

Clinical Task Force



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ADRC Data During COVID

Data Steering Committee

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News from the Clinical Task Force

- **Use the revised UDS3 telephone packets** by either video or telephone, document the route of administration
- **Information about COVID-19:** a short set of questions for participants and caregivers are discussed for uniform data collection as part of a **new form in the revised UDS3 packet**
- **UDS3 T-Cog battery** will include adaptations of most instruments that have been administered in the existing UDS3.0 evaluations. Estimated time ~ 30 minutes

Digital audio recording - Challenges



NIA and the CTF strongly encourage digital audio recording and secure sharing of the session data to facilitate quality assurance and future item level psychometric analysis.



Need to set-up new audio storage and retrieval for ~ 1 hour per participant per visit.



Need to determine how secure audio can be recorded and saved if interviewer is remotely working (ADC center specific)



Unanticipated cost of large audio file storage



Uncertain how long audio is to be stored

Highly encouraged tests to better assess memory and executive functions (~30 minutes of testing):

- UDS3 T-Cog Battery: UDS3 tests that directly translate to phone-based assessment including (Blind MoCA, Craft Story, Number Span Forwards and Backwards, Category Fluency, Verbal Fluency (“F” and “L”), Geriatric Depression Scale (GDS; Form B6).
- Recommended optional tests: Modified for telehealth-based assessment and include Oral Trail Making Test and Verbal Naming Test (naming to description as opposed to pictures).
- Auditory Verbal Learning Test Options: The widely employed Rey AVLT is recommended and instructions will be included in the packet. CTF recognizes that centers use different AVLT measures and are encouraged to administer the AVLT of their choice. Forms for the Rey AVLT will be included. Options for data capture and transmittal of other AVLT measures will be explored later.

New
participants?

- The CTF will be drafting **revisions to the initial visit packages** to accommodate enrollment and assessment



Milestone Form suggested edits

Box A 2a Item 1 : Include other forms of contact (telehealth vs teleform)

2b: include COVID-19 related options

Box B 5b: Include 3rd option: Autopsy unavailable due to COVID-19

6b: If 2nd option then ask COVID-19 or Non COVID related

Milestone packets Box A reasons are mirrored in the T1 Telephone follow-up packet.

NP v 10 form- NP Core Steering Committee

Death : Expecting fewer autopsies due to risk of COVID-19, should there be any modification to NPv10 forms?

Information about whether CV testing was done: Before or after death. Type and specificity of the test? Whether antibody testing was performed, what type (IgG and/or IgM), and the result

Information on CV risk factors (agonal fever, CV contact, etc.)

Information about, if the autopsy _wasn't_ done, was it a reason related to the pandemic? (Milestone form could handle this)

Should integrate data fields about Aging-related tau astroglialopathy (ARTAG)

Other Questions

Does NACC have capacity to certify electronic forms or would ADCs use paper prior before electronic forms are certified?

Some ADC do not use paper forms, thus creating a workflow obstacle

B5- NPIQ form for If “Anxiety on NPIQ is “Yes” was he/she anxious before COVID?

Statistical Considerations

Privacy & bias concerns due to subjects performing at-home cognitive testing in the presence of family members

Unless the intervals are very wide - about the average time for subjects to develop an event - there isn't much loss of efficiency

Challenges in harmonization across optional measures and non-uniform application of “in home” assessments

Data Core Conclusions

- Quality control, whether audio or other format, should be ADC site specific
- Optional tests, which may be difficult to harmonize, such as versions of the AVLTL should be site specific and not required
- Roll out of any new form will take time: including possible IRB or consent changes, creation and certification of new forms, training of personnel and secure storage
- Changes to the Milestone form should include COVID-19 data
- Long intervals will have minimal loss of efficiency