

# NDWS Data Use Agreement

## Agreement

This Agreement, entered into as of \_\_\_\_\_ (“Effective Date”), between \_\_\_\_\_ (“Accessing Agency”) on behalf of \_\_\_\_\_ (“Primary User”), and the Regents of the University of Michigan (“U-M”) allows the Primary User and any Other Authorized User(s) to access and use the Restricted Data, outlined in Exhibit A and contained in the NDWS Study Workspace, in ways authorized by this Agreement, for the following Authorized Project:

[PROJECT TEAM TO INSERT STUDY ABSTRACT HERE]

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## Definitions

“Accessing Agency,” means the employer of the Primary User and any Authorized User that is authorized to encumber the Primary User and any Authorized Users to the stipulations contained in this Agreement.

“Aggregate Statistical Information” means de-identified aggregate data that does not permit the re-identification of any individual person, family, household, employer, establishment, or benefit provider, except sole source providers of public benefits (e.g., frequency tabulations, magnitude tabulations, means, variances, regression coefficients, and correlation coefficients).

“Agreement,” means this Restricted Data Use Agreement in whole and in part.

“NDWS” is the National Dementia Workforce Study.

“NDWS Study Workspace” is the data enclave which holds both NDWS Survey Data as well as linked data from the National Institute on Aging (“NIA”) Data Linkage Program Enclave (“LINKAGE”).

“NDWS Survey Data” are a novel component of the NDWS Study Workspace; survey data documentation is available on the NDWS website (<https://www.ndws.org>).

“Other Authorized User(s)” are employees of the Accessing Agency who are appropriately authorized members of Primary User’s Proposed Project who are permitted to access and use Restricted Data from the NDWS Study Workspace.

“Authorized Project” means the project proposed by the Primary User for scientific and public policy statistical research authorized by NDWS to access and use Restricted Data from the NDWS Study Workspace; a brief description of the Authorized Project is included in this agreement.

“Restricted Data” means any data contained in the NDWS Study Workspace; a list of Restricted Data requested by the Primary User is included as Exhibit A.

“Primary User” means the primary researcher, who is an employee of the Accessing Agency, responsible for the Proposed Project to access and use Restricted Data from the NDWS Study Workspace.

In consideration of NDWS providing access to its Restricted Data via the LINKAGE Enclave, the **Accessing Agency** agrees that:

### *Authorized access and use*

1. It will ensure that the Primary User and any Other Authorized User will access and use the Restricted Data in ways authorized by this Agreement;

### *Breach and liability*

1. If NDWS notifies the Accessing Agency that a breach of this Agreement has occurred, and alleges that the breach constitutes scientific misconduct, the Accessing Agency will handle the allegation according to its above referenced policies and procedures applicable to scientific integrity and misconduct;
2. It assumes all liability for damages which may arise from the Primary User’s or Other Authorized User’s use, storage, disclosure, or disposal of Restricted Data. U-M will not be liable to the Accessing Agency for any loss, claim or demand made by the Accessing Agency, or made against the Accessing Agency by any other party due to or arising from the use of the Restricted Data by the Primary User or Other Authorized User, except to the extent required by law when caused by negligence or omissions of U-M; and
3. No indemnification for any loss, claim, damage, or liability is intended or provided by either party under this Agreement.

In consideration of NDWS providing access to its Restricted Data via the NDWS Study Workspace, the **Accessing Agency** agrees on behalf of the Primary User that:

### *General stipulations*

1. That the Accessing Agency Institutional Review Board (“IRB”) or Ethics Committee has authorized the Authorized Project, which is incorporated by reference into this Agreement, and documentation of that authorization has been provided to NDWS (determinations of Exempt, Not Human Subjects, or Not Regulated are also acceptable);

2. They will ensure that no other person other than the Primary User or Other Authorized User(s) view the Restricted Data (e.g., by not viewing Restricted Data in a public place or sharing with non-authorized users via videoconferencing software);
3. Access to Restricted Data will be limited solely to the Primary User and Other Authorized User(s) who are authorized under this Agreement and approved by NDWS;
4. They will ensure that any Other Authorized User will access and use the Restricted Data in ways authorized by this Agreement;

