

**1066 Dementia Research Group**  
**Data use agreement**

**RE:**

Dear Colleague,

We are delighted to inform you that your request for the use of 10/66 resources will be review by members of the 10/66 Dementia Research Group. To facilitate the review process, the receipt of 10/66 resources requires your acceptance and compliance with the following obligations and requests:

1. The recipient must provide documentation of Institutional Review Board (IRB) approval, valid for the analysis of 10/66 data. Alternatively, an acknowledgment from your IRB stating that receiving coded data without access to identifiers does not require review. **Note: This documentation has NOT been received.**
2. The recipient agrees to protect the confidentiality of 10/66 participants and will not attempt to identify participants.
3. The recipient agrees to secure the dataset in accordance with the most stringent protections possible, compliant with local IRB, country regulations, and Health Insurance Portability and Accountability Act (HIPAA for US sites) standards for such sensitive data.
4. The recipient acknowledges that this approval is valid for 18 months starting from the effective date of this Agreement. If a longer time is needed to deliver the proposed output, the recipient agrees to notify the 10/66 research group.
5. The recipient acknowledges that this approval is valid for 18 months starting from the effective date of this Agreement. If a longer time is needed to deliver the proposed output, the recipient agrees to notify the 10/66 research group.
6. The recipient understands that the license is exclusive, and other individuals and groups will not be given access to the data for the same analyses. Exclusivity is guaranteed until the expiry of the agreed time period. If an extension is required, the recipient agrees to apply at least three months before expiry.
7. The recipient agrees that no data sharing with a third party is allowed without permission from the 10/66 Steering Committee. The recipient will not disclose these data beyond the uses outlined in this agreement, and redistribution of data in any manner is prohibited.
8. The recipient commits to using the dataset exclusively for the specified purposes, as approved by the oversight committee. If there is a need for any additional or different use beyond the initially agreed-upon purpose, the recipient agrees to submit a new application to the oversight committee and await their approval before proceeding.
9. The recipient agrees to ensure that only those investigators named in the proposal can access the dataset and will not make further copies, distribute, or publish the dataset without approval.
10. Acceptance of 10/66 resources requires the recipient to cite/reference the grant according to the specified format.
  - a) acknowledgement - "This is a secondary analysis of data collected by the 10/66 Dementia Research Group ([www.alz.co.uk/1066](http://www.alz.co.uk/1066)). The principal investigators, data custodians and responsible for research governance in each site are Martin Prince (United Kingdom), Juan Llibre Rodriguez (Cuba), Daisy Acosta (Dominican Republic), Mariella Guerra (Peru), Aquiles Salas (Venezuela), Ana Luisa Sosa (Mexico),

Ivonne Jimenez (Puerto Rico) and Yueqin Huang (China). The 10/66 Dementia Research Group's research has been funded by the Wellcome Trust Health Consequences of Population Change Programme (GR066133 – Prevalence phase in Cuba and Brazil; GR080002- Incidence phase in Peru, Mexico, Argentina, Cuba, Dominican Republic, Venezuela and China), the World Health Organization (India, Dominican Republic and China), the US Alzheimer's Association (IIRG – 04 – 1286 - Peru, Mexico and Argentina), the Puerto Rico State Legislature (Puerto Rico), and FONACIT/ CDCH/ UCV (Venezuela).”

11. The overarching considerations for 10/66 publications are collaboration and inclusiveness. Thus, for studies using 10/66 data, the recipient will invite 10/66 dementia research groups (country PIs and other members suggested by country PIs) to collaborate on the manuscript. Additionally, 10/66 members may also communicate their desire to collaborate when a study is reviewed. Contact the resource director (Juan J Llibre-Rodriguez) for details about site PIs.
12. Should funding result from this research, the recipient agrees to notify the 10/66 Resource Director (Juan J Llibre-Rodriguez) promptly with details for reporting purposes.
13. The recipient agrees not to share, publish, or release any findings or conclusions derived from the analysis of data without prior approval from the 10/66 Dementia Research Group. Manuscripts should be submitted 2 (if 1066 study member was involved in the analysis) OR 4 weeks (if no 1066 study member was consulted during the analysis) before journal submission to allow time for review and response to recommendations. The recipient agrees to notify the data provider of manuscript submissions, including the title and journal, as and when they occur. Additionally, the recipient agrees to notify the data provider of acceptance for publication and forward a PDF copy of the accepted manuscript at that time.
14. The recipient acknowledges that a breach of any provisions of this Agreement will lead to immediate termination of access to all services provided by the Data Provider, either permanently or temporarily, at the discretion of a member of the Data Provider. Legal action may be taken in such cases. The failure to exercise or delay in exercising a right or remedy provided by this Agreement or by law does not constitute a waiver of the right or remedy or other rights or remedies.

**Before the 10/66 Coordinating Center provides data, we request your signature to confirm your acceptance of the above terms. Please sign and return this letter at your earliest convenience.**

**Applicant Signature:**

**Date:**

**Printed name:**

**Institution:**