

Amsterdam University Medical Center
100+ study

Alzheimer's Disease Genetics Hub
AGHub

AGHUB REGISTRY
TERMS AND CONDITIONS

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AGHUBTERMS AND CONDITIONS

1 Definitions

1.1 Definitions

Words beginning with a capital letter shall have the meaning defined either herein or in the EU GDPR.

1.2 Additional Definitions

"AGHub"

AGHub means Stichting VUmc.

"AGHub Compute"

AGHub Compute means an amount of capacity to have AGHub process Datasets and have AGHub perform requested computations on those Datasets.

AGHub Compute Contribution Addendum

AGHub Compute Contribution Addendum means the addendum to this Registry Agreement on the topic of AGHub Compute, which is incorporated by reference, and any future modifications and/or amendments to it.

"Anonymized"

Anonymized means Personal Data that has been Processed to no longer relate to any identified or identifiable natural person or Personal Data that has been rendered anonymous in such a manner that the Data Subject is not or no longer identifiable.

"Background"

Background means "Data, know-how or information whatever its form or nature (tangible or intangible), including any rights such as intellectual property rights — that is:

A) held by the Participants before they agreed to the Registry Agreement or is developed or acquired by them in parallel with and independently of the Registry, and Needed as defined below; or

B) held, developed, or acquired by AGHub independently of the Registry.

Each of the Participants retains full ownership or right of disposal on any Background.

"Data"

Data means any information provided to the Registry, such as personal data as defined in the GDPR and/or data generated with sequencing, mass spectrometry, clinical and animal phenotyping, molecular biological techniques, imaging, sensor or other technologies, including data derived from human and non-human tissue.

"Dataset"

Dataset means any Data from the Registry made accessible for a Project.

“EU GDPR”

EU GDPR means Regulation (EU) 2016/679 of the European Parliament and of the Council of 27 April 2016 on the protection of natural persons with regard to the processing of personal data and on the free movement of such data.

“Host”

Host means the third party hosting the Registry.

“Needed”

Needed means:

For the implementation of the Registry:

Access Rights are Needed if, without the grant of such Access Rights, operating the Registry by AGHub would be technically or legally impossible, significantly delayed, or require significant additional financial or human resources.

For the implementation of a Project:

Access Rights are Needed if, without the grant of such Access Rights, carrying out the Project by the recipient Participant would be technically or legally impossible, significantly delayed, or require significant additional financial or human resources.

For exploitation of own Results:

Access Rights are Needed if, without the grant of such Access Rights, the exploitation of own Results would be technically or legally impossible.

“Participant”

Participant means any person who is a party to a Registry Agreement, excluding AGHub.

“Project”

Project means any activity between for which a Dataset is made accessible.

“Project Description”

Project Description means the description of the Project. The Project Description is part of the Project Proposal.

“Project Proposal”

Project Proposal means a proposal for a Project.

“Provider”

Provider means any Participant that provides Data to the Registry under the Registry Agreement.

"Pseudonymized"

Pseudonymized means Personal Data that has been Processed in a way that the Personal Data can no longer be attributed to a Data Subject without the use of additional information, which is kept separately and subject to technical and organizational measures to ensure non-attribution.

"Recipient"

Recipient means a Participant that receives Data or access to Data from the Registry under the Registry Terms Agreement.

"Registry"

Registry means the AGHub registry.

"Registry Agreement"

Registry Agreement means the agreement between AGHub and the Participant, in which they agree, *inter alia*, to these Registry Terms and Conditions, and any future modifications and/or amendments to it.

"Registry Terms and Conditions"

Registry Terms and Conditions means these terms and conditions including its appendices, addenda, and any future modifications and/or amendments to it and them.

"Results"

Result(s) mean(s) any (tangible or intangible) output of a Project such as Data, knowledge or information — whatever its form or nature, whether it can be protected or not — that is generated in a Project, as well as any rights attached to it, including intellectual property rights.

Two or more Participants own results jointly if: (a) they have jointly generated them and (b) it is not possible to establish the respective contribution of each Participant, or separate them for the purpose of applying for, obtaining or maintaining their protection.

"Scientific Committee"

Scientific Committee means the Registry's scientific committee appointed by AGHub.

2 Purpose

Alzheimer's Disease (AD) and other neurodegenerative disease have a large impact on society. The goal of this registry is to enable the identification of (rare) (high impact) variants that play a role in these diseases, in order to improve the understanding of their (shared) etiology, to improve clinical diagnosis/prognosis capabilities, and to enable the development of precision medicine. To this end, the registry seeks to bring together the genetic data from both AD patients and healthy controls, in order to process and analyze them in a unified manner.

The main objectives of the Registry are: a) to build a centralized registry of genetic data related to neurodegenerative diseases, with a focus on AD, in a way that fully adheres to relevant privacy laws and regulations; b) to provide Projects access to a Dataset, which are preprocessed in a unified manner; c) to enhance collaboration between research groups and researchers involved in the field of the

genetics of neurodegeneration; and d) to accelerate momentum for the discovery of new genetic risk variants for these disease.

The purpose of the Registry Agreement is to specify with respect to the Registry the relationship between AGHub and the Participants, in particular concerning the Registry and the rights and obligations of AGHub and the Participants concerning inter alia AGHub Compute, liability, Access Rights and dispute resolution, and the organisation of Projects.

3 Survival of rights and obligations

The provisions relating to Access Rights, Dissemination and confidentiality, for the time period mentioned therein, as well as for liability, applicable law and settlement of disputes shall survive the expiration or termination of the Registry Agreement.

4 Termination

Without prejudice to any other right or remedy (including any right to claim damages) that a Participant may have, the Registry Agreement with a Participant and/or a Participant's participation in a project may be terminated:

- ☐ immediately by AGHub at any time by written notice to a Participant; or
- ☐ immediately by a Participant by written notice to AGHub if (i) that Participant becomes insolvent or unable to pay its debts as and when they become due, (ii) an order is made or a resolution is passed for the winding up of that Participant (other than voluntarily for the purpose of solvent amalgamation or reconstruction), (iii) a liquidator, administrator, administrative receiver, receiver or trustee is appointed in respect of the whole or any part of that Participant's assets or business, (iv) that Participant makes any composition with its creditors, (v) that Participant ceases to continue its business, or (vi) as a result of debt and/or maladministration that Participant takes or suffers any similar or analogous action.

Termination shall not affect any rights or obligations of a Participant leaving the Project incurred prior to the date of termination, unless otherwise agreed between the Participants. This includes the Participant's obligation to provide all necessary input, deliverables and documents for the period of its participation.

