



**DATA USE AGREEMENT AND PUBLICATION POLICY  
Alzheimer's Disease Repository Without Borders (ARWiBo)**

**INTRODUCTION**

This document outlines the recommendations for sharing data from the ARWiBo as well as policies for publication and publication credits for those who use ARWiBo data. The intent of these policies is to facilitate the sharing of data with all interested investigators, to encourage academic productivity, and to provide a mechanism for tracking data requests, intended analyses and publications related to and resulting from ARWiBo data.

**DATA REQUEST**

ARWiBo data will be shared with the granted members of the “scientific community”. The applications of each investigator requesting data will be reviewed internally and a judgment based on investigator affiliation and on the basis of the reason for the request will be made. It is anticipated that most requests will be legitimate and can be approved rapidly.

**DATA APPLICATION AND TRACKING**

A web-based, semi-automated data sharing application system will be instituted to manage the data requests. Users will complete a web-based application form and a Data Use Agreement. When the application will be received and approved, the applicant will be given permission to access the data using the on-line interactive web-portal (<https://neugrid2.eu>).

Applicants will be required to provide the following information:

- Name
- Address and Contact information
- Academic Affiliation (if any) or Institution/Company Name
- Proposed analyses
- Certification to each point of the Data Use Agreement.

Applicants will receive annual requests to update the application information. These requests will also solicit responses to the following queries about manuscripts:

- Title of each manuscript in development
- Lead author of each manuscript in development and contact information for that author
- Status of each manuscript in development (In development, In submission, In press/published)
- Upload a file of each published manuscript

Non-compliance with the required updates will block further access to ARWiBo data.

**PUBLICATION POLICY**

I request access to data stored in the Alzheimer's Disease Repository Without Borders (ARWiBo) for the purpose of scientific or clinical investigation, and agree to the following terms:

1. I will receive access to de-identified data and will not attempt to establish the identity of, or attempt to contact any of the ARWiBo subjects.
2. I will not further disclose these data beyond the uses outlined in this agreement and my data use application and **I understand that redistribution of primary (i.e., raw unprocessed individual participant-level) data in any manner is prohibited.** Reports and publication of summary (not participant-level) data are allowed.
3. I will not disclose any derived datasets beyond the uses outlined in this agreement. I understand that the distribution of secondary data (e.g. post-processed images) should be agreed with the Principal Investigator of ARWiBo, who will determine if and how data may be distributed.



4. **I will not utilize AI tools**, especially (but not exclusively) those with public-facing interfaces, which do not offer guarantees regarding the containment of data inputs for ARWiBo data. The use of AI tools, including generative and analytical models, poses a potential risk of inadvertent data sharing due to the nature of how these AI tools process information and may lead to data being sent, saved, viewed, or used by third parties not covered by the agreement, which is a direct violation of ARWiBo policies.
5. I will require anyone on my team who utilizes these data, or anyone with whom I share these data to comply with this data use agreement. I understand that I am not allowed to distribute ARWiBo data outside of my team.
6. I will respond promptly and accurately to annual requests to update information about my use of ARWiBo data and to possible requests to update this data use agreement.

In any publication using data or results from ARWiBo, I agree to the following:

7. I will cite ARWiBo as the source of data as the editorial policy allows.
8. I will take full responsibility for the results that I will obtain and/or publish.

If I publish manuscripts using data from ARWiBo, I agree to the following:

9. On the by-line of the abstract or the manuscript, after the named authors, I will include the sentence “and the Alzheimer's Disease Repository Without Borders Investigators\*” with the asterisk referring to the following statement and list of names:

*\*Data used in preparation of this article were obtained from the Alzheimer's Disease Repository Without Borders (ARWiBo) database (<https://www.arwibo.it>). As such, the researchers within the ARWiBo contributed to the design and implementation of ARWiBo and/or provided data but did not participate in analysis or writing of this report. A complete listing of ARWiBo researchers can be found at:*

<https://www.arwibo.it/acknowledgments.pdf>

10. I will mandatorily include language similar to the following in the methods section of my manuscripts in order to accurately acknowledge data gathering by the ARWiBo personnel. Depending upon the length and focus of the article, it may be appropriate to include more or less than the example below:

*Data used in the preparation of this article were obtained from the Alzheimer's Disease Repository Without Borders (ARWiBo) (<https://www.arwibo.it>). The primary aim of ARWiBo is to publish all clinical, neuropsychological, EEG, neuroimaging, and biological data of patients with neurodegenerative diseases and healthy controls collected in over 10 years by a number of researchers of IRCCS Fatebenefratelli, Brescia, Italy (Frisoni et al., 2009; Riello et al., 2004). The overall goal of ARWiBo is to contribute, thorough synergy with neuGRID (<https://neugrid2.eu>), to global data sharing and analysis in order to develop effective therapies, prevention methods and a cure for Alzheimer' and other neurodegenerative diseases. The Principal Investigator of ARWIBO is Giovanni B.Frisoni, MD, University Hospitals and University of Geneva, Geneva, Switzerland, and IRCCS Fatebenefratelli, The National Centre for Alzheimer's and Mental Diseases, Brescia, Italy. ARWIBO is the result of effort of many researchers of IRCCS Fatebenefratelli: G.Binetti, MD, Neurobiology; L.Bocchio-Chiavetto, PhD, Neuropharmacology; M.Cotelli, PhD, Neuropsychology Unit; C.Minussi, PhD, Neurophysiology; M.Gennarelli, PhD, Genetic Unit; R.Ghidoni, PhD, Proteomics Unit; D.Moretti, MD, and O.Zanetti, MD, Alzheimer's Unit.*

