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

<table>
<thead>
<tr>
<th></th>
<th>Entry</th>
<th>12m f/u</th>
</tr>
</thead>
<tbody>
<tr>
<td>AD</td>
<td>83%</td>
<td>58%</td>
</tr>
<tr>
<td>MCI</td>
<td>79%</td>
<td>59%</td>
</tr>
<tr>
<td>Control</td>
<td>66%</td>
<td>54%</td>
</tr>
</tbody>
</table>
Survey Results (cont.)

Measures eliminated from 10/18/03 draft UDS

- Clinical
  - Hypercholesteremia; sleep disorders (Health Hx)
  - # of affected non-1\textsuperscript{st} 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
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
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