5 Responsibilities

5.1 General principles

Each Participant shall ensure that its activities under this Registry Agreement complies fully with all applicable local, government and international laws, regulations and guidelines. Furthermore, each Participant undertakes to diligently fulfil its respective obligations as set forth in the Registry Agreement and the Registry Terms and Conditions. In doing so, each Participant shall act in accordance with the principle of good faith, as defined by Dutch law, and provide the cooperation and assistance reasonably required to enable AGHub to comply with its legal obligations.

Each Participant undertakes to notify AGHub promptly, of any significant information (such as specific obligations following from its national mandatory law), fact, problem or delay likely to affect AGHub's processing of the Data in relation to the Registry.

Each Participant shall take reasonable measures to ensure the accuracy of any information or materials it supplies to AGHub.

Each Participant may only access the Registry if, under applicable laws, including the country where it resides or from which it accesses the Registry, it is permitted to access the Registry.

6 Providing Data

6.1.1

Any Participant may, acting as Provider, offer Data to the Registry through modification of the Registry Agreement's list of provided Data. AGHub decides on the acceptance of Data to the Registry. Provider will only provide Data free of charge.

6.1.2

The Provider shall provide AGHub with the conditions, if any, under which the Data may be processed into Datasets to which Recipient(s) receive access for use in a Project.

Additionally, AGHub may request each Provider for permission to process its Data into a Dataset to which Recipient(s) will get access for use in a Project.

6.1.3

Section 14 is applicable to providing Data to the Registry.

7 Receiving access to a Dataset

7.1.1

A Participant may, acting as Recipient, request AGHub for access to a Dataset for the purpose of conducting a Project by sending AGHub a Project Proposal.

In case of multiple Recipients receiving access to a Dataset, each such Recipient is jointly and severally responsible for the obligations placed on the Recipient.

7.1.2

The Project Proposal must contain at least the following information:

1. Contact details of the researcher at Recipient who is responsible for the Project;
2. The Project Description (research question, approach to answer the question);
3. Which Datasets are requested;
4. A complete list of the proposed Recipients;
5. Whether a AGHub Compute Contribution is requested; and
6. Analysis plan.

7.1.3

The Recipient ensures that it has obtained any necessary authorizations and/or opinions and taken appropriate measures for use of the Dataset.

7.1.4

AGHub shall provide the Recipient with the conditions for access to the Dataset as indicated by the Provider(s).

7.1.5

AGHub shall decide on providing access to the Dataset and may involve the Scientific Committee in its decision.

8 AGHub Compute

8.1 Initial AGHub

Each Participant receives limited initial AGHub Compute at the first execution of the Registry Agreement. The AGHub Compute Contribution Addendum does not apply to this limited initial amount of AGHub Compute.

8.2 AGHub Compute granted as contribution to a Project

AGHub may, at its sole discretion, offer any amount of AGHub Compute to any Project as a contribution. Any Recipient may request AGHub Compute from AGHub as a contribution for a Project. Any AGHub Compute is provided under the conditions of the AGHub Compute Contribution Addendum.

It is agreed that if any Recipient uses the offered AGHub Compute Contribution, this constitutes acceptance and agreement of the offered AGHub Compute, including the AGHub Compute Contribution Addendum.

Upon request, the Recipient will re-confirm their acceptance in writing to AGHub.

If AGHub Compute is granted to the Recipient as a contribution to a Project, it is agreed between AGHub and the Recipient that the AGHub Compute Contribution Addendum apply in respect of that Project.

9 Results, Background, Access Rights

9.1 Ownership of Background

AGHub shall retain all right, title and interest in and to all of its Background. No Participant will make any representation or do any act which may be taken to indicate that it has any right, title or interest in or to the ownership or use of any of the Background of AGHub except under the terms of this Registry Agreement.

9.2 Ownership of Results

Results are owned by the Participant that generates them. Such Participant will decide alone on the protection measures to be taken for its solely owned Results and initiate them in its own name and at its expense.

9.3 Joint ownership

Unless otherwise agreed:

- each of the joint owners shall be entitled to use their jointly owned Results for non-commercial research and teaching activities on a royalty-free basis, and without requiring the prior consent of the other joint owner(s).
- each of the joint owners shall be entitled to otherwise Exploit the jointly owned Results and to grant non-exclusive licenses to third parties (without any right to sub-license), if the other joint owners are given: (a) at least 45 calendar days advance notice; and (b) fair and reasonable compensation for the other joint owners.

The joint owners shall agree on all protection measures and the division of related cost in advance.

9.3.1 Access Rights to AGHub for implementation

Each Provider grants AGHub non-exclusive Access Rights to the Data it provides for the implementation of the AGHub Registry, on a royalty-free basis, excluding any rights to sublicense unless expressly stated otherwise, and free of any administrative transfer costs. Such Access Rights allow AGHub, *inter alia*, to receive Data from (a) Provider(s), to Process the Data into (a) Dataset(s), and to provide Datasets to Recipient(s).

Each Participant grants AGHub non-exclusive Access Rights to its (solely or jointly owned) Results and Background Needed for the implementation of the AGHub Registry, on a royalty-free basis, excluding any rights to sublicense unless expressly stated otherwise, and free of any administrative transfer costs.

9.3.2 Access Rights for Provider

Each Recipient grants the Provider of Data used in the Dataset non-exclusive Access Rights to its (solely or jointly owned) Results for the purposes of teaching, internal research, and patient care, on a royalty-free basis, excluding any rights to sublicense, and free of any administrative transfer costs. Each Recipient grants such Provider non-exclusive Access Rights to Background for the sole purpose of using those Results for the aforementioned purposes, on fair and reasonable conditions, subject to any third party rights and upon written agreement between Recipient and that Provider.

10 Dissemination

Each Participant agrees, in every dissemination of Results, to acknowledge the use of and contribution by AGHub to the Project, in accordance with the standard academic and publication practices, reflecting the nature and extent of the contribution made by AGHub.

11 Warranties

11.1 AGHub

In respect of any Dataset to which access is provided by AGHub to Recipient, no warranty or representation of any kind is made, given or implied as to (i) the sufficiency, accuracy, or fitness for purpose of that Dataset; or (ii) that such Dataset does not infringe any proprietary rights of third parties. Therefore, the Recipient shall in all cases be entirely and solely liable for the use to which it puts the access to the Dataset.

11.2 Provider

Provider represents and warrants that it has the right to provide the Data to AGHub.

In respect of the Data provided by any Provider to AGHub, no warranty or representation of any kind is made, given or implied as to the sufficiency, accuracy, or fitness for purpose of a that Data, other than listed in this Section 11.2.

