CAN DATA BE SHARED?  
This Decision tree is used to determine if consent forms permit sharing data with third parties for secondary research on Alzheimer’s Disease.

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UPDATED NOVEMBER 2019

1. Does the consent form state that data will be used only for the study in which they were collected?  
Example: “Data collected in this study will not be used for any purposes other than the present study.”

2. Does the consent form address sharing of data with third parties for secondary research purposes?  
Yes

3. Does the consent form restrict the parties with whom data can be shared?  
Examples: “Data will be shared with the sponsor’s third party collaborators for future research.” OR “Data will be shared with third party contractors working with the sponsor for future research.”

4. Is the desired third party recipient a permitted recipient under the consent form based on the restrictions analyzed in question 3 above?  
Yes

5. Does the consent form restrict the subject matter of secondary research?  
Example: “Your data will only be used for additional studies on cancer.”

6. Does Alzheimer’s Disease fall within the restricted subject matter of secondary research?

7. Does the consent form state that data may only be shared if certain identifiers are removed?  
Examples: “Your name, date of birth, and Social Security Number will be removed and replaced with a unique code before your data are shared with third parties for secondary research purposes.”

STOP. The data should not be used for secondary research purposes.

Remove the specified identifiers before sharing. Of the remaining identifiers, ensure that only the minimum number of identifiers necessary to accomplish the research are shared.

STOP. The data should not be shared with the party in question.

Ensure that only the minimum number of identifiers necessary to accomplish the research are shared.

STOP. The data should not be used for a secondary study on Alzheimer’s Disease.

INSTRUCTIONS:  
Before data collected in a primary study can be shared with other researchers for secondary research related to Alzheimer’s Disease, it is important to determine whether the consent forms under which the data were collected permit such sharing for secondary research. Note that relevant language in even a single study’s consent form often changes over time, so it is necessary to analyze each relevant consent form separately and determine which data collected in the primary study are subject to which version of the consent form to conduct accuracy this analysis.

This decision tree will help you analyze the consent forms to determine whether they permit the desired sharing. If this decision tree indicates that your desired sharing or uses of the data are precluded by the consent form, you should contact [legal/administrative] colleagues to explore possible alternatives.