UDS 4.0 TIMING & STRATEGIES TO MINIMIZE IN-CLINIC BURDEN

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DISCLOSURES

• Grants

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- NIH P30 AG072946, U24 AG057437, R01 AG053798, R01 AG063689, U19 AG010483, R01 AG054029, R01 AG061848
- Contract Research
 - Cassava, Cyclerion, Eisai, Lilly, Suven, Vivoryon
- Educational Programming
 - Medscape, CEConcepts/ AAFP, Mid-America Institute on Aging and Wellness
- Leadership Roles
 - Alzheimer's Association ALZ-NET, ACTC, ADCS, AAN Education, ADRC Clinical Steering Committee & Task Force
- Consulting/Speaker's Bureau
 - None
- Stock, Royalties, or Intellectual Property
 - None



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PARTICIPANT VS. STAFF INCREASED BURDEN...

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The additional time added includes 10 minutes of patient facing time & 3 minutes of clinician time

NDIVIDUAL FORM BURDEN...



THIS DOESN'T INCLUDE UPDRS, SUPRASPAN WORD LIST, OR AUDIO RECORDING OF NEUROPSYCH TEST BATTERY

- The UPDRS will add 5-10 minutes exam and 2-3 minutes form time...
- The supraspan wordlist will add 30 minutes if you aren't already doing one...
- Logistics of recording and uploading audio will take another 5 minutes...
- In total visits could take up to an hour total time longer (if you are not already doing a supraspan wordlist), but for most centers this will only be 30 minutes extra...

STRATEGIES THAT MAY HELP AT YOUR CENTER...

THE CTF KNOWS THAT TIME IS PRECIOUS, AND THAT MINIMIZING PARTICIPANT BURDEN IS INCREDIBLY IMPORTANT

- REDCAP form logic will help keep forms shorter for those that are normal or who have fewer issues...
 - This is not going to help with complex participants unfortunately
- Auto-populated follow-up forms will help for successive visits
 - Just update information
- Much of the data can be collected remotely by survey or over the telephone or video conferencing...
 - Some of the increased time for UPDRS and supraspan word list cannot be minimized by remote strategies

WHICH FORMS AND OR DATA IS MOST HELPFUL TO COLLECT IN REMOTELY TO MINIMIZE CLINIC BURDEN?

- Focus on A1-Demographics & A5-Health history forms for maximal reduction in clinic time (-20 minutes)
- Collect A2, NPI, FAQ, and CDR from study partner remotely (-20 minutes)
- Collect GDS, medications, family Hx remotely (-15 minutes)



You could save almost an hour of in-clinic time!

HOW TO COLLECT SUCH DATA REMOTELY?

- Pre-visit phone calls or videoconferencing?
- Personalized REDCAP or other E-surveys?
- Use EHR data for A4-medications & A5-Health Hx?

We would love to hear your thoughts on your center helps make UDS 4.0 more practical to implement!



WE HAVE TO THINK OUTSIDE THE BOX HERE!

- Improved data collection will advance the field
- But it comes with a cost...
- I know we can do this!
- If we can't, no one can...



THANKS! QUESTIONS? COMMENTS? SOLUTIONS?

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