Provider represents and warrants that the Data it provides to the Registry is provided in compliance with the Registry Agreement and all applicable rules, laws or regulations, especially concerning data protection. In particular:

- ☐ Provider represents and warrants that, if required, properly signed informed consent and acknowledgement forms from any human subjects, or their legal guardians, for the Data provided, are obtained and maintained; and
- ☐ Provider represents and warrants that it has obtained and maintains, if required, properly signed informed consent and acknowledgement forms from any human subjects, or their legal guardians, for the Data provided to the Registry.

Provider represents and warrants that the Data it provides to the Registry does not infringe any proprietary rights of third parties.

Provider represents and warrants that it has secured all necessary approvals (including from relevant research ethics committees, where applicable) to transfer the Data it provides to the Registry.

12 Liability

12.1 Limitations of contractual liability

AGHub shall not be responsible to any Participant(s) for any indirect or consequential loss or similar damage such as, but not limited to, loss of profit, loss of revenue or loss of contracts, to the fullest extent permitted by Dutch Law.

AGHub's general aggregate liability towards any Participant(s) shall be limited to the amount paid out by the AGHub's insurer.

AGHub' liability shall not be limited under either of the two foregoing paragraphs to the extent such damage was caused by a willful act or gross negligence or to the extent that such limitation is not permitted by law.

AGHub shall not be responsible or liable for any failure of a Participant to comply with applicable law and/or its institutional policies with regard to the transferring of Data into the Registry or accessing a Dataset.

12.2 Damage caused to third parties

AGHub and each Participant shall be solely liable for any loss, damage or injury to third parties resulting from the performance of those person's obligations by it or on its behalf under the Registry Agreement or from its use of Results or Background.

12.3 Force Majeure

Force majeure means any situation or event that prevents AGHub from fulfilling their obligations under the Agreement, was unforeseeable, exceptional situation and beyond AGHub's control, was not due to error or negligence on their part (or on the part of other participants involved in the action), and proves to be inevitable in spite of exercising all due diligence.

AGHub shall not be considered to be in breach of the Registry Agreement if it is prevented from fulfilling its obligations under the Registry Agreement by Force Majeure.

AGHub will immediately take all the necessary steps to limit any damage due to Force Majeure and will do its best to resume the Registry as soon as possible.

AGHub will notify the Participants of any Force Majeure without undue delay, stating the nature, likely duration and foreseeable effects.

12.4 Export control

AGHub or a Participant shall be considered to be in breach of the Registry Agreement if it is prevented from fulfilling its obligations under the Registry Agreement due to a restriction resulting from import or export laws and regulations and/or any delay of the granting or extension of the import or export license or any other governmental authorisation, provided that the party concerned has used its reasonable efforts to fulfil its obligations and to apply for any necessary license or authorisation properly and in time.

Each Participant will notify AGHub of any such restriction without undue delay. If the consequences of such restriction for the Project are not overcome within 6 weeks after such notice, the transfer of tasks - if any - shall be decided by the other Participants.

13 Non-disclosure of information

13.1

All information in whatever form or mode of communication, which is disclosed by AGHub to any Participant in connection with the Registry, and which has been explicitly marked as "confidential" at the time of disclosure, or when disclosed orally has been identified as confidential at the time of disclosure and has been confirmed and designated in writing within 15 calendar days from oral disclosure at the latest as confidential information by AGHub, is "**Confidential Information**".

13.2

Participants hereby undertakes for a period of 5 years after receipt of the Confidential Information:

- not to use Confidential Information otherwise than for the purpose for which it was disclosed;
- not to disclose Confidential Information without the prior written consent by AGHub;
- to ensure that internal distribution of Confidential Information by that Participant shall take place on a strict need-to-know basis; and
- to return to AGHub, or destroy, on request all Confidential Information that has been disclosed to that Participant including all copies thereof and to delete all information stored in a machine-readable form to the extent practically possible. That Participant may keep a copy to the extent it is required to keep, archive or store such Confidential Information because of compliance with applicable laws and regulations or for the proof of on-going obligations provided that the

Recipient complies with the confidentiality obligations herein contained with respect to such copy.

13.3

The Participant shall be responsible for the fulfilment of the above obligations on the part of its employees or third parties and shall ensure that they remain so obliged, as far as legally possible, during and after the end of the Registry and/or after the termination of the contractual relationship with the employee or third party.

13.4

The above shall not apply for disclosure or use of Confidential Information, if and in so far as the Participant can show that:

- the Confidential Information has become or becomes publicly available by means other than a breach of the Participant's confidentiality obligations;
- AGHub subsequently informs the Participant that the Confidential Information is no longer confidential;
- the Confidential Information is communicated to the Participant without any obligation of confidentiality by a third party who is to the best knowledge of the Participant in lawful possession thereof and under no obligation of confidentiality to AGHub;
- the Confidential Information, at any time, was developed by the Participant completely independently of any such disclosure by AGHub;
- the Confidential Information was already known to the Participant prior to disclosure, or
- the Participant is required to disclose the Confidential Information in order to comply with applicable laws or regulations or with a court or administrative order, subject to the provision Section 13.7 hereunder.

13.5

The Participant shall apply the same degree of care with regard to the Confidential Information disclosed within the scope of the Project as with its own confidential and/or proprietary information, but in no case less than reasonable care.

13.6

Each Participant shall promptly inform AGHub by written notice of any unauthorised disclosure, misappropriation or misuse of Confidential Information after it becomes aware of such unauthorised disclosure, misappropriation or misuse.

13.7

If any Participant becomes aware that it will be required, or is likely to be required, to disclose Confidential Information in order to comply with applicable laws or regulations or with a court or administrative order it shall, to the extent it is lawfully able to do so, prior to any such disclosure

- notify AGHub, and
- comply with AGHub's reasonable instructions to protect the confidentiality of the information.

14 Data processing

14.1 Roles

14.1.1

Each Provider shall determine the purpose and means of the processing of the Data it provides, is therefore a Controller, and shall fulfil all obligations of a Controller under applicable privacy law.

14.1.2

AGHub shall determine the purposes and means of the processing of Datasets, is therefore the Controller of Datasets, and shall fulfil all obligations of a Controller under applicable privacy law.

Each Recipient only receives access rights to a Dataset and may request AGHub to process the Dataset. In performing the processing of the Dataset, AGHub is not a processor on behalf of the Recipient.

Each Recipient may download or receive the result of the processing of the Dataset, without personal data or in an anonymized form.

14.2 Prohibition of procedures to identify Data Subjects

AGHub and Recipient(s) shall not carry out or attempt to carry out any procedures with the Data and/or Dataset - such as linking, comparison, or processing - with which the identity of a Data Subject could be derived.

14.3 AGHub

14.3.1

AGHub operates the Registry in accordance with the Registry Agreement and the laws applicable to AGHub.

AGHub shall inform the Participants about the method of encoding and the location of the Registry (and any changes to the location).

