Data Use Agreement

AMYPAD PNHS

I request access to the data collected in the digital repository of the AMYPAD Prognostic and Natural History Study (PNHS), part of the Amsterdam UMC – location VUmc, established in Amsterdam, The Netherlands (hereinafter referred to as the AMYPAD PNHS).

By accepting this agreement, I become a data processor (as defined under the GDPR law) of the data that I have access to, and I am responsible for accessing these data under the following terms:

1. I will comply with all relevant rules and regulations imposed by my institution and my government. This agreement never has prevalence over existing general data protection regulations that are applicable in my country.
2. I will not attempt to establish or retrieve the identity of the study participants. I will not link these data to any other database in a way that could provide identifying information. I shall not request the pseudo-anonymization key that would link these data to an individual's personal information, nor will I accept any additional information about individual participants under this Data Use Agreement.
3. I will not redistribute these data or share access to these data with others, unless they have independently applied and been granted access to these data, i.e., signed this Data Use Agreement. This includes individuals in my institution.
4. When sharing secondary or derivative data (e.g., group statistics or derived images), I will only do so if they are on a group level, and cannot be deduced information from individual participants.
5. I will reference the specific source of the accessed data when publicly presenting any results or algorithms that benefited from their use:
    a. Papers, book chapters, books, posters, oral presentations, and all other presentations of results derived from the data should acknowledge the origin of the data as described in the *AMYPAD PNHS Publication Policy*.
    b. Authors of publications or presentations using the data should cite relevant publications describing the methods developed and used by the AMYPAD PNHS to acquire and process the data. The specific publications that are appropriate to cite in any given study will depend on what data were used and for what purposes (see appendix).
    c. Planned communications should be informed to the AMYPAD Steering Committee, for its acceptance or rejection, at least 30 days before they can be presented at scientific meetings (amypad.pnhs@amsterdamumc.nl).
    d. Neither the Amsterdam UMC nor the researchers that provide access to this data will be liable for any results and/or derived data. They shall not be included as authors of publications or presentations without consent.
6. Failure to abide by these guidelines will result in the termination of my privileges to access these data.

Appendix: Relevant Publications

1. Lopes Alves, I., Collij, L. E., Altomare, D., Frisoni, G. B., Saint-Aubert, L., Payoux, P., Kivipelto, M., Jessen, F., Drzezga, A., Leeuwis, A., Wink, A. M., Visser, P. J., van Berckel, B. N. M. M., Scheltens, P., Gray, K. R., Wolz, R., Stephens, A., Gismondi, R., Buckely, C., … AMYPAD Consortium. (2020). Quantitative amyloid PET in Alzheimer's disease: the AMYPAD prognostic and natural history study. *Alzheimer's & Dementia : The Journal of the Alzheimer's Association*, *16*(5), 750–758. https://doi.org/10.1002/alz.12069

2. Image Harmonization paper (WP2), *work in progress*

3. AMYPAD PNHS data integration (WP4), *work in progress*