

## Criteria for Access to Indiana University's DAC Project Data

I, \_\_\_\_\_, request access to data collected by the DIGITAL project for the purpose of scientific investigation, teaching or the planning of clinical research studies 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 DIGITAL subjects.
2. I will not attempt to make direct contact with DIGITAL PIs or staff at sites concerning the specific results of individual subjects.
3. I will not further disclose or share these data beyond the uses outlined in this agreement and my data use application and understand that redistribution of data in any manner is prohibited.
4. 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.
5. I will accurately provide the requested information for persons who will use these data and the analyses that are planned using these data.
6. I will respond promptly and accurately to annual requests to update this information.
7. I will comply with any rules and regulations imposed by my institution and its institutional review board in requesting these data. If I publish abstracts using data from DIGITAL, I agree to the following:
8. I will cite DIGITAL as the source of data and the DIGITAL funding sources in the abstract or manuscript as space allows.
9. I agree that acknowledgement of DIGITAL will not be cited in the authorship line of the abstract. If I publish manuscripts using data from DIGITAL I agree to the following: On the by-line of the manuscript, after the named authors, I will include the phrase "for the DIGITAL Study\*" with the asterisk referring to the following statement and list of names: "\*\*Data used in preparation of this article were obtained from the DIGITAL study data set housed at the Alzheimer's Disease Data Initiative (ADDI) (<https://www.alzheimersdata.org/>). As such, the investigators of the DIGITAL study contributed to the design and implementation of DIGITAL and/or provided data but did not participate in analysis or writing of this report. Willis DR<sup>1</sup>, Fowler NR<sup>2,3</sup>, Swartzell KL<sup>2,3</sup>, Hammers D<sup>4</sup>, Brosch J<sup>4</sup>, Summanwar D<sup>1</sup>, Murray J<sup>5</sup> from Indiana University School of Medicine, Department of Family Medicine<sup>1</sup>, Department of Medicine<sup>2</sup>, Center for Aging Research<sup>3</sup>, Department of Neurology<sup>4</sup>, Davos Alzheimer's Collaborative<sup>5</sup>."
- 10 I will include language similar to the following in the methods section of my manuscripts in order to accurately acknowledge data gathering by the DIGITAL personnel. Depending upon the length and focus of the article, it may be appropriate to include more or less than the example below, however inclusion of some variation of the language shown below is mandatory. "Data used in the preparation of this article were obtained from the DIGITAL study data set housed at the Alzheimer's Disease Data Initiative (ADDI) (<https://www.alzheimersdata.org/>). The DIGITAL study was launched in June of 2022 as part of the Davos Alzheimer's Collaborative Healthcare Systems Preparedness program. The primary goal of DIGITAL was to assess the feasibility and acceptability of screening individuals at least 65 years old for cognitive impairment in primary care and to assess the system's ability to make screening scalable and be implemented as part of the delivery of routine primary care." If a DIGITAL study paper has been published in the peer review literature describing the implementation of the study, I will use the citation of that paper as a reference for this statement.
- 11 I will acknowledge the resource support from the DIGITAL project in the support acknowledgement section of the manuscript using language similar to the following: "Data collection and sharing for this project was provided by the DIGITAL study. DIGITAL was funded by the Davos Alzheimer's Collaborative."
12. I will submit all manuscripts to the DIGITAL study leadership team prior to submitting to a conference or journal by sending it to [iufammed@iu.edu](mailto:iufammed@iu.edu). This review will not be a scientific review

but is intended to ensure that items 7-11 above are correctly implemented. The DIGITAL study leadership team will maintain confidentiality of the manuscript and will complete its review within 2 weeks.

13. I will ensure that Investigators who utilize DIGITAL data use appropriate administrative, physical and technical safeguards to prevent use or disclosure of the data other than as provided for by this Agreement.
14. 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.
15. Unusual Situations - the DIGITAL leadership does anticipate the possibility of some unusual circumstances and, if these occur, then the DIGITAL Leadership Team may take the following action.
  - a) 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 DIGITAL leadership team can recommend to the authors that it not be submitted without significant revision. If the authors choose to submit the manuscript anyway, the DIGITAL leadership team will have three options: 1) request that the acknowledgement credit be withheld; 2) request that the authors publish a statement to the effect that while DIGITAL data were used, the DIGITAL study leadership team did not find this manuscript of sufficient merit to warrant submission for publication, or; 3) revocation of privileges to use DIGITAL study data in the future.
  - b) Failure to Follow Data Use Agreement. If users inadvertently violate the Data Use Agreement, it is likely that they will self-correct as infractions are discovered. If users willfully violate the Data Use Agreement, the sole sanction available to the DIGITAL study will be to revoke access to the DIGITAL study data.
  - c) Fraudulent Use of Data. Open access using only email registration raises the possibility that individuals could obtain access to data under false pretenses. Should the DIGITAL study leadership team discover an attempt to publish data obtained fraudulently, immediate steps will be taken to cure the breach or end the violation. This may include discontinuing the user's data access and/or reporting the violation. As soon as the DIGITAL leadership team becomes aware of any breach of the Data Use Agreement, immediate steps will be taken to cure the breach or end the violation. This may include discontinuing the user's data access and/or reporting the violation.
  - d) Journal Objections. It is possible that journal editors may object to the acknowledgement format with the caveat that those DIGITAL names credited have gathered data but not participated in the analysis and writing of the paper. The DIGITAL leadership team can authorize exceptions to the acknowledgement policy or can negotiate with journal editors as needed on a case-by-case basis.

*I understand and accept the forementioned potential actions that may be taken if any of the events described in the sub-bullets a through d listed above should occur.*

- 16 I will familiarize myself with the analysis methods so that I am aware of the limitations of these data prior to using them for scientific purposes. Finally, because "preliminary data" will be posted on the database, in the event that I download data from the ADDI 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 DIGITAL study data.