

NCRAD Consent Language Guidance



- The biological samples will be submitted to the National Centralized Repository for Alzheimer's Disease and Related Dementias (NCRAD), with all identifying information removed.
- The samples will be stored indefinitely.
- The samples could be used for research into any type of disease.
- Access to de-identified participant data and samples will be controlled.
- The samples and unidentified data will be available to researchers at hospitals, universities, and commercial organizations.
- A possible risk from participation involves the loss of privacy as a result of providing biological samples for research.
- When referencing genetic sequencing, do not restrict to one type of technology. Allow for expansion as technologies change over time.
- Because all samples and data are de-identified, no results will be returned to research participants.
- The data resulting from the use of the biological samples by an approved researcher will be submitted to an approved database, with all identifying information removed.
- Taking part in this study is voluntary. Samples and data that have already been distributed for approved research will not be retrieved.
- GINA language should be included.
- If NIH funded, Certificate of Confidentiality language should be included.
- When possible, it is best not to include check boxes. Tracking of the various responses possible when check boxes are present can be challenging and lead to potential errors.
- All studies and institutions have different requirements but the more broad the consent can be written initially, the more flexibility you will have in the future.