution agrees to be bound by these terms and conditions.

## Definitions

**Authorized Personnel:** The individuals at the User Institution to whom The FirstKSGAR consortium grants access to the Data. This includes the User, the individuals listed in Appendix II and any other individuals for whom the User Institution subsequently requests access to the Data. Details of the initial Authorised Personnel are set out in Appendix II.

**Data:** The managed access datasets to which the User Institution has requested access.

**Data Producers:** Members of "The First Korean Stroke Genetics Association Research" (*The FirstKSGAR*) consortium and the collaborators listed in Appendix I responsible for the development, organization, and oversight of these Data.

**External Collaborator:** A collaborator of the User, working for an institution other than the User Institution.

**Project:** The project for which the User Institution has requested access to these Data. A description of the Project is set out in Appendix II.

**Publications:** Includes, without limitation, articles published in print journals, electronic journals, reviews, books, posters and other written and verbal presentations of research.

**Research Participant:** An individual whose data form part of these Data.

**Research Purposes:** Shall mean research that is seeking to advance the understanding of genetics and genomics, including the treatment of disorders, and work on statistical methods that may be applied to such research.

**User:** The principal investigator for the Project.

**User Institution(s):** The Institution that has requested access to the Data.

**XXXXXX:** Your Institution details here

1. The User Institution agrees to only use these Data for the purpose of the Project (described in Appendix II) and only for Research Purposes. The User Institution further agrees that it will only use these Data for Research Purposes which are within the limitations (if any) set out in Appendix I.
2. The User Institution agrees to preserve, at all times, the confidentiality of these Data. In particular, it undertakes not to use, or attempt to use these Data to compromise or otherwise infringe the confidentiality of information on Research Participants. Without prejudice to the generality of the foregoing, the User Institution agrees to use at least the measures set out in Appendix I to protect these Data.
3. The User Institution agrees to protect the confidentiality of Research Participants in any research papers or publications that they prepare by taking all reasonable care to limit the possibility of identification.
4. The User Institution agrees not to link or combine these Data to other information or archived data available in a way that could re-identify the Research Participants, even if access to that data has been formally granted to the User Institution or is freely available without restriction.
5. The User Institution agrees only to transfer or disclose these Data, in whole or part, or any material derived from these Data, to the Authorised Personnel. Should the User Institution wish to share these Data with an External Collaborator, the External Collaborator must complete a separate application for access to these Data.
6. The User Institution agrees that the Data Producers, and all other parties involved in the creation, funding or protection of these Data: a) make no warranty or representation, express or implied as to the accuracy, quality or comprehensiveness of these Data; b) 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 these Data or from the unavailability of, or break in access to, these Data for whatever reason and; c) bear no responsibility for the further analysis or interpretation of these Data.
7. The User Institution agrees to follow the *Publication Policy* in Appendix III. This includes respecting the moratorium period for the Data Producers to publish the first peer-reviewed report describing and analyzing these Data.
8. The User Institution agrees not to make intellectual property claims on these Data and not to use intellectual property protection in ways that would prevent or block access to, or use of, any element of these Data, or conclusion drawn directly from these Data.
9. The User Institution can elect to perform further research that would add intellectual and resource capital to these data and decide to obtain intellectual property rights on these downstream discoveries. In this case, the User Institution agrees to implement licensing policies that will not obstruct further research and to follow the U.S. National Institutes of Health *Best Practices for the Licensing of Genomic Inventions* (2005) ([https://www.icgc.org/files/daco/NIH\\_BestPracticesLicensingGenomicInventions\\_2005\\_en.pdf](https://www.icgc.org/files/daco/NIH_BestPracticesLicensingGenomicInventions_2005_en.pdf)) in conformity with the Organisation for Economic Co-operation and Development *Guidelines for the Licensing of the Genetic Inventions* (2006) (<http://www.oecd.org/science/biotech/36198812.pdf>).

10. The User Institution agrees to destroy/discard the Data held, once it is no longer used for the Project, unless obliged to retain the data for archival purposes in conformity with audit or legal requirements.
11. The User Institution will notify members of The FirstKSGAR steering committee (acting on behalf of The FirstKSGAR collaborators) within 30 days of any changes or departures of Authorised Personnel.
12. The User Institution will notify The FirstKSGAR steering committee (acting on behalf of The FirstKSGAR collaborators) prior to any significant changes to the protocol for the Project.
13. The User Institution will notify The FirstKSGAR steering committee (acting on behalf of The FirstKSGAR collaborators) as soon as it becomes aware of a breach of the terms or conditions of this agreement.
14. The FirstKSGAR steering committee may terminate this agreement by written notice to the User Institution. If this agreement terminates for any reason, the User Institution will be required to destroy any Data held, including copies and backup copies. This clause does not prevent the User Institution from retaining these data for archival purpose in conformity with audit or legal requirements.
15. The User Institution accepts that it may be necessary for the Data Producers to alter the terms of this agreement from time to time. In the event that changes are required, the Data Producers or their appointed agent will contact the User Institution to inform it of the changes and the User Institution may elect to accept the changes or terminate the agreement.
16. If requested, the User Institution will allow data security and management documentation to be inspected to verify that it is complying with the terms of this agreement.
17. The User Institution agrees to distribute a copy of these terms to the Authorized Personnel. The User Institution will procure that the Authorized Personnel comply with the terms of this agreement.

