

## DATA ACCESS AGREEMENT

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

**Authorised Personnel:** The individuals at the User Institution to whom Division of Human Genetics, Medical University Innsbruck 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:** Division Human Genetics, Medical University Innsbruck and the collaborators listed in Appendix I responsible for the development, organisation, 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.

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.
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 *Fort Lauderdale Guidelines* ([http://www.wellcome.ac.uk/stellent/groups/corporatesite/@policy\\_communications/documents/web\\_document/wtd003207.pdf](http://www.wellcome.ac.uk/stellent/groups/corporatesite/@policy_communications/documents/web_document/wtd003207.pdf)) and the *Toronto Statement* (<http://www.nature.com/nature/journal/v461/n7261/full/461168a.html>). This includes but is not limited to recognising the contribution of the Data Producers and including a proper acknowledgement in all reports or publications resulting from the use of these Data.
8. The User Institution agrees to acknowledge in any work based in whole or part on the Data, the published paper from which the Data derives as well as the Data Producers. Furthermore, the User Institution agrees to follow the *Publication Policy* in Appendix III.
9. The User Institution agrees to publish individual-level results only for the set of genes of interest that is specified explicitly for each Research Participant and to not report any findings concerning other genes. See Appendix I for more details.
10. 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.

11. 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>).
12. 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.
13. The User Institution will notify the Data Access Committee within 30 days of any changes or departures of Authorised Personnel.
14. The User Institution will notify the Data Access Committee prior to any significant changes to the protocol for the Project.
15. The User Institution will notify the data access committee as soon as it becomes aware of a breach of the terms or conditions of this agreement.
16. The Data Access 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.
17. The User Institution accepts that it may be necessary for the Data Producers to alter the terms of this agreement from time to time. As an example, this may include specific provisions relating to the Data required by Data Producers other than Division of Human Genetics, Medical University Innsbruck. 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.
18. The User Institution accepts that the Data is protected by and subject to international laws, including but not limited to the UK Data Protection Act 1998, and that they are responsible for ensuring compliance with any such applicable law. The Data Access Committee reserves the right to request and inspect data security and management documentation to ensure the adequacy of data protection measures in countries that have no national laws comparable to that which pertain in the European Economic Area (EEA).
19. The User Institution agrees to distribute a copy of these terms to the Authorised Personnel. The User Institution will procure that the Authorised Personnel comply with the terms of this agreement.
20. 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 Austria and shall be subject to the exclusive jurisdiction of the Austrian courts.

**Agreed for User Institution**

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

**Principal Investigator**

**I confirm that I have read and understood this Agreement.**

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

**Agreed for the Data Access Committee**

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

- APPENDIX I – DATASET DETAILS**
- APPENDIX II —PROJECT DETAILS**
- APPENDIX III — PUBLICATION POLICY**

## **APPENDIX I – DATASET DETAILS**

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

EGAS00001002481: CNV detection in targeted NGS panel data

The aim of this study was to compare copy-number-variation (CNV) detection methods for targeted NGS panel data in a clinical diagnostic setting. We present targeted NGS panel data from 170 samples that were processed using the TruSight(TM) Cancer (TSC) panel (Illumina, San Diego, CA, USA), which targets 94 genes and 284 SNPs associated with a predisposition towards cancer. The samples are enriched for CNVs in the genes of interest. All CNVs have previously been assessed with MLPA and can therefore be considered as confirmed.

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

panelcn.MOPS: Copy-number detection in targeted NGS panel data for clinical diagnostics.

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

Institute of Bioinformatics, Johannes Kepler University Linz  
Medical Genomics Laboratory, Department of Genetics, University of Alabama at Birmingham

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

To prevent incidental findings, individual-level results may only be reported for the set of genes of interest that is specified explicitly for each Research Participant and not for other genes of the panel. The report of summary statistics that do not allow for the mapping of results to individual samples are permitted.

### **Minimum protection measures required**

***File access:** Data can be held in unencrypted files on an institutional compute system, with Unix user group read/write access for one or more appropriate groups but not Unix world read/write access behind a secure firewall. Laptops holding these data should have password protected logins and screenlocks.*

**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**

<b><i>Name</i></b>	<b><i>Email</i></b>	<b>Affiliation</b>	<b><i>Job Title</i></b>	<b><i>Supervisor*</i></b>

***\* PhD student applicants must include their supervisors as a co-applicant***

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

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

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

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 European Genome-phenome Archive at the European Bioinformatics Institute) and its accession numbers (e.g., EGAS00001002481), and acknowledge that the research makes use of Data generated by the Data Producer. Further, the publication should reference the paper Povysil G, Tzika A, Vogt J, et al. panelcn.MOPS: Copy-number detection in targeted NGS panel data for clinical diagnostics. *Human Mutation*. 2017;38:889–897. <https://doi.org/10.1002/humu.23237>