14.4 Provider

14.4.1

Each Provider shall, if required, obtain properly signed informed consent and acknowledgement forms from any human subjects, or their legal guardians, for the Data provided.

Each Provider shall secure all necessary approvals (including from relevant research ethics committees, where applicable) before providing Data to the Registry.

14.4.2

Provider shall transfer Data into the Registry in Anonymized or Pseudonymised form only, in accordance with the guidelines and instructions of AGHub. The key to coded Data is held at the Provider's own location for its own Data Subjects and is the responsibility of the Provider.

14.4.3

Each Provider shall use best efforts to ensure the accuracy of any Data that it provides into the Registry.

Each Provider shall use best efforts to notify AGHub of any errors in Provider's Data that Provider becomes aware of.

Each Provider shall, if so instructed by AGHub, correct errors in the Provider's Data in the Registry.

14.5 Recipient

14.5.1

The Recipient undertakes that the Dataset will be used in accordance with the Registry Agreement, the Project Description, and applicable legal and regulatory provisions, notably the provisions relating to the protection of the personal data and to medical secrecy.

The Recipient undertakes that the Dataset will only be used for the sole purposes of conducting the Project, in accordance with the Project Description, for which access to the Dataset is provided, and to only use it for as long as it is necessary for this purpose, to the exclusion of any other application, in particular for commercial purposes.

14.5.2

The Recipient undertakes that the Dataset will no longer be accessed in the event of the termination of the Project and/or Registry Agreement and/or upon the expiry thereof.

14.5.3

The Recipient undertakes to not access Personal Data in the Registry.

The Recipient undertakes to not, directly or indirectly, download the Dataset, or extract from or Process the Dataset to access any personal data, such as individual-level or other privacy-sensitive data.

The Recipient undertakes that the Dataset will be accessed exclusively on the Registry.

The Recipient will inform AGHub immediately if a Dataset to which it has access, or a substantial portion thereof, is available via means other than AGHub, such as the case where a Dataset has been downloaded or where the case where personal data (such as individual-level or other privacy-sensitive data) is extracted or otherwise Processed from a Dataset.

14.6 Participants

Participants shall ensure that the privacy of the Data Subjects and the confidentiality of Data and Dataset are protected in accordance with the statutory requirements applicable in their own country and the policies of the institution of which the Subject is a patient.

Except as specifically agreed otherwise among the relevant Participants in respect of a particular processing of a Dataset, the Recipient acknowledges and agrees that the Data and/or Dataset is a research tool supplied "as is", without any guarantee of any kind, whether express or implied, particularly as regards the preservation, use or manipulation of the Data and/or Dataset, the fitness and sufficiency or the possibility of using them for a given purpose, or infringement of third party's rights. In particular,

the Data and/or Dataset are supplied without any guarantee of any kind, whether express or implied, particularly as regards the possibility of using it for a given purpose.

14.6.1 Recipients ensure that personal data is:

- processed lawfully, fairly and in a transparent manner in relation to the data subjects;
- collected for specified, explicit and legitimate purposes and not further processed in a manner that is incompatible with those purposes;
- adequate, relevant and limited to what is necessary in relation to the purposes for which they are processed;
- accurate and, where necessary, kept up to date;
- kept in a form which permits identification of data subjects for no longer than is necessary for the purposes for which the data is processed; and
- processed in a manner that ensures appropriate security of the data.

14.6.2 The Participants may grant their personnel access to personal data only if it is strictly necessary for implementing, managing and monitoring that Project. The Participants must ensure that the personnel is under a confidentiality obligation.

15 Miscellaneous

15.1 Attachments, inconsistencies and severability

These Registry Terms and Conditions consists of this core text and:

- Attachment 1 (AGHub Compute Contribution Addendum)
- Attachment 2 (Model Registry Agreement)

In case of conflicts between the attachments and the core text of the Registry Agreement, the latter shall prevail.

Should any provision of the Registry Agreement become invalid, illegal or unenforceable, it shall not affect the validity of the remaining provisions of the Registry Agreement. In such a case, the Participants concerned shall be entitled to request that a valid and practicable provision be negotiated that fulfils the purpose of the original provision.

15.2 No representation, partnership or agency

No Participant shall be entitled to act or to make legally binding declarations on behalf of AGHub or any other Participant. Nothing in the Registry Agreement shall be deemed to constitute a joint venture, agency, partnership, interest grouping or any other kind of formal business grouping or entity between the Participants.

15.3 Formal and written notices

Any notice to be given under the Registry Agreement shall be addressed to the recipients as listed in the most current address list kept by the Coordinator.

Any change of persons or contact details shall be immediately communicated to the Coordinator by written notice. The address list shall be accessible to all Participants.

Formal notices:

If it is required in the Registry Agreement that a formal notice, consent or approval shall be given, such notice shall be signed by an authorised representative of a Participant and shall either be served personally or sent by mail with recorded delivery with acknowledgement of receipt.

Written notice:

Where written notice is required by the Registry Agreement, this is fulfilled also by other means of communication such as e-mail with acknowledgement of receipt.

15.4 Assignment

No rights or obligations of the Participants arising from the Registry Agreement may be assigned or transferred, in whole or in part, to any third party without AGHub's prior formal approval.

15.5 Unilateral modification

AGHub reserves the right to unilaterally modify or revise these Terms and Conditions. Any such modifications will take effect 30 days after their publication on our website, or after notification has been sent to the User, unless otherwise stipulated. The 30-day notice period does not apply if it is reasonably impossible to do so due to circumstances arising from laws or regulations, governmental provisions, user safety concerns, user privacy considerations, technical integrity, preventing disruption of the Registry for other users, or due to natural disasters, catastrophic events, war, or other similar circumstances beyond AGHub's reasonable control.

In the event of material adverse changes to the Registry Agreement, AGHub shall notify the Participant by sending an email to the Participant's last-known email address, or by prominently displaying a notice on the AGHub website.

If the Participant does not object to the amended Registry Terms and Conditions within 30 days of receiving the notification, or, if no notification is required, within 30 days of their publication, the Participant is deemed to have accepted the changes.

Should the Participant disagree with the amended Registry Terms and Conditions, they have the right to terminate their Registry Agreement prior to the date on which the new Terms and Conditions take effect, without incurring any penalties or fees.

Regarding paid services related to the Registry, AGHub will not make materially adverse changes to the Registry before the expiration of the current payment term unless such changes are reasonably necessary due to laws or regulations, governmental provisions, user safety concerns, user privacy considerations, technical integrity, preventing disruption of the Registry for other users, or to prevent issues arising from natural disasters, catastrophic events, war, or other similar circumstances beyond AGHub's reasonable control.

