



Clinical Task Force Report

ADC Directors' Meeting

April 24, 2004, San Francisco

- Review of plans from 10/18/03 Directors' Meeting
- UDS survey results
- Post-survey UDS modifications
- Present modified UDS

Task Force Plans

- Survey all Clinical Cores on clinical and neuropsych batteries for UDS
- Assimilate responses and comments, modify batteries as indicated
- Distribute draft batteries to ADCs for “final” comment
- Present batteries for approval at ADC Directors’ Meeting, 4/04, San Francisco
- With NACC, develop Manual of Operations for adopted batteries



Consensus

A state of mutual agreement among members of a group where all legitimate concerns of individuals have been addressed to the satisfaction of the group
(Saint & Lawson, 1994)

- Agreement means unity (not unanimity)
- Each person has the opportunity to express concerns that are understood and considered by group members
- Trust
- Focus on facts
- Commitment to the group above self interests

Uniform Data Set (UDS)

- Collaborative research critically important for ADCs/NIA
- Foundation for collaborative research, even in absence of *a priori* hypotheses
- Initial focus on normal aging → MCI → AD
- Balance: ideal UDS with low burden
- UDS will evolve
 - Obtain data appropriate for other conditions
 - With experience, refine/modify measures



Clinical Task Force Data Collection Survey: Jan/04

THANK YOU!

- All 29 funded ADCs completed the survey
- Many provided thoughtful and helpful comments
- Followup and analysis by Erin Pfeiffer, Maggie Connor, and NACC

Survey Results

- Most ADCs already collect the large majority of the proposed UDS measures
- 12m f/u interval for control (84%), MCI (81%), and AD (93%) subjects
- Data obtained from informants/study partners

	<u>Entry</u>	<u>12m f/u</u>
AD	83%	58%
MCI	79%	59%
Control	66%	54%

Survey Results (cont.)

Measures eliminated from 10/18/03 draft UDS

- Clinical
 - Hypercholesteremia; sleep disorders (Health Hx)
 - # of affected non-1st degree relatives (Family Hx)
 - Medication groupings
- Neuropsych
 - Visual target cancellation
 - CERAD Word List Recall
 - Benton Visual Form Discrimination
 - Digit Symbol

Survey Results (cont.)

- Modified measures from 10/18/03
 - Obtain only the motor component of UPDRS
 - Obtain Rosen modification of Ischemic Scale
 - Obtain the NPI-Q
 - Obtain the 15 Item GDS
 - “WORLD” backward for MMS (rather than serial 7s)
 - 30 item Boston Naming Test
- Added diagnoses
 - Cognitive dysfunction assoc with medications
 - Associated medical illnesses
 - Deferred

Survey Results (cont.)

- Activity of Daily Living Scales
 - No single scale used by majority of ADCs (BDS used by about 50%)
 - Functional Activities Questionnaire (FAQ) recommended by Task Force: brief (<10 min); informant; IADL only; published data on sensitivity for AD vs control
- Medication inventory – to be developed



Comments

- An achievement for the ages; a veritable tour de force!
- This UDS is stunningly brilliant! It is perfect in every way, do not change anything!
- You guys are the best! We owe you big time for all your hard work.



Comments

- Some measures (e.g., CSF, PET) obtained only on selected subjects
- Health hx obtained directly from subject (control and MCI)
- Demographics, health hx updated annually but not re-evaluated otherwise
- Some data recorded in clinical dictation (e.g., neurology exam) or in narrative format (e.g., onset/course of dementia)
- Dementia Diagnosis section confusing
- Funds needed to reconfigure databases, training!
- Alternative/additional measures: WMS-R Visual Reproduction (I and II); Block Design; Controlled Oral Word Association; Finger Tapping or Grooved Pegboard

UDS-R (4/20/04)

- Expands the Minimum Data Set with clinical and psychometric variables relevant for cognitive aging, MCI, and AD
- Obtains data from informants/study partners for all subjects, including controls
 - ❖ A separate category will allow data from control subjects without informants to be entered
- Obtains data longitudinally
- Will standardize data collection across all ADCs
- Overlaps cognitive tests of Genetics Initiative

Remaining Issues

- Licensing of copyrighted tests (WMS; WAIS)
- Measures of nonverbal memory and visuospatial ability; IADL/ADL scales
- Development of Manual of Operations
- Monitor UDS implementation
- ADOPTION OF UDS