

NACC

National Alzheimer's Coordinating Center

Department of Epidemiology, School of Public Health and Community Medicine, University of Washington

AGONAL STATE SURVEY (ADC NEUROPATHOLOGY CORE) - SUMMARY OF RESULTS -

1. Is agonal state information collected at your ADC?

	Count (N=28)	Percent (%)
Yes	14	50.0
No	14	50.0

2. How do you define agonal period (N=13)?

- "Last month, week, and day of life. Conditions of the patient and circumstances preceding, and at the time of death of the patient."
- "Caregiver notifies Nurse Coordinator that condition has changed. Surveillance is increased depending on clinical condition. Details are available through Clinical Core."
- "The period of time when death is expected based on mental and physical symptoms. The subject may experience high fever, labored breathing, intense suffering or torment. They also may have hallucinations and lose consciousness."
- "We collect data within three days to death, two weeks prior to death, and since the time of the last evaluation."
- "Final few days (1-3 days)."
- "Flexible; period immediately preceding death."
- "Since this is difficult to define, we collect the data noted below on peri-death events, but the best monitor of agonal state is to examine brain proteins, DNA, and RNA for integrity on a routine ongoing manner which is our gold standard."
- "Clinical information from 2 weeks prior to death is reviewed and collected."
- "Immediate time period preceding expiration. If not a sudden death we ask about circumstances in last two weeks prior to death."
- "24 hour period prior to death."
- "24 hour period prior to death."
- "Not formally, but informally the 24 hour period prior to death."
- "The period of time that constitutes the participant's terminal illness or terminal event."

NACC

National Alzheimer's Coordinating Center

Department of Epidemiology, School of Public Health and Community Medicine, University of Washington

3. When is the agonal state data collected?

	Count (N=14)	Percent (%)
Antemortem	1	7.1
Postmortem	10	71.5
Antemortem and Postmortem	3	21.4

(if both antemortem and postmortem, please explain):

- "We speak to our clinicians before and after the death of a patient."
- "Routinely done postmortem, but some information collected antemortem when family calls to report changes as outlined in our autopsy/brain donation guidelines."

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

	Count (N=14)	Percent (%)
Clinical Core	7	50.0
Neuropath Core	9	64.3
Other	2	14.3

(please specify other):

- "Religious Orders Study Core"
- "Family or other knowledgeable caregiver also will have information relevant to this"

NACC

National Alzheimer's Coordinating Center

Department of Epidemiology, School of Public Health and Community Medicine, University of Washington

5. How is the data collected (check all that apply)?

	Count (N=14)	Percent (%)
Postmortem Interview*	12	85.7
Chart Review	7	50.0
Other	5	35.7

* postmortem interview with a caregiver or medical physician

(please specify other):

- "Data collected by Autopsy Nurse Coordinator in caregiver interview."
- "We are just beginning to collect this."
- "Medical records and occasional postmortem interview with caregiver or physician."
- "We discuss this as needed with nurses and other health care personnel."
- "We do complete autopsies - this yields information on terminal illness."

6. What agonal period data is collected by the Clinical Core (check all that apply)?

	Count (N=14)	Percent (%)
Location of death	7	50.0
Unexpected death	7	50.0
Death during sleep	5	35.7
Breathing difficulties	7	50.0
Ventilatory support	7	50.0
Fever	7	50.0
Infection	7	50.0
Myocardial infarction	7	50.0
Cancer	7	50.0
Broken hip	6	42.9
Other accidents/injuries	6	42.9
Major surgery/anesthesia	6	42.9
Stroke, TIA, hemorrhage	7	50.0
Loss of consciousness	7	50.0
Focal neurological deficit	6	42.9
Head injury	6	42.9
Medications	9	64.3
CT, MRI, or brain scan	6	42.9
Other	5	35.7

(please specify other):

- "Pneumonia, UTI, infection, oxygen, antibiotics, CPR, feeding tube"
- "We record anything else that seems relevant."
- "Seizures on day of death, evidence of dehydration."
- "Seizures, nature of death (e.g. sudden, comatose, oxygen."

NACC

National Alzheimer's Coordinating Center

Department of Epidemiology, School of Public Health and Community Medicine, University of Washington

**7. What agonal period data is collected by the Neuropathology Core
(check all that apply)?**

	Count (N=14)	Percent (%)
Location of death	7	50.0
Unexpected death	5	35.7
Death during sleep	5	35.7
Breathing difficulties	6	42.9
Ventilatory support	8	57.1
Fever	7	50.0
Infection	9	64.3
Myocardial infarction	7	50.0
Cancer	8	57.1
Broken hip	6	42.9
Other accidents/injuries	7	50.0
Major surgery/anesthesia	7	50.0
Stroke, TIA, hemorrhage	8	57.1
Loss of consciousness	7	50.0
Focal neurological deficit	5	35.7
Head injury	8	57.1
Medications	5	35.7
CT, MRI, or brain scan	4	28.6
Other	5	35.7

(please specify other):

- "Other data obtained by clinical core."
- "All else that seems relevant."
- "Donor cognitively alert, supplemental fluids, coma, CPR administered."
- "Anything in the chart or supplied by caregiver during interview that is relevant."

NACC

National Alzheimer's Coordinating Center

Department of Epidemiology, School of Public Health and Community Medicine, University of Washington

8. How is the data stored (N=14)?

- "In centralized ADRC database on 17-item peri-mortem form."
- "Data are stored by paper records currently. Electronic database is under development by the clinical core."
- "Subject charts."
- "Electronically."
- "Written in clinical records thus far."
- "In record of patient chart and autopsy forms."
- "Database."
- "In hard copy on paper in a secure file."
- "Data indicated in #6 is stored electronically in relational database tables and additional clinical information is available in each subject chart."
- "On paper, in file. Expiration summary dictated. Paper file is of retrospective post-mortem interview."
- "Phone contact."
- "Paper forms, currently. Future upgrade to ACCESS/SQL Server."
- "In neuropath report if relevant, otherwise on a check sheet used at the time of death."
- "Currently, the data are collected using a standardized semi-structured interview and recording form with a copy being maintained in the participant's chart and another sent to the NP core. This information will be maintained in our database in the near future."

9. Is the data available electronically?

	Count (N=14)	Percent (%)
Yes	6	42.9
No	8	57.1

10. Who has access to the database?

	Count (N=6)	Percent (%)
Clinical Core	6	100.0
Neuropath Core	5	83.3
Other	1	16.7

(please specify other):

- "All cores have access."

NACC

National Alzheimer's Coordinating Center

Department of Epidemiology, School of Public Health and Community Medicine, University of Washington

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

	Count (N=28)	Percent (%)
Yes	11	39.3
No	17	60.7

11B. If "Yes", which tests are performed (check all that apply)?

	Count (N=11)	Percent (%)
pH	6	54.5
Western blot	5	45.5
Other	6	54.5

(please specify other):

- "Northern blot for ribosomal RNA."
- "RNA from year 2003 onward."
- "In some cases, isolate RNA and use for rt-PCR studies."
- "Examination of RNA and DNA as needed to monitor effects of agonal state. Also, antemortem info is available for most, but not all, ADC cases and is often in records that need to be reviewed."
- "Rarely PCR for HIV suspects."
- "RNA PCR."