**Agreed for User Institution (Applicant Part)**

<b>Signature:</b>	
<b>Title/Name:</b>	
<b>Affiliation:</b>	
<b>Date:</b>	

**Principal Investigator (Applicant Part)**

I confirm that I have read and understood this Agreement.

<b>Signature:</b>	
<b>Title/Name:</b>	
<b>Affiliation:</b>	
<b>Date:</b>	

**Agreed for The FirstKSGAR steering committee (acting on behalf of The FirstKSGAR collaborators)**

<b>Signature:</b>	
<b>Title/Name:</b>	
<b>Affiliation:</b>	
<b>Date:</b>	

**APPENDIX I – DATASET DETAILS**

**APPENDIX II —PROJECT DETAILS**

**APPENDIX III — PUBLICATION POLICY**

## **APPENDIX I – DATASET DETAILS (to be completed by the data producer before passing to applicant)**

### **Dataset reference (EGA Study ID and Dataset Details)**

The Sacred Heart Hospital Stroke Database, which includes biospecimen (e.g., Plasma, DNA, RNA), methylation, GWAS-chip and whole-exome sequencing (WES) samples from stroke and its subtypes such as infarction, ischemic hemorrhage, and intracranial aneurysm, produced under the consortium named: South Korea (including samples from Hallym (main center), Seoul National, Konkuk, Jeju National University, and 10 more University-centered medical centers) and UK (including samples from Southampton General Hospital). The same dataset includes GWAS-chip and WES samples from genotypes for all individuals in the consortium.

### **Name of project that created the dataset**

The FirstKSGAR consortium (The First Korean Stroke Genetics Association Research).

### **Names of The FirstKSGAR steering committee members:**

- Jin Pyeong Jeon: Hallym University College of Medicine, Chuncheon, South Korea
- Eun Pyo Hong: Hallym University College of Medicine, Chuncheon, South Korea
- Bong Jun Kim: Hallym University College of Medicine, Chuncheon, South Korea
- Dong Hyuck Youn: Hallym University College of Medicine, Chuncheon, South Korea
- Jun Hyong Ahn: Hallym University College of Medicine, Chuncheon, South Korea
- Heung Cheol Kim: Hallym University College of Medicine, Chuncheon, South Korea
- Jae Jun Lee: Hallym University College of Medicine, Chuncheon, South Korea
- Yong Jun Cho: Hallym University College of Medicine, Chuncheon, South Korea
- Seung Won Kwon: Kyung Hee University College of Oriental Medicine, Seoul, South Korea
- Jeong Jin Park: Konkuk University Medical Center, Seoul, South Korea
- Jeong Eun Kim: Seoul National University, Seoul, South Korea
- Gyojun Hwang: Bundang CHA University Medical Center, Seungnam, South Korea
- Keunsoo Kang: Dankook University College of Science & Technology, Cheonan, South Korea
- Sehyeon Nam: Hanyang University Materials Science & Chemical Engineering, South Korea
- Hyojong Yoo: Hanyang University Materials Science & Chemical Engineering, South Korea
- Jong Kook Rhim: Jeju National University College of Medicine, Jeju, South Korea
- Ian Galea: University of Southampton Southampton General Hospital, Southampton, UK
- Ben Gastra: University of Southampton Southampton General Hospital, Southampton, UK

### **Names of other data producers/collaborators**

*Under construction to be continued...*

### **Specific limitations on areas of research**

In support of points 2 and 3 of this agreement, no research aimed to develop or evaluate methodology to identify the anonymous donors can be performing with this data.

### **Minimum protection measures required**

***File access:*** Data can be held in unencrypted files on an institutional compute system, with Linux user group read/write access for one or more appropriate groups but not Linux world read/write access behind a secure firewall. Laptops holding these data should have password protected logins and screenlocks (set to lock after 5 min of inactivity). If held on USB keys or other portable hard drives, the data must be encrypted.

**APPENDIX II – PROJECT DETAILS (to be completed by the Requestor)**

**Details of dataset requested i.e., EGA Study and Dataset Accession Number**

**Brief abstract of the Project in which the Data will be used (500 words max)**

**All Individuals who the User Institution to be named as registered users**

<i><b>Name of Registered User</b></i>	<i><b>Email</b></i>	<i><b>Job Title</b></i>	<i><b>Supervisor*</b></i>

**All Individuals that should have an account created at the EGA**

<b>Name of Registered User</b>	<b>Email</b>	<b>Job Title</b>

### **APPENDIX III – PUBLICATION POLICY**

XXXXX intend to publish the results of their analysis of this dataset and do not consider its deposition into public databases to be the equivalent of such publications. XXXXX anticipate that the dataset could be useful to other qualified researchers for a variety of purposes.

In any publications based on these data, please describe how the data can be accessed, including the name of the hosting database (e.g., The Korean Genome-phenome Archive at the Korean Bioinformatics Institute) and its accession numbers (e.g., KGAS00000000029), and acknowledge its use in a form agreed by the User Institution with The FirstKSGAR consortium.