In such a case, AGHub will refund that Participant a prorated amount of any prepaid fees for the ongoing payment term. AGHub shall not be liable to any Participant for any changes to the Registry or the Registry Terms and Conditions made in accordance with this section 15.5.

15.6 Rejection of Participant general terms and conditions

The provisions of the Registry Agreement shall exclusively govern the rights, obligations, and relations between AGHub and the Participants in respect of the Registry, in accordance with Dutch law.

AGHub expressly rejects (*Dutch: wijst uitdrukkelijk van de hand*) each and every Participant's general terms and conditions (*Dutch: algemene voorwaarden*).

No terms, conditions, understandings, or agreements that seek to modify or differ from the terms of the Registry Agreement shall have any effect, unless explicitly agreed in a written agreement and duly signed by AGHub and those Participants. This includes any general terms and conditions contained in any purchase orders, confirmations, specifications, or other documents issued by any of the Participants, if relevant to the Registry.

15.7 Use of names, logos or trademarks

Nothing in the Registry Agreement shall be construed as conferring rights to use in advertising, publicity or otherwise the name of AGHub or any of its logos or trademarks without AGHub's prior written approval.

AGHub may (but shall not be obligated to) use each Participant's name, logo and other business information, including contact information, as provided by the Participant, in connection with the provision of the Registry, and the provision of the Datasets through the Registry, provided that such use shall be accurate and not misleading, and shall not suggest or imply any affiliation or endorsement between AGHub and that Participant.

15.8 Mandatory national law

Nothing in the Registry Agreement shall be deemed to require a Participant to breach any mandatory statutory law under which the Participant is operating.

15.9 Language

The Registry Agreement and these Registry Terms and Conditions are drawn up in English, which language shall govern all documents, notices, meetings, arbitral proceedings and processes relative thereto.

15.10 Applicable law

The Registry Agreement and the Registry Terms and Conditions shall be construed in accordance with and governed by the laws of the Netherlands excluding its conflict of law provisions.

15.11 Settlement of disputes

The Participants shall endeavour to settle their disputes amicably.

All disputes between AGHub and Participant(s), arising out of or in connection with the Registry Agreement or the Registry Terms and Conditions, which cannot be solved amicably, shall be finally settled by the courts of Amsterdam.

REGISTRY TERMS AND CONDITIONS ATTACHMENT 1: AGHUB COMPUTE CONTRIBUTION ADDENDUM

AGHUB COMPUTE CONTRIBUTION ADDENDUM

1 Definitions

1.1 Definitions

Words beginning with a capital letter shall have the meaning defined either herein, in the Registry Agreement, or in the EU GDPR.

1.2 Additional Definitions

“Defaulting Participant”

Defaulting Participant means a Participant which AGHub has declared to be in breach of the Registry Agreement as specified in Section 4 of the AGHub Compute Contribution Addendum.

“Project Coordinator”

Means the Participant in a Project, who is designated by the Project’s Participants to coordinate that Project.

“Project Participant”

Means a Participant of a Project.

2 AGHub Compute Contribution

2.1 Applicability

The following clauses shall only apply to any Project to which AGHub contributes AGHub Compute under Section 8.2 of the Registry Agreement.

Project Participants must obtain the prior written consent of AGHub to diverge from this AGHub Compute Contribution Addendum.

2.2 General

The Project Participants jointly undertake to take part in the efficient implementation of the Project, and to cooperate, perform and fulfil, promptly and on time, all of its obligations under the Registry Agreement and the Project Proposal (including the Project Description), as may be reasonably required from it and in a manner of good faith as prescribed by Dutch law.

Each Project Participant undertakes to notify the other Project Participants promptly, of any significant information, fact, problem or delay likely to affect the Project.

Each Project Participant shall promptly provide all information reasonably required by the other Project Participants to carry out their tasks.

Each Project Participant shall take reasonable measures to ensure the accuracy of any information or materials it supplies to the other Project Participants. Each party in a Project shall ensure that its work on that Project complies fully with all applicable local, government and international laws, regulations and guidelines. In this regard, each Project Participant shall maintain the confidentiality, in accordance

with the Registry Agreement, of all materials, samples and data relating to the use of human subjects, which is created or used in the course of that Project.

Each Project Participant shall secure all necessary approvals from the relevant research ethics committees before undertaking any part of the Project requiring ethics committee approval and shall, if required, obtain properly signed informed consent and acknowledgement forms from any human subjects, or their legal guardians, who they will involve in that Project.

3 Accessing Data from the Registry

3.1.1

Each Project appoints one of the Project Participants as Project Coordinator.

3.1.2

The Project Coordinator may request AGHub for access to a Dataset for the purpose of conducting that Project by sending AGHub a Project Proposal.

3.1.3

In addition to the requirements of Section 7, the Project Proposal must contain the following information:

1. the internal organisation of the Project (Project governance);
2. list of Project Participants' Background for the Project
3. the amount agreed to be each Project Participant's general aggregate liability towards the other Project Participants collectively, referred to in Section 6.2.

3.1.4

AGHub shall provide the Project Coordinator with the conditions for access to the Dataset as indicated by the Provider(s) in each Registry Agreement.

3.1.5

AGHub may involve the Scientific Committee.

3.1.6

Only employees or associates of the Project Coordinator can submit a Project Proposal to AGHub.

3.1.7

All Project Participants must have signed a Registry Agreement.

4 Breach

Each Project Participant will notify the Project Coordinator if that Project Participant identifies a breach of the obligations under the Registry Agreement and/or the Project Proposal. In the case of an identified breach of the Registry Agreement, the Project Coordinator shall notify AGHub.

Where an identified breach is substantial and is not remedied within that period or is not capable of remedy:

- ☐ the Project Coordinator may decide to declare that Project Participant to be a Defaulting Participant and to decide on the consequences thereof which may include termination of its participation in that Project; and/or
- ☐ AGHub may decide on the consequences thereof which may include termination of the Registry Agreement.

The Scientific Committee shall, upon request of AGHub, provide an opinion on the matter.

5 Involvement of third parties in a Project

Project Participants shall not involve third parties in a Project without the consent of the Provider and all Project Participants.

A Project Participant that enters into a subcontract or otherwise involves third parties in a Project remains responsible for carrying out its relevant part of that Project and for such third party's compliance with the provisions of the Registry Agreement. Such Project Participant has to ensure that the involvement of third parties does not affect the rights and obligations of the other Project Participants under the Registry Agreement.

6 Liability towards each other

6.1 No warranties

Each Project Participant undertakes to perform its work at its own risk and under its sole liability and shall support all consequences in compliance with the provisions hereunder.

In respect of any information or materials (incl. Results and Background) supplied by one Project Participant to another under that Project, no warranty or representation of any kind is made, given or implied as to (i) the sufficiency, accuracy, or fitness for purpose of such information or materials; or (ii) that such information or materials does not infringe any proprietary rights of third parties.

