Form	Question	Answer
A1	What about border town cities where participants spend an equal amount of time in Mexico and US?	The question is not perfect, especially for people living on the border as you suggest. Just ask them to identify one or the other (or if they don't want to pick one, they can choose not to answer)
A1	Will there be consideration to wording the race/ethnicity category of "white" as white non-hispanic to avoid potentially offending some participants?	Participants can choose multiple race/ethnicities as applicable (e.g., white and Hispanic/Latino). The wording comes directly from OMB: https://www.federalregister.gov/documents/2024/03/29/2024-06469/revisions-to-ombs-statistical-policy-directive-no-15-standards-for-maintaining-collecting-and
A1	What if someone identifies as White but unknown heritage? Would that be White, then other?	Participants can select White and other, or leave the heritage blank if they do not know
A1	What age range would we consider "childhood"?	We are considering childhood the breadth of birth to age 18. What you want to capture is the spirit of the formative years - or what the participant and or co-participant feel was that most influential childhood developmental geographic location. It may be that somebody's childhood, from birth to age 8 was in Cuba, and then they moved to the United States. Cuba may be the most appropriate answer. It may be that if they were born and only lived a year in Cuba, and then immigrated to the United States. In that case, listing the United States may be most appropriate. Ultimately, this is a judgment.
A1	What's the purpose of the first three digits of zip code? Thanks!	Geographic region
A1	How up to date is the Hollinshead job list? A list I have used in a previous studies was developed a long time ago and it was sometimes difficult to match current jobs to the list.	This was updated to include modern job types. You also have the option to pick one of the 8 major categories (e.g., "skilled manual employees") if there is not a good match for the specific occupation.
A1	Have others noticed that participants get annoyed at the sex and sextual orientation questions. This is a self ID and presenter mentioned that if one is not indigenous then	If participants do not want to answer the gender identity or sexual orientation questions, they can choose not to answer. For the two-spirit identification, it is meant to be respectful culturally - if a person volunteers the two-spirit answer for

Form	Question	Answer
	we should not use two- spirit. Does this go against the self-identifying idea?	themselves (not prompted) and are not from a tribal community, then go ahead and record that answer that they choose.
A1a	If it's mandatory for the first visit, how should we ensure it's only given to people who are normal-mci	For the pilot, administer to all participants. We will review these instructions after the pilot.
A1a	What if we do the SDOH but then the CDR is 1+. Do we throw it out?	Please submit it
A1a	How do we indicate that we're not submitting the A1a at all due to cognitive impairment? (I only see reason codes for 'remote,' not for 'not completed.')	For the pilot, administer to all participants. We will review these instructions and reason codes after the pilot.
A1a	is this a form we would physically hand to the patient and have them fill out themselves?	Yes, this should be self-administered, or can be administered to the participant by ADRC staff.
A1a	Couldn't this training be divided accordingly. That way we focus on the forms that we are responsible to fill out and less time blocked for training.	We will also be posting the recordings of this training separately by form.
A1a	So if you give the form, and the person was diagnosed as MCI, do you enter the SDOH data or not?	yes, please submit it
A1a	So, you need us to submit it for everyone then?	Yes, this should be collected for everyone, regardless of identity or CDR
A1a	Are any items on the SDoH questionnaire actionable, for example, if a participant indicates that they do not feel safe in their home or neighborhood?	We don't distinguish in terms of neighborhood, why they don't feel safe. We know that as people age, they might feel unsafe in their neighborhood just because they cannot get across the street in time with the traffic light, or there are not sidewalks or something like that. With a lot of centers now are moving toward having a social worker embedded in the center. And I do think that if someone indicates that they don't feel safe in their home, that would be something for the clinicians in the space to follow up on. We want someone to understand why that's happening. But these were not meant to be screening questions. They're more meant to get at, if a given health behavior stops or if or changes,