11. I will acknowledge funding by ARWiBo in the support acknowledgement section of the manuscript using language similar to the following:

*Data collection and sharing for this project was supported by the Italian Ministry of Health, under the following grant agreements: Ricerca Corrente IRCCS Fatebenefratelli, Linea di Ricerca 2; Progetto Finalizzato Strategico 2000-2001 “Archivio normativo italiano di morfometria cerebrale con risonanza magnetica (età 40+)”; Progetto Finalizzato Strategico 2000-2001 “Decadimento cognitivo lieve non dementigeno: stadio preclinico di malattia di Alzheimer e demenza vascolare. Caratterizzazione clinica,*



*strumentale, genetica e neurobiologica e sviluppo di criteri diagnostici utilizzabili nella realtà nazionale,”; Progetto Finalizzata 2002 “Sviluppo di indicatori di danno cerebrovascolare clinicamente significativo alla risonanza magnetica strutturale”; Progetto Fondazione CARIPLO 2005-2007 “Geni di suscettibilità per gli endofenotipi associati a malattie psichiatriche e dementigene”; “Fitness and Solidarietà”; and anonymous donors.*

12. I will submit all manuscripts to the ARWiBo staff at the following e-mail box: [info@arwibo.it](mailto:info@arwibo.it) prior to submit it to a journal. This review will not be a scientific review, but is intended to ensure that items 6-10 above are correctly implemented. The ARWiBo staff will maintain confidentiality of the manuscript and will complete its review within 2 weeks.
13. I will provide full citation of all published manuscripts and abstracts to the ARWiBo staff upon acceptance of manuscripts or abstracts. I will provide a copy of the manuscript to the ARWiBo staff upon publication of the manuscript. If permitted by the journal, I will agree that a version of the article or link to the article will be available on-line at the ARWiBo web site.
14. I will ensure that investigators who utilize ARWiBo data use appropriate administrative, physical and technical safeguards to prevent use or disclosure of the data other than as provided for by this agreement.
15. I will report any use or disclosure of the data not provided for by this agreement of which I become aware within 15 days of becoming aware of such use or disclosure.

#### **IMPORTANT NOTE**

ARWiBo is a continuously growing repository. It is the policy of ARWiBo to make reliable data available to investigators as quickly as possible. However, because “preliminary data” will be posted on the database, in the event that I download data from the ARWiBo database for the purposes of analysis and future publication in the form of abstracts and/or publications, I will note the version of the data I download, and I will check the database to determine if updated data has been provided prior to submission of any material for publication. I understand that failure to abide by these guidelines will result in termination of my privileges to access ARWiBo data.

#### **UNUSUAL CIRCUMSTANCES**

It is expected that most users of ARWiBo data will follow these guidelines in good faith and that most analyses will be of reasonable quality. The ARWiBo staff does not intend to review manuscripts for scientific quality, preferring to let the peer-review process sort out quality. It is recognized that ARWiBo data may even be used to support publications with conflicting results. However, ARWiBo anticipates the possibility of some unusual circumstances:

16. *Egregiously Poor Manuscripts.* If a review of a proposed manuscript reveals that it is egregiously poor in terms of language, writing or sensible substance, the ARWiBo staff can recommend to me that it not be submitted without significant revision. If I choose to submit the manuscript anyway, the ARWiBo staff will have three options: 1) request that the group authorship credit be withheld; 2) request that the authors publish a statement to the effect that while ARWiBo data were used, the ARWiBo did not find this manuscript of sufficient merit to warrant submission for publication, or; 3) revocation of privileges to use ARWiBo data in the future.
17. *Failure to Follow the ARWiBo Use Agreement and Publication Policy.* If I inadvertently violate the ARWiBo Use Agreement and Publication Policy, it is likely that I will self-correct as infractions are discovered. If I willfully violate the ARWiBo Use Agreement and Publication Policy, the sole sanction available to the ARWiBo will be to revoke access to the ARWiBo data.
18. *Fraudulent Use of Data.* As soon as the ARWiBo staff becomes aware of any breach of the ARWiBo Data Use Agreement and Publication Policy, immediate steps will be taken to cure the breach or end the violation. This may include discontinuing my data access and/or reporting the violation.
19. *Journal Objections:* It is possible that journal editors may object to the group authorship format with the caveat that those ARWiBo names credited have gathered data but not participated in the analysis and writing of the paper. The ARWiBo staff can authorize exceptions to the authorship policy or can negotiate with journal editors as needed on a case by case basis.



**IRCCS CENTRO SAN GIOVANNI DI DIO  
FATEBENEFRATELLI**



User's first and family name: \_\_\_\_\_

Institution: \_\_\_\_\_

Email: \_\_\_\_\_

Date (dd-mm-yyyy): \_\_\_\_\_ Signature: \_\_\_\_\_