Therefore,

- the recipient Project Participant shall in all cases be entirely and solely liable for the use to which it puts such information and materials, and
- no Project Participant granting Access Rights shall be liable in case of infringement of proprietary rights of a third party resulting from any other Project Participant exercising its Access Rights.

6.2 Limitations of contractual liability

No Project Participant shall be responsible to any other Project Participant for any indirect or consequential loss or similar damage such as, but not limited to, loss of profit, loss of revenue or loss of contracts, to the fullest extent permitted by Dutch Law.

Each Project Participant's general aggregate liability towards the other Project Participants collectively shall be limited to the amount agreed in the Project Description.

Each Project Participant's liability shall not be limited under either of the two foregoing paragraphs to the extent such damage was caused by a willful act or gross negligence or to the extent that such limitation is not permitted by law.

7 Financial provisions

Each Project Participant shall bear their own costs for the execution and performance of the Project.

7.1.1 Justifying Costs

In accordance with its own usual accounting and management principles and practices, each Project Participant shall be solely responsible for justifying its costs with respect to that Project towards any third person, such as a grantor (if applicable) or another contributor.

Neither AGHub nor any of the other Participants shall be in any way liable or responsible for such justification of costs towards any such third person.

7.1.2 Financial Consequences of the termination of the participation of a Participant

A Project Participant leaving the Project shall refund to the Project Coordinator any payments it has received except the amount of contribution accepted by a grantor (if applicable) or another contributor.

In addition, a Project Participant declared to be a Defaulting Participant shall, within the limits specified in Section 6.2, bear any reasonable and justifiable additional costs occurring to the other Project Participants in order to perform the leaving Project Participant's task and necessary additional efforts to fulfil them as a consequence of the Project Participant leaving the Project.

8 Results

The Project Coordinator shall promptly inform AGHub of all Results of the Project.

8.1 Ownership of Background

AGHub, and each Project Participant shall retain all right, title and interest in and to all of its Background. For the avoidance of doubt, all Background used in connection with a Project shall remain the property of the Project Participant introducing the same. No Project Participant will make any representation or do any act which may be taken to indicate that it has any right, title or interest in or to the ownership or use of any of the Background of the other Project Participants except under the terms of this Agreement.

8.2 Transfer of Results

Each Project Participant may transfer ownership of its own Results, including its share in jointly owned Results, upon 45 days prior notice to the other Project Participants. Such Project Participant is however obligated to ensure that all obligations related to the Results also apply to the new owner and that this new owner has the obligation to pass them on in any subsequent transfer.

8.2.1

The transferring Project Participant shall, however, at the time of the transfer, inform the other Project Participants of such transfer and shall ensure that the rights of the other Project Participants under the Registry Agreement will not be affected by such transfer.

8.2.2

The Project Participants recognise that in the framework of a merger or an acquisition of an important part of its assets, it may be impossible under applicable EU and national laws on mergers and acquisitions for a Project Participant to give at least 45 calendar days prior notice for the transfer.

8.2.3

The obligations above apply only for as long as other Participants still have - or still may request - Access Rights to the Results.

8.3 Dissemination

8.3.1

For the avoidance of doubt, the confidentiality obligations set out in Section 9 apply to all dissemination activities described in this Section 8.3 as far as Confidential Information is involved.

8.3.2 Dissemination of own (including jointly owned) Results

Each Project Participant shall use reasonable endeavours to disseminate its solely or jointly owned Results, including content and methodologies, and to enable these to be used by other researchers and care- and/or educational practitioners (e.g. doctors, nurses, welfare workers, teachers) developing and/or implementing preventive approaches for non-communicable diseases.

Results are published as soon as possible. Having regard to the expected exploitation rights, the Project Coordinator may postpone publication of Results for up to nine months after they have been determined.

As soon as they are published, the Results should be immediately subject to Open Access to ensure their optimum dissemination or application. Copyrights may only be transferred to third parties to the extent that this does not obstruct the possibility of their publication under Open Access.

In any publication of Project Results, it must be indicated that the Project has received funding from the Dutch Research Council (NWO), including the mention of the NWO project number and the funding instrument under which the project falls. The NWO logo should be displayed. Where applicable, the formal designation of NWO in the relevant language must be used:

- ☐ (Dutch) Nederlandse Organisatie voor Wetenschappelijk Onderzoek;
- ☐ (English) Dutch Research Council;
- ☐ (French) Organisation Néerlandaise pour la Recherche Scientifique;
- ☐ (German) Niederländische Organisation für wissenschaftliche Forschung;
- ☐ (Italian) Organizzazione nazionale olandese per la ricerca scientifica; or
- ☐ (Spanish) Organización neerlandesa de investigaciones científicas.

8.3.2.1

Prior notice of any planned publication shall be given to the other Project Participants at least 45 calendar days before the publication. Any objection to the planned publication shall be made by written notice to the Coordinator and to the Project Participant or Project Participants proposing the

dissemination within 30 calendar days after receipt of the notice. If no objection is made within the time limit stated above, the publication is permitted.

8.3.2.2

An objection is justified if

- a) the protection of the objecting Project Participant's Results or Background would be adversely affected, or
- b) the objecting Project Participant's legitimate interests in relation to its Results or Background would be significantly harmed, or
- c) the proposed publication includes Confidential Information of the objecting Project Participant.

The objection has to include a precise request for necessary modifications.

8.3.2.3

If an objection has been raised the involved Project Participants shall discuss how to overcome the justified grounds for the objection on a timely basis (for example by amendment to the planned publication and/or by protecting information before publication) and the objecting Project Participant shall not unreasonably continue the opposition if appropriate measures are taken following the discussion.

8.3.2.4

The objecting Project Participant can request a publication delay of not more than 90 calendar days from the time it raises such an objection. After 90 calendar days the publication is permitted, provided that the objections of the objecting Project Participant have been addressed.

8.3.3 Dissemination of another Project Participant's unpublished Results or Background

A Project Participant shall not include in any dissemination activity another Project Participant's Results or Background without obtaining the owning Project Participant's prior written approval, unless they are already published.

8.3.4 Cooperation obligations

The Project Participants undertake to cooperate to allow the timely submission, examination, publication and defense of any dissertation or thesis for a degree that includes their Results or Background subject to the confidentiality and publication provisions agreed in the Registry Agreement.

8.3.5 Use of names, logos or trademarks

Nothing in the Registry Agreement shall be construed as conferring rights to use in advertising, publicity or otherwise the name of the Project Participants or any of their logos or trademarks without their prior written approval.