Form	Question	Answer
		you know what could be the determinant of that. What are the barriers there.
A1a	we have participants that do not how to write, does the coordinator administer the forms?	Yes, in that case, please have center staff administer the form.
A1a	For form A1a, if the participant is too cognitively impaired to complete the form is there a way to mark that as the reason for the form being blank?	For now, use the "prefer not to answer" codes as needed. We will review these instructions and reason codes after the pilot.
A4	Currently medications are not stored and need to be newly input at every visit. Is there a way to keep the list for the next visit and change as needed?	REDCap does enable bringing forward the responses from the previous visit which can be filled in and updated as needed.
A4	Is that a new function because that is not currently and option	It's done using piping/default values which some Centers are currently using on their local REDCap instances. The NACC instance will have this in place for certain forms (approved by CTF to minimize potential biases)
A4	So, are we only to include the OTC meds if a doctor told the participant they should be taking it?	No, include all OTC drugs whether or not a doctor instructed use.
A4	Will medications carry forward from past visit.	REDCap does enable bringing forward the responses from the previous visit which can be filled in and updated as needed.
A4	What should sites who do not use Redcap use for inputting medications not on the form?	Similar to UDSv3, put on paper form and enter. Find code using RXnav browser.
A4	What does REDCap-EHR integration for medications data look like in practice? Does medications data from the EHR automatically import into the corresponding REDCap form?	We do not yet have REDCap - EHR integration for medications.
A4	Then why say OTC drugs are optional?	They are optional (as with UDSv3) in the sense that some participants are taking dozens of supplements, so you may have to record the most important that may have biologic effects.
A4	Will they be updating the 100 mediations to the most prescribed one	Yes, these have been updated.

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A4	So we will no longer be using the NACC website Drug Lookup function?	Correct, the RXNav site is open-access and a link to the look-up tool will be included on the A4 form
A4	will we be sent new login information for the new site we use for drug lookup	The site is open-access and a link to the look-up tool will be included on the A4 form
A4	Is there a set up that our study teams needs to register to access the RX look up as with NACC?	The RXNav site is open-access and a link to the look-up tool will be included on the A4 form
A4a	Do we have to fill this form for everyone, even those who are cog normal at baseline?	This form is required for everyone (this was decided the Friday before the ADRC meeting, so the headers on the form do not currently reflect this). The first question "Has the participant ever been prescribed a treatment or been enrolled in a clinical trial of a treatment expected to modify ADRD biomarkers?" can be marked as "No" if they are not in a trial or on treatment, and then you can close the form.
A4a	What does end date mean? Is it the last date the treatment is supposed to be given or the last date that the patient has received the treatment?	The end date is the last date they received the treatment. We are revising the form to put in "88/8888" if it's ongoing
A4a	If a clinic patient is receiving lecanemab as part of clinical care this is not a “clinical trial.” The answer to #1 on the form would be “no” which then ends the form. You may want to reword the question since there are patients receiving the drug now outside of clinical trials.	The question is "Has a participant ever been prescribed a treatment or been enrolled in a clinical trial?", so you would answer "yes" as they've been prescribed a treatment.
A4a	if there was a start date but no en date??? what would you put in the last date given or something else?	We are revising the form to put in "88/8888" if it's ongoing
A4a	For follow-up visits, what do we do with this form if nothing has changed since the previous visit?	In REDCap, values will be carried forward from the prior visit.
A4a	if they go from blinded to open-label, will a new form need to be submitted? So, will there need to two forms for blinded vs open-label?	Submit a new form at the next UDS visit.
A4a	are there going to be unknown codes? like if someone can't remember dates	We will add these to the form after the pilot

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Form	Question	Answer
A4a	Are we expecting study coordinators or clinicians to fill out this form?	Either is fine.
A5/D2	How many of the A5-D2 questions are going to be on the Follow-up visit version?	Most of the questions will be included on the follow-up visit version; however, the REDCap version will likely carry forward or display the previous responses for most questions.
A5/D2	Any information collected on antiseizure medications?	All medications will be collected in detail on Form A4: Participant Medications
A5/D2	Can cannabis does that include CBD products only? I would say 99% of the participants that I see and who have sleeping issues have taken or are taking CBD products. Would this be positive cannabis use?	It is not specified in the coding guidebook right now, so we will work on clarifying this. During the UDSv4 Pilot, we do want people to make comments on things like this so we can update the coding guidebook for more clarity.
A5/D2	For section 4g, should military blast exposure be considered a “head impact” for the purposes of this form?	Yes, a military blast injury/impact would be considered a head injury if there were any symptoms associated with the military blast.
A5/D2	About seizure frequency, is it all types of seizures or general tonic clonic or generalized seizures only?	All types of seizures
A5/D2	For psychiatric condition, should we diagnose them using DSM criteria, or the report by the participant or informant is enough?	**Aimee:** These forms allow us to make a code a new diagnosis for patients, so if we are coding a new diagnosis, then we should be using the DSM-5. However, if we do medical record review, and a clinician can see that the participant is being treated by a psychiatrist or antidepressants, then I think that that is good enough for coding it as a psychiatric condition here, as long as we have every reason to think on that these are, you know, good and reputable health professionals. **Kostas:** Yeah, I think the point is, if we believe a psychiatric disorder is present and contributing etiologically, we need to define that in a way that's consistent across the Centers, and the DSM-5 is the way that's done. As far as I know, there's no other classification. The risk of not using DSM-5 is that that we would have variable diagnoses that we couldn't place great faith into. In terms of deciding whether someone meets DSM criteria, it's not a very difficult thing - I would suggest that people just look at the criteria for 2 or 3 of the common