#### *Access and Use*

5. The access and use of Restricted Data will be confined to the research described in the Authorized Project and cannot be used for any other purpose, including any criminal, civil, or administrative investigation;
6. Restricted Data will be used only to generate Aggregate Statistical Information;
7. To use approved data transfer procedures for uploading or downloading Restricted Data or Aggregate Statistical Information from any system or storage media;
8. That export requests should only include presentation/publication ready files and should be in presentation-ready format (e.g., a .pdf or similar format) with a total of < 50 pages per request;
9. To employ the Centers for Medicare & Medicaid Services (CMS) Cell Suppression Policy, including that:
  - a. No cell containing 10 observations or fewer may be downloaded or reported externally;
  - b. Percentages or other mathematical formulas will not be used if they result in the display of a cell containing 10 observations or fewer;
  - c. The cell suppression policy also applies to the reporting of excluded cases; and
  - d. A value of zero does not violate the minimum cell size policy.

#### *Prohibited uses*

10. Primary User and Other Authorized User(s) will make no attempt to:
  - a. Re-identify or contact participants whose data reside in the NDWS Study Workspace;
  - b. Link the Restricted Data with any other available data, including outside the NDWS Study Workspace (e.g., geographical data), not already approved by the Authorized Project;
  - c. Take screenshots, video, pictures, or otherwise capture images of any Restricted Data in the NDWS Study Workspace;
  - d. Make handwritten notes, typed records, or audio recordings of the Restricted Data and/or analyses performed in the NDWS Study Workspace;
  - e. Disclose Restricted Data to a third party without written permission from U-M.
11. If the identity of any participant or establishment in the NDWS Study Workspace is inadvertently re-identified, then the Primary User will, and Accessing Agency ensure, that: (a) NDWS is promptly made aware of the incident, (b) the re-identification is handled as reasonably requested by NDWS; (c) no third party will be informed of the re-identified data, and (d) no use will be made of the re-identified data;

#### *Publication*

12. To publish and/or present only Aggregate Statistical Information derived from the Restricted Data, which includes results that identify geographic areas, not already approved by the Authorized Project;
13. To provide drafts of any manuscripts analyzing or derived from Restricted Data for a timely review by NDWS at least 30 days before submission for publication or presentation;
14. To provide the final, published version of any manuscripts to the NDWS within 30 days of presentation or publication; and

15. To cite the University of Michigan, the University of California San Francisco, and NDWS as the data source in any publications or presentations based on the Restricted Data, using the following citations:
  - a. In text: "The National Dementia Workforce Study data is sponsored by the National Institute on Aging (Grant U54AG084520) and is conducted by the University of Michigan and the University of California San Francisco."
  - b. In references: "National Dementia Workforce Study. Produced and distributed by the University of Michigan and the University of California San Francisco with funding from the National Institute on Aging (Grant U54AG084520), Ann Arbor, MI."

*Breach of this Agreement*

16. If U-M determines that this Agreement has been breached, U-M or NDWS may:
  - a. Immediately suspend or terminate access to the Restricted Data;
  - b. Report the alleged violation(s) to the Accessing Agency's office;
  - c. Report the alleged violation(s) to the National Institute on Aging;
  - d. Prohibit the Primary User, any of the applicable Authorized Users, and/or the Authorized Accessing Agency, from obtaining access to Restricted Data in the future; and
  - e. Utilize such other remedies as may be available under law.

This Agreement will be in effect until the three (3) year anniversary of the Effective Date. The Primary User will provide annually, within thirty (30) calendar days of the anniversary of this Agreement, the following:

1. Project title and a brief justification for continued Restricted Data access;
2. A list of any deletions or additions to the list of Other Authorized Users;
3. Detail of changes or modifications in the research plans; and
4. Citations for any papers, publications, or presentations using the restricted data.

If any one or more of the provisions of this Agreement is found to be invalid, illegal or unenforceable in any respect, the validity, legality and enforceability of the remaining provisions contained herein shall not in any way be affected or impaired thereby.

By signing this Agreement, the Accessing Agency Representative represents that they are to enter into this contractual agreement on behalf of the Accessing Agency, Primary User and Other Authorized Users.

signature page follows

**Read and understood:**

**Primary User**

Signature/Date

Typed Name

Title

Institution

Street Address

City, State, Zip

Email

Phone Number

**Agreed:**

**Accessing Agency Representative**

Signature/Date

Typed Name

Title

Institution

Street Address

City, State, Zip

Email

Phone Number

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**EXHIBIT A**

**Restricted Data Requested by the Primary User**

**[Project Team to insert a list of all datasets requested]**

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