8.4 Access Rights

8.4.1 Access Rights for teaching, research, patient care, and development of AGHub Registry

Each Project Participant grants AGHub non-exclusive Access Rights to its (solely or jointly owned) Results for the purposes of teaching, research, patient care, and development of AGHub Registry, on a royalty-free basis, including any rights to sublicense, and free of any administrative transfer costs. Each Project Participant grants AGHub non-exclusive Access Rights to Background for the sole purpose of using the Results for such purposes, on fair and reasonable conditions, subject to any third party rights and upon written agreement between AGHub and that Project Participant.

8.4.2 Background included

8.4.2.1

In each Project Description, the Project Participants identified and agreed on the Background for the Project and have also, where relevant, informed each other that Access to specific Background is subject to legal restrictions or limits.

Anything not identified in the Project Description shall not be the object of Access Right obligations regarding Background.

8.4.2.2

Any Project Participant may add additional Background to the Project Description during the Project provided they give written notice to the Project Coordinator. However, approval of the Project Coordinator is needed should a Project Participant wish to modify or withdraw its Background in the Project Description.

8.4.3 General Principles

8.4.3.1

Each Project Participant shall implement its tasks in accordance with the Project Description and shall bear sole responsibility for ensuring that its acts within the Project do not knowingly infringe third party property rights.

8.4.3.2

Any Access Rights granted exclude any rights to sublicense unless expressly stated otherwise.

8.4.3.3

Access Rights shall be free of any administrative transfer costs.

8.4.3.4

Access Rights are granted on a non-exclusive basis.

8.4.3.5

Results and Background shall be used only for the purposes for which Access Rights to it have been granted.

8.4.3.6

All requests for Access Rights shall be made in writing. The granting of Access Rights may be made conditional on the acceptance of specific conditions aimed at ensuring that these rights will be used only for the intended purpose and that appropriate confidentiality obligations are in place.

8.4.3.7

The requesting Project Participant must show that the Access Rights are Needed.

8.4.4 Access Rights for implementation

Access Rights to Results and Background Needed for the performance of the own work of a Project Participant under the Project shall be granted on a royalty-free basis, unless otherwise agreed for Background in Attachment 1.

8.4.5 Access Rights for exploitation

8.4.5.1 Access Rights to Results

Access Rights to Results if Needed for exploitation of a Project Participant's own Results shall be granted on Fair and Reasonable conditions and upon written agreement between the concerned Project Participants.

Access rights to Results for internal research and for teaching activities shall be granted on a royalty-free basis.

8.4.5.1.1

Access Rights to Background if Needed for exploitation of a Project Participant's own Results, shall be granted on Fair and Reasonable conditions, subject to any third party rights and upon written agreement between the concerned Project Participants.

8.4.5.1.2

A request for Access Rights may be made up to twelve (12) months after the end of the Project or, in the case of Section 8.4.8.2.1.2, after the termination of the requesting Project Participant's participation in the Project.

8.4.6 Access Rights for entities under the same control

Entities under the same control have Access Rights.

Such Access Rights must be requested by the entity under the same control from the Project Participant that holds the Background or Results. Alternatively, the Project Participant granting the Access Rights may individually agree with the Project Participant requesting the Access Rights to have the Access Rights include the right to sublicense to the latter's entity or entities under the same control. Access Rights to an entity under the same control shall be granted on Fair and Reasonable conditions and upon written bilateral agreement.

Entities under the same control which obtain Access Rights in return fulfil all confidentiality obligations accepted by the Project Participants under the Registry Agreement and shall comply with the Registry Agreement as if such entities were Project Participants.

Access Rights may be refused to entities under the same control if such granting is contrary to the legitimate interests of the Project Participant which owns the Background or the Results.

Access Rights granted to any entity under the same control are subject to the continuation of the Access Rights of the Project Participant with whom it is under the same control, and shall automatically terminate upon termination of the Access Rights granted to such Project Participant.

Upon cessation of the status as an entity under the same control, any Access Rights granted to such former entity under the same control shall lapse.

Further arrangements with entities under the same control may be negotiated in separate agreements.

8.4.7 Additional Access Rights

For the avoidance of doubt any grant of Access Rights not covered by the Registry Agreement shall be at the absolute discretion of the owning Project Participant and subject to such terms and conditions as may be agreed between the owning and receiving Project Participants.

8.4.8 Access Rights for Project Participants entering or leaving the Project

8.4.8.1 New Project Participants entering the Project

As regards Results developed before the accession of the new Project Participant, the new Project Participant will be granted Access Rights on the conditions applying for Access Rights to Background.

8.4.8.2 Project Participants leaving the Project

8.4.8.2.1 Access Rights granted to a leaving Project Participant

8.4.8.2.1.1 Defaulting Participant

Access Rights granted to a Defaulting Participant and such Project Participant's right to request Access Rights shall cease immediately upon receipt by the Defaulting Participant of the formal notice of the decision of the Project Coordinator or AGHub to terminate its participation in the Project.

8.4.8.2.1.2 Non-defaulting Participant

A non-defaulting Project Participant leaving voluntarily and with the other Project Participants' consent shall have Access Rights to the Results developed until the date of the termination of its participation.

It may request Access Rights within the period of time specified in Section 8.4.5.1.2.

8.4.8.2.1.3 Access Rights to be granted by any leaving Project Participant

Any Project Participant leaving the Project shall continue to grant Access Rights pursuant to the Registry Agreement as if it had remained a Project Participant for the whole duration of the Project.

9 Non-disclosure of information

9.1

All information in whatever form or mode of communication, which is disclosed by a Project Participant (the “**Disclosing Project Participant**”) to any other Project Participant (the “**Recipient**”) in connection

with the Project during its implementation and which has been explicitly marked as “confidential” at the time of disclosure, or when disclosed orally has been identified as confidential at the time of disclosure and has been confirmed and designated in writing within 15 calendar days from oral disclosure at the latest as confidential information by the Disclosing Project Participant, is “**Confidential Information**”.

9.2

The Recipient hereby undertakes for a period of 5 years after the completion of the Project:

- not to use Confidential Information otherwise than for the purpose for which it was disclosed;
- not to disclose Confidential Information without the prior written consent by the Disclosing Project Participant;
- to ensure that internal distribution of Confidential Information by a Recipient shall take place on a strict need-to-know basis; and
- to return to the Disclosing Project Participant, or destroy, on request all Confidential Information that has been disclosed to the Recipients including all copies thereof and to delete all information stored in a machine-readable form to the extent practically possible. The Recipients may keep a copy to the extent it is required to keep, archive or store such Confidential Information because of compliance with applicable laws and regulations or for the proof of on-going obligations provided that the Recipient complies with the confidentiality obligations herein contained with respect to such copy.

