

## *ADC Clinical Task Force*

### Mission

To develop an expanded, standardized dataset on ADC subjects to improve clinical assessment and diagnosis, provide data in support of current projects, and stimulate research.

### Expanded Minimum Dataset (MDS) will:

- improve its administrative value
- encourage standardization across ADCs
- serve as a unique research resource for:
  - natural history studies (MCI transition; rare disorders)
  - comorbidities
  - variability across ethnic groups, geographic regions
- provide phenotypic descriptions to identify multiplex families (Genetics Initiative)

## *ADC Clinical Task Force*

### Members

Helena Chui (USC)  
Jeffrey Cummings (UCLA)  
Charles DeCarli (UCD)  
Steven Ferris (NYU)  
Norman Foster (U Michigan)  
Douglas Galasko (UCSD)  
Neill Graff-Radford (Mayo Clinic)  
John Morris (Washington U) - Chair  
Elaine Peskind (U of Washington)  
Sandra Weintraub (Northwestern)

### Affiliates

NACC  
Walter Kukull  
ADC Genetics Initiative  
Richard Mayeux  
NIA  
Creighton Phelps  
Neil Buckholtz  
Elisabeth Koss  
Marcelle Morrison-Bogorad

## *Clinical Task Force Activity*

Meetings:      October 12, 2002 (NYC)  
                  January 24, 2003 (Salt Lake City)

Teleconferences: - 12/23/02  
                      - 12/31/02  
                      - 1/3/03  
                      - 3/5/03

Survey of psychometric measures: 11/02

## *Clinical Task Force Principles*

- Uniform MDS to be incorporated by the ADCs
- MDS does not preclude collection of additional datasets at individual ADCs
- Informants required for cases and controls
- ADCs must budget the added costs for the MDS in their renewal applications
- MDS is a work-in-progress; revisions expected

## *Clinical Task Force - MDS*

### Current MDS (55,800 cases; 5,100 autopsies)

- Designed for cataloguing basic information
- Primarily cross-sectional data
- Lacks information on diagnostic processes used to identify cases and controls
- Missing data

### Proposed (expanded) MDS - Goals

- To the extent possible, focus on data, scales, and measures already in use by the ADCs
- Transition; begin with newly enrolled subjects
- Collect and enter data longitudinally
- Encourage electronic case report forms
- Assess domains needed to distinguish nondemented aging, mild cognitive impairment, and Alzheimer disease

## *Clinical Task Force*

### Clinical Variables (1/24/03)

- Demographic data
- Informant observations
  - Mode of onset and course
  - Key features
  - Health history
  - Medication inventory
  - Family history
- Global Clinical Dementia Rating
- Diagnosis
  - Nondemented aging
  - Mild cognitive impairment
  - Dementia
  - Differential diagnosis
- Subject examination
  - Neurologic findings
    - Parkinson's scale
    - Ischemic scale
  - Neuropsychiatric Inventory - Q
  - Geriatric Depression Scale (15 item)
  - Activities of Daily Living Scale
  - Mini Mental State

# *Clinical Task Force*

## Psychometric Variables (1/24/03)

### MEASURES

Visual Target Cancellation

Wechsler Logical Memory R, I and II;  
CERAD Word List - 10 item

Trailmaking A and B; Digit Symbol

Boston Naming Test (30 item);  
Verbal Fluency (animal naming)

Benton Visual Form Discrimination (?)

Finger tapping speed

### DOMAINS

Attention; speed of processing

Episodic memory

Executive function

Language

Visual perception

Motor