Form	Question	Answer
		conditions and think through about whether those are met. Major depression might be the more complicated one, but there are other DSM diagnoses for a depressive disorder that doesn't quite meet criteria for major depression. So there, there are options, and it's not terribly difficult. I would encourage people to have a look. And, Aimee, I agree with you. If a a colleague who's a professional in the area has been diagnosing and treating someone as such, I would trust that.
A5/D2	Does this mean the Covid Survey is going away?	No, we will continue to collect the COVID survey. A follow-up version of the survey will be released soon.
A5/D2	When we ask about birth control pills would we also include other forms of hormonal birth control methods like the patch/ring etc. or only pills?	Include female hormone replacement pills or patches (e.g. estrogen). Do not include topical or intravaginal hormone gel or cream.
A5/D2	Will section 7 be need on the follow-up visit?	Most of the questions will be included on the follow-up visit version; however, the REDCap version will likely carry forward or display the previous responses for most questions.
A5/D2	When participant does not know answer are we using 99 or 88	The informative missing codes are noted on the form/REDCap instrument. They are usually "9" for this A5-D2. You can review the form here and see these missing codes: https://files.alz.washington.edu/UDS4/preview-forms/FormA5D2-Preview-April2024.pdf
A5/D2	If we have non clinician staff members conducting clinical interviews/data collection, how do you advice explicitly using the DSM-5-TR criteria? Should psychologists/psychiatrists at our sites begin to train our interviewers on DSM-5-TR criteria?	**Cindy:** I think we've talked before about training people on your team on how to use the DSM criteria. **Kostas:** I am open to doing a webinar to walk people through what the criteria mean for a select number of diagnoses, perhaps the most common diagnoses NACC anticipates based on UDSv3 data. I can walk people through what the criteria mean, and how to confirm whether someone meets criteria. It's probably sufficient to do it over 2-3 diagnoses since a lot of the concepts carry over to pretty much everything else.
A5/D2	Regarding questions concerning psychiatric diagnoses, who is analyzing for meeting DSMV criteria?	see above

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Form	Question	Answer
A5/D2	Will data relevant to neurologic and psychiatric history entered in A5-D2 be compared with data entered in the D1a & D1b?	We are working on developing the data quality checks for UDSv4. We may write alerts that ask you to confirm that this information can be different (e.g., active depression on A5/D2 but no depression present on D1a), but we do need to discuss with the CTF whether these alerts make sense or if there are anticipated differences between the responses on these forms
A5/D2	For what reasons were the menstrual/reproductive health questions added?	We had investigators studying menstrual/reproductive health provide the Clinical Task Force with scientific evidence that this should be added and we rigorously vetted and narrowed down the questions that were added to only those screening questions with the highest scientific merit.
A5/D2	If we should use DSM, a discrepancy may emerge between psychiatric and non-psychiatric condition. For example, if somebody says that he had stroke or myocardial infarction, why not confirming the diagnoses?	Traditionally, UDS data collection has been very general regarding psychiatric conditions, so we are trying to improve that. All of the questions on A5/D2 are only broad categorizations of medical conditions of highest relevance to dementia pathology. We could not make it exhaustive or it would be even longer. If ADRCs individually want to add more specific questions on specific medical conditions, they are welcome to do so and that could help inform UDSv5.
A5/D2	A review or presentation on the PTSD diagnostic criteria would be helpful. I encounter many participants that disclose a hx of trauma and state that they feel they have PTSD but have not been diagnosed, and I find it challenging to determine when I should document a PTSD dx. Thank you!	Thank you - we will make sure that PTSD is including in the webinar. This is important to Veteran health as well as many others.
A5/D2	Why are we not using DSM 5 TR diagnostics for cognitive disorders?	The A5/D2 form specifies use DSM-5-TR: https://files.alz.washington.edu/UDS4/preview-forms/FormA5D2-Preview-April2024.pdf
B3	On the UPDRS, what about if patient can't cooperate - that can be coded as "untestable", yes?	Yes, code as "untestable".
B3	So if arm swing is reduced d/t rotator cuff or cervical conditions we would still mark that?	Yes, there's 2 ways to do this, but the suggestion for UPDRS going forward is rate what you see, even if there is a musculoskeletal component.

