



# *Clinical Task Force Update*

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# *CTF Report*

- Crosswalk Study Report: Clinical Core Meeting
- LP Survey: Clinical Core Meeting
- CTF Progress and Future

# *Crosswalk Study Report*

- Thanks to Sandy Weintraub and her Work Group: Hiroko Dodge, Steve Ferris, Bruno Giordani, Felicia Goldstein, Joel Kramer, David Loewenstein, Po Lu, Dan Marson, Dan Mungas, David Salmon, Kathie Welsh-Bohmer
- Thanks to Sarah Monsell, Bud Kukull, and the NACC staff
- And – thanks to the 23 participating ADCs!
- 797 packets completed (including 159 minority participants)
- Very good correlations between UDS 2.0 and proposed UDS 3.0 measures: Work Group recommends adoption of UDS 3.0 measures

# LP Study Report

- Thanks to Krista Moulder
- Thanks to Sarah Monsell, Bud Kukull, and the NACC staff, and to Maria Carrillo and the Alzheimer's Association
- And – thanks to the 18 participating ADCs!
- Frequency of LP complications
  - Type of needle (Quincke vs. Sprotte)

No difference;  $p < 0.28$
  - Amount of post-LP rest

Less rest is better (?!)  
24% incidence of complication with  $< 1$  hr rest  
vs. 39% with  $\geq 1$  hr ( $p < 0.002$ )

# *Origins of the CTF*

- Organized by Tony Phelps and Marcelle Morrison-Bogorad from NIA in 2002
- Initial meeting: Oct. 12, 2002 (at ADC Directors' Meeting, Roosevelt Hotel, New York, NY)
  - 5 Clinical Core Steering Committee members: Charles DeCarli, Norman Foster, Neill Graff-Radford, John Morris, Elaine Peskind
  - 5 NIA appointees: Helena Chui, Jeff Cummings, Steve Ferris, Doug Galasko, Sandra Weintraub
  - Liaisons: Bud Kukull (NACC), Richard Mayeux (Genetics Initiative)

# *Original CTF Goals*

- “To develop expanded and standardized clinical datasets on all ADC subjects to improve clinical assessment and diagnosis, provide data in support of current projects, and to stimulate research”
- Limitations of the Minimum Dataset
  - Primarily cross-sectional data
  - Non-uniform; e.g., no information on diagnostic processes for contributed cases
  - Incomplete (25% missing data)
- CTF principles
  - Data collected longitudinally
  - Focus on cognitively normal aging and MCI/early stage symptomatic AD; address later FTLD, VaD, and DLB

# *CTF Leadership*

- Accomplishing goal of NIA- mandated new standardized clinical and cognitive protocol to be used uniformly across all ADCs meant CHANGE, thus RESENTMENT & RESISTANCE
- Essential qualities for CTF Chair



“The Most Interesting Man in the World”

# CTF Process – I.

- Review existing ADC clinical and neuropsychological protocols to evaluate current measures and instruments for:
  - Frequency of use
  - Ease of use
  - Reliability
  - Value in characterizing MCI/early stage AD and CN aging
- Informant report is essential to clinically assess both CN and MCI/early stage AD individuals
- Allow existing measures and batteries already in use at ADCs to be continued



# CTF Process – II.

- Iterative development of the Uniform Dataset with input from all ADCs: surveys, comments, reports at all ADC Directors' Meetings. *Animated* discussions with slings and arrows...



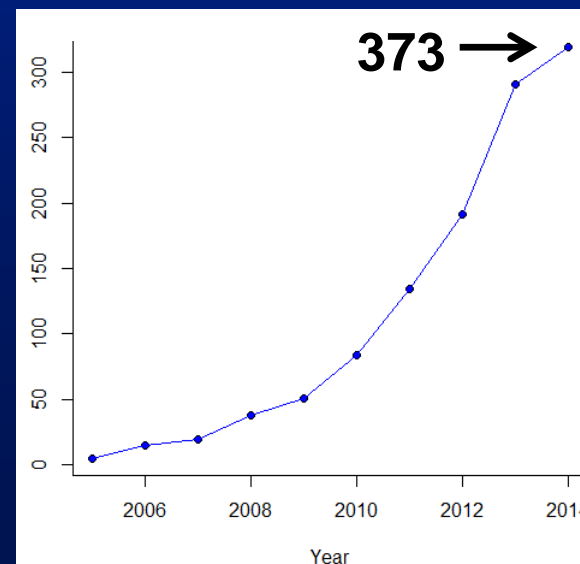
# *CTF: Adoption of UDS*

- Formally approved by the ADCs at the October 2, 2004, Directors' Meeting (Westin Harbour Castle Hotel, Toronto, Canada)
- CTF and NACC then developed forms and codebook, with each version circulated by email to all ADCs for review and comment
- After finalization of forms, UDS implemented in September 2005
  - Standardization and Training Meeting for all ADCs and ADNI sites held November 18, 2005, at the Chicago (IL) O'Hare Hilton Hotel

# *The UDS is Now Well Established*

- Over time, growing acceptance and recognition of the value of the dataset
- 30,327 Initial Visit Packets and 59,553 Follow-Up Assessments (including 3,741 with 6 or more annual assessments) submitted to NACC by 4-21-14
- 340 investigator requests to NACC for UDS data and growing: 13 requests in 2007, 100 in 2013

Cumulative UDS  
Publications:  
(Courtesy of Sarah Monsell, NACC)



# *Improvements in the UDS*

- The UDS is far from perfect and continues to evolve
  - V2 implemented February 2008
  - FTLD module implemented January 2012
- Now, V3 to be implemented
  - Streamline: e.g., drop Form A5 Health History from follow-up packets
  - Nonproprietary measures
    - » MMSE → MoCA
    - » WMS LM I and II → Craft story
    - » BNT → MINT
    - » WMS Digit Span → Number Span
    - » FTLD module: Benson Complex Figure and Letter Fluency (F and L)

# *UDS V3 Implementation*

- CTF has reviewed draft forms, meets this afternoon
- After discussion/approval of forms, the UDS V3 will be distributed to all ADCs for review and comment (email)
  - Deadline to submit comments
  - No response to CTF/NACC by deadline constitutes “approval” of UDS V3
- Target implementation: July-August 2014

# *The Future of the CTF*

- The UDS will continue to evolve
  - More modules (e.g., DLB)
  - Incorporation of biomarkers into diagnostic algorithms
- After UDS V3 implemented, I will relinquish chairing the CTF; new leadership anticipated for Oct 2014 ADC Directors' Meeting
- As I step down, I bequeath my successor...

