



This document is indicated for Principal Investigators who are receiving Core Support from the Michigan Alzheimer's Disease Center, and the Principal Investigator agrees to abide by the conditions stated below:

### **Affirmation and Acknowledgement**

All study team members are responsible for ensuring participant eligibility criteria is met and are responsible for obtaining informed consent, filing adverse events and protocol deviations. Study teams will be responsible for processing/labeling/shipping/transporting their lab kits and biospecimens. Study teams utilizing MADC research exam space are responsible for cleaning up the room(s) after the research visit.

### **MADC MINDSet Registry**

The MADC MINDSet Research Registry includes healthy controls, individuals with Mild Cognitive Impairment and patients with various forms of dementia based on clinical criteria and research consensus. A list of subjects who potentially qualify for consideration for the applied study only can be generated from MINDSet by the MADC Database Manager. Once approved, the names and addresses of potential subjects are sent to the investigator. The names generated on this list are limited to those who have completed an MADC-affiliated Research Volunteer Form, indicating their interest in learning about current studies from MADC-approved investigators. The Research Volunteer Form, when completed by the patient or his/her care partner, authorizes MADC investigators to review the patient's medical records and to contact him/her regarding study participation. Once a list is generated from the database, investigators are then authorized to contact the potential subjects. We require that all initial contact of subjects occurs via mail. The MADC will provide the investigator a cover letter to include in the subject mailing. Investigators are required to return information to the database manager on a monthly basis regarding the status of each subject referred.

The MADC also manages well-characterized datasets to facilitate data analysis for MADC-supported projects and publications.

### **MADC Confidentiality Agreement**

These data are to be used for informational purposes only. Any effort to determine the personal identity of any data provided is prohibited. Data requests, analyses and potential publications using the information contained in this database are subject to review by the Michigan Alzheimer's Disease Center (MADC). Distribution or release of data analysis files and/or recruitment referral lists obtained from the MADC to third parties is prohibited. Downloading these data indicates that you accept the terms of this agreement; you agree to (1) maintain data confidentiality, (2) will not distribute the data file to a third party without discussing with the MADC, and 3) acknowledge partial support from NIH/NIA grant 5P30AG053760 in your publications, presentations, web-sites, posters, and other dissemination efforts that are related to MADC research, development and training activities and also include an approved MADC logo.



MICHIGAN ALZHEIMER'S DISEASE CENTER

**Any publications, presentations, web-sites, posters, and other dissemination efforts must be reported to Nancy Laracey (contact information below).**

**Text must read:** This <project/study (choose one)> was partially supported by the NIH/NIA funded Michigan Alzheimer's Disease Center (5P30AG053760).

**Logos:** For approved MADC logos to use in posters and presentations, please contact:

Arijit Bhaumik – [arijit@med.umich.edu](mailto:arijit@med.umich.edu)

Nancy Laracey – [laracey@med.umich.edu](mailto:laracey@med.umich.edu)

Renee Gadwa – [rgadwa@med.umich.edu](mailto:rgadwa@med.umich.edu)

### **Reporting Requirements for Investigators Receiving Support**

1. All investigators receiving support from the MADC must complete the MADC Research Study Initialization Meeting upon receiving full IRB approval. Study team must contact the MADC Research Administrator to schedule this meeting.
2. An annual written progress report should be submitted to the MADC Administrator (e.g. for NIH funded research, please provide a copy of the competing / noncompeting renewal). A final report must be submitted upon completion of the study.
3. For investigators who have been given a list of subjects from the MADC database, the following information, reported on a monthly basis, is required: a) did the subject qualify for your study? If not, please specify the reason (i.e., too old, no caregiver, living in nursing home, etc.); b) did the subject agree to participate? If not, please specify the reason; or c) is the subject currently under evaluation for study appropriateness. Patients who did not qualify for this study may then be referred to investigators from other studies in the priority order assigned.
4. At the conclusion of the study, a 5-10 minute presentation may be given to the MADC Executive Committee.
5. All publications resulting from use of MADC resources must be reported to the MADC Administrator UPON ACCEPTANCE FOR PUBLICATION. A reprint is required for the MADC files.
6. Any grant funds received as a result of the use of MADC Resources must be reported to the MADC Administrator/Research Projects Manager.

The study PI or designee affirms and acknowledges MADC Resources Policy Guidelines.