9.3

The Recipient shall be responsible for the fulfilment of the above obligations on the part of its employees or third parties involved in the Project and shall ensure that they remain so obliged, as far as legally possible, during and after the end of the Project and/or after the termination of the contractual relationship with the employee or third party.

9.4

The above shall not apply for disclosure or use of Confidential Information, if and in so far as the Recipient can show that:

- the Confidential Information has become or becomes publicly available by means other than a breach of the Recipient’s confidentiality obligations;
- the Disclosing Project Participant subsequently informs the Recipient that the Confidential Information is no longer confidential;
- the Confidential Information is communicated to the Recipient without any obligation of confidentiality by a third party who is to the best knowledge of the Recipient in lawful possession thereof and under no obligation of confidentiality to the Disclosing Project Participant;
- the Confidential Information, at any time, was developed by the Recipient completely independently of any such disclosure by the Disclosing Project Participant;
- the Confidential Information was already known to the Recipient prior to disclosure, or
- the Recipient is required to disclose the Confidential Information in order to comply with applicable laws or regulations or with a court or administrative order, subject to the provision Section 13.7 hereunder.

9.5

The Recipient shall apply the same degree of care with regard to the Confidential Information disclosed within the scope of the Project as with its own confidential and/or proprietary information, but in no case less than reasonable care.

9.6

Each Recipient shall promptly inform the relevant Disclosing Project Participant by written notice of any unauthorised disclosure, misappropriation or misuse of Confidential Information after it becomes aware of such unauthorised disclosure, misappropriation or misuse.

9.7

If any Recipient becomes aware that it will be required, or is likely to be required, to disclose Confidential Information in order to comply with applicable laws or regulations or with a court or administrative order it shall, to the extent it is lawfully able to do so, prior to any such disclosure

- notify the Disclosing Project Participant, and
- comply with the Disclosing Project Participant's reasonable instructions to protect the confidentiality of the information.

REGISTRY TERMS AND CONDITIONS ATTACHMENT 2: MODEL AGHUB REGISTRY AGREEMENT

AGHub Registry Agreement

THIS REGISTRY AGREEMENT is made on the date of last signing of this agreement hereinafter referred to as the Effective Date,

BETWEEN:

1. **Stichting VUmc (AGHub/VUmc)**, having its registered office at De Boelelaan 1117, 1081HV Amsterdam, The Netherlands; and
2. **Participant (Participant)**, having its registered office at [x].

hereinafter, jointly or individually, referred to as "Participants" or "Participant",

relating to the Registry entitled

Alzheimer's Disease Genetics Hub

in short

AGHub

hereinafter referred to as "**Registry**",

WHEREAS:

AGHub provides a registry as a service for data on Alzheimer Disease and other neurodegenerative diseases under the conditions of the Registry Terms and Conditions.

Participant wants to participate in the AGHub Registry.

The Participants wish to specify binding commitments among themselves.

NOW, THEREFORE, IT IS HEREBY AGREED AS FOLLOWS:

1 Definitions

1.1 Definitions

Words beginning with a capital letter shall have the meaning defined either herein or in the Registry Terms and Conditions.

1.2 Additional Definitions

"Principal Researcher"

Means the researcher of the Participant that is responsible for this AGHub Registry Agreement.

2 Entry into force, duration and termination

2.1 Entry into force

This Registry Agreement come into force upon signature of this Registry Agreement by a duly authorised representative of AGHub and Participant.

These Registry Terms and Conditions shall have effect from the Effective Date.

3 Duration and termination

This Registry Agreement shall continue in full force and effect until termination by AGHub or Participant upon thirty (30) days written notice.

4 Registry Terms and Conditions

AGHub and Participant agree that the Registry Terms and Conditions apply and are incorporated by reference. In particular, Participant acknowledges, approves, and agrees to Section 15.5 of the Registry Terms and Conditions.

Participant declares to have received a copy of the Registry Terms and Conditions.

A copy of the Registry Terms and Conditions is attached to this Registry Agreement, and the most recent version can be found at alzheimergenetics.org/documentation.

Participant agrees to accept all the rights and obligations of a Participant starting from the Effective Date.

AGHub declares to accept Participant as a Participant of the Registry.

5 Amendments and modifications

Amendments and modifications to this core text of the Registry Agreement requires a separate written agreement to be signed between AGHub and the Participant. Amendments and modifications of the Registry Terms and Conditions are governed by the Registry Terms and Conditions.

6 Providing Data

Participant may, in accordance with the Registry Terms and Conditions, provide Data to AGHub. Participant will identify any Data provided in Attachment 1 to this Registry Agreement.

Participant may, by notice to AGHub or via the AGHub website, remove any Data it provided from the Registry by unilateral modification of Attachment 1 of this Registry Agreement. Any such modifications will take effect 30 days after notification has been sent to AGHub, unless otherwise stipulated or the Data is Needed for a Project. The 30-day notice period does not apply if it is reasonably impossible to do so due to circumstances arising from laws or regulations, governmental provisions, user safety concerns, user privacy considerations, technical integrity, preventing disruption of the Registry for other users, or due to natural disasters, catastrophic events, war, or other similar circumstances beyond AGHub's reasonable control.

In the event of modification of Attachment 1, AGHub may notify the Participants, such as by sending an email to the Participant's last-known email address, or by prominently displaying a notice on a section of the AGHub website visible to the Participants.

7 Participant Principal Researcher

The Principal Researcher for Participant will be [...].

8 Attachments and inconsistencies

This Registry Agreement consists of this core text and:

- Registry Agreement Attachment 1 (Data provided)
- Registry Agreement Attachment 2 (Registry Terms and Conditions)

In case of conflicts between the attachments and the core text of the Registry Agreement, the latter shall prevail.

9 Signatures

AS WITNESS:

AGHub and Participant have caused the Registry Agreement to be duly signed by the undersigned authorised representatives in separate signature pages the day and year first above written.

Stichting VUmc (AGHub)

Signature(s):

Name(s):

Title(s):

Date:

Full statutory name (Participant)

Signature(s):

Name(s):

Title(s):

Date:

REGISTRY AGREEMENT ATTACHMENT 1: DATA PROVIDED

Participant must identify the Data provided. This is the purpose of this attachment.

DATA PROVIDED

Describe Data		
License		Opt-in: I want to approve each use of the Data
		Opt-out: I do not need to approve each use of the Data, but I do want to be informed of each use of the Data.
Specific restrictions and/or conditions for implementation of (a) Project(s)		
Specific restrictions and/or conditions for exploitation		

This represents the status at the time of signature of the Registry Agreement.

REGISTRY AGREEMENT ATTACHMENT 2: REGISTRY TERMS AND CONDITIONS

The latest version of the Registry Terms and Conditions can be found at alzheimergenetics.org/documentation.