Clinical Task Force (CTF) Clinical Measures & Diagnosis Working Group Update

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Clinical Task Force (CTF) Organization and Working Groups

**Administrative Oversight**
- Nina Silverberg – NIA
- Cerise Elliott - NIA
- Grayson Donley - NIA
- Bud Kukull (Ex officio) - NACC

**Clinical Task Force**
Allan Levey (Chair)

**Clinical Measures & Diagnosis Working Group**
- Greg Jicha* (Co-lead, Neurology, Univ Kentucky)
- Cindy Carlsson* (Co-lead, Geriatrics, Univ Wisc)
- Liana Apostolova* (Neurology, Indiana Univ)
- Brad Boeve (Neurology, Mayo)
- Jeff Burns* (Neurology, Univ Kansas)
- Teresa Gomez-Isla (Neurology, Mass General)
- Howie Rosen* (Neurology, UCSF)
- Suzanne Schindler (Neurology, Wash Univ)

- Symptoms - Forms: B1, 4-9
- Risk factors - Forms: A1-5
  - Demographics
  - Family history
  - Past medical history
  - Medications
  - Add social determinants of health
- Diagnosis - Forms: D1-2

**Cognitive Working Group**
- Andy Saykin (Co-lead, Indiana Univ)
- Lisa Barnes (Co-lead, Rush)
- Rhoda Au (Boston Univ)
- Suzanne Craft (Wake Forest)
- Mary Sano* (Mt. Sinai)
- Sandy Weintraub (Northwestern)

- Existing Paper/Pencil tests - Forms: C
- Future Computerized tests - Forms: New C
- Future Wearables - Forms: New C

*Clinical Core Steering Committee member

Modified from schema created by Greg Jicha
Guidelines and Principles for Working Group in Long-term Planning for UDS4

1. Maintain and enhance value of longitudinal data
2. Improve standardization and quality control
3. Minimize participant and center burden
4. Facilitate important research efforts that otherwise can't be done readily by individual research studies
5. Facilitate expansion of disease and racial heterogeneity in the UDS
6. Improve capture of behavioral, cognitive, and motor symptoms to facilitate understanding of dementia trajectories
7. Move toward full electronic data capture and EMR data integration
8. Review all items, measures, and tests for reliability and administration efficiency
9. New instruments should be piloted and validated before center wide adoption, and cross-walk studies performed
CTF Clinical Measures & Diagnosis Working Group Update

• With onset of COVID-19 pandemic, emphasis shifted to development of short-term guidelines for ADRCs on remote data collection

• Most urgent need was telephone administered cognitive battery

• Current UDS3 Telephone Visit Packet (TVP) clinical and diagnostic measures reviewed to see if modifications needed during acute period

• Modified Delphi method used to assess TVP Form items

Current NACC UDS3 Telephone Visit Packet Checklist

<table>
<thead>
<tr>
<th>Form</th>
<th>Language: English Spanish</th>
<th>Description</th>
<th>Submitted: Yes</th>
<th>No</th>
<th>If not submitted, specify reason (see KEY):</th>
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<tbody>
<tr>
<td>T1</td>
<td>1 2</td>
<td>Inclusion Form</td>
<td></td>
<td></td>
<td>Required</td>
</tr>
<tr>
<td>A1</td>
<td>1 2</td>
<td>Subject Demographics</td>
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<td>Required</td>
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<tr>
<td>A2</td>
<td>1 2</td>
<td>Co-participant Demographics</td>
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<td>Required</td>
</tr>
<tr>
<td>A3</td>
<td>1 0</td>
<td>Subject Family History</td>
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</tr>
<tr>
<td>A4</td>
<td>1 0</td>
<td>Subject Medications</td>
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<tr>
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<td>Clinician Judgment of Symptoms</td>
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<td>Clinician Diagnosis</td>
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<tr>
<td>D2</td>
<td>1 2</td>
<td>Clinician-assessed Medical Conditions</td>
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</tbody>
</table>

KEY: If the specified form was not completed, please enter one of the following codes:
95 = Physical problem
96 = Cognitive or behavioral problem
97 = Other problem
98 = Verbal refusal
CTF Clinical Measures & Diagnosis Working Group Update

• Most UDS3 TVP Form Items will likely remain as they are for short-term period

• Issues still under discussion:
  – Should additional items be moved to “optional” status?
  – How to best capture COVID-19 disease burden and potential impact on general health, brain health, biomarkers, and cognition (questionnaire developed)
  – How to best capture physical exam findings over the phone/video
  – Use of telephone visit packets for initial visits (currently used only for follow up)
  – Completion and documentation of consensus conference diagnoses using remote data