

**AGONAL STATE SURVEY
(ADC Neuropathology Core)**

The ADC Clinical Core Task Force is making progress in determining which new clinical data will be collected to expand the NACC Minimum Data Set, but they have not yet finalized agonal state variables. The new data collected is intended to be widely useful, and the Task Force is therefore encouraging the Neuropathology Core Leaders to discuss and recommend variables which they would like to have collected by Clinical Core personnel.

If you have questions regarding the information requested, please contact Chris Hulette, Chair of the NP Core Steering Committee, at hulet001@mc.duke.edu or (919) 684-0057, ext. 3801.

Please return your completed form as an email attachment or forward to:

Erin Pfeiffer/NP Surveys
National Alzheimer's Coordinating Center
4311 11th Avenue NE #300
Seattle, WA 98105
fax: (206) 616-5927

Deadline for submission: Friday, September 5, 2003

Center name: _____ Date completed: _____

Completed by (NP Core Leader): _____

1. Is agonal state information collected at your ADC?

- Yes
- No (*If the answer is 'no', skip to question 11A.*)

2. How do you define agonal period?

3. When is the agonal state data collected?

- a. Antemortem
- b. Postmortem
- c. Both antemortem and postmortem (*please explain*):

4. Who collects this data? (*Check all that apply*)

- a. Clinical Core
- b. Neuropath Core
- c. Other (*please specify*):

5. How is the data collected? (*Check all that apply*)
- a. Post-mortem interview with a caregiver or medical physician
 - b. Chart review
 - c. Other (*please specify*):
6. What agonal period data is collected by **Clinical Core** personnel at your ADC? (*Check all that apply*)
- a. Location of death (home, assisted living quarters, nursing home, etc.)
 - b. Unexpected death
 - c. Death during sleep
 - d. Breathing difficulties
 - e. Ventilatory support
 - f. Fever
 - g. Infection
 - h. Myocardial infarction
 - i. Cancer
 - j. Broken hip
 - k. Other accidents/injuries
 - l. Major surgery/anesthesia
 - m. Stroke, TIA, hemorrhage
 - n. Loss of consciousness
 - o. Focal neurological deficit
 - p. Head injury
 - q. Medications
 - r. CT, MRI, or brain scan
 - s. Other (*please specify*):
7. What agonal period data is collected by **Neuropathology Core** personnel at your ADC? (*Check all that apply*)
- a. Location of death (home, assisted living quarters, nursing home, etc.)
 - b. Unexpected death
 - c. Death during sleep
 - d. Breathing difficulties
 - e. Ventilatory support
 - f. Fever
 - g. Infection
 - h. Myocardial infarction

- i. Cancer
- j. Broken hip
- k. Other accidents/injuries
- l. Major surgery/anesthesia
- m. Stroke, TIA, hemorrhage
- n. Loss of consciousness
- o. Focal neurological deficit
- p. Head injury
- q. Medications
- r. CT, MRI, or brain scan
- s. Other (*please specify*):

8. How is the data stored?

9. Is the data available electronically?

- Yes
- No (*If the answer is 'no', skip to question 11A.*)

10. Who has access to the database? (*Check all that apply*)

- a. Clinical Core
- b. Neuropath Core
- c. Other (*please specify*):

11A. Is any testing of the autopsy brain tissue routinely performed at the Neuropathology Core to assess integrity of the tissue?

- Yes
- No

11B. If 'yes', please indicate which tests are performed. (*Check all that apply*)

- a. pH
- b. Western blot
- c. Other (*please specify*):