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B3	Re: UPDRS: Wouldn't there be value to giving the evaluator the ability to comment if we believe some or all findings not to be related to parkinsonism	There are 2 ways to record the UPDRS and we decided as a group to follow the recommendations of the MDS-UPDRS. And you can see where this is a bit of a quandary. If we're going to do a cross sectional analysis of data, it's going to be contaminated by muscular skeletal and other contributions. However, if people are doing a longitudinal assessment, you want that per person already factored in, because they may have an elevated score that isn't Parkinsonism. It may be musculoskeletal, or at least contributed by that. And if that worsens over time that would suggest worsening Parkinsonism. So again, there's pros and cons with each one, but it is preferred to rate what you see.
B3	Hi! Does the UPDRS form includes if the participant is ON or OFF levodopa?	That would be captured in the A4 medication form, although we won't record timing of the last dose.
B3	Can you share the link to the UPDRS video and article cited earlier?	https://pubmed.ncbi.nlm.nih.gov/19802812/ This is also included on the form. Preview here: https://naccdata.org/nacc-collaborations/uds4-updates
B8	So, it is thought that we can do a “comprehensive” neurological exam via video?	A lot of the exam you can. The only thing you just can't record (must check not assessed) would be for things like rigidity. Anything you have to put hands on and do detended reflexes or Habinski sign, you'll have to say not assessed. But those things you can assess by video. We will revise the form to indicate that only focused/partial exam via telehealth may be chosen if done via video.
B8	or even by phone (!!)?	No, we will revise the form to indicate that no neurological exam may be performed if video is administered via telephone.
B8	Would there be a possibility for NACC to put together a video that includes all the abnormal findings for training purposes? Many are rarely seen in our participants and it would be helpful to be able to refresh periodically.	The video referenced in the form is very well done and that's the reference for the UDPRS. We can do a training video of the full exam.

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Form	Question	Answer
B8	Is there any guidelines for this neuro exam and/or training sources for clinicians that are not specialized in neurology?	The video referenced in the form is very well done and that's the reference for the UDPRS. We can do a training video of the full exam.
B8	Should the neurological exam be done the same as UPDRS as what is done? For example, gaze paresis because of some ocular problems, not neurological one? Or, we should tick untestable.	Traditionally, we've rated what we see that we believe is CNS-related. If you would call that person as having gaze palsy, even if they have existing ocular problems that are more ocular (as opposed to brain) related, I'd want to record to the best you can, is that a CNS problem?
B8	Right - the forms suggest you can. You can check you did it by phone and indicate they had a normal exam, it appears.	We will clarify that in the guidebook
B8	I would suggest that if you did it by phone, it should default to “No Neurological Exam”	We will clarify that in the guidebook
B8	Rarely, we have staff to administer UDS & cog testing measures but don't have a clinician available to do a neuro exam. My understanding of UDS3 is that a neuro exam isn't required only when doing a remote visit with a T-Cog. Will UDS4 allow us to submit the full UDS with full in-person neuropsych testing with a neuro exam omitted?	A neuro exam is required for any in-person eval.
B8	A compilation of specific eval for each of the possible exam findings (things that go beyond the basic comprehensive neuro exam) and video of real participants with all the possible abnormal exam findings would be super helpful!	Great suggestions!
B9	#2 says 'Decline', #5 says 'Change' Is that intentional for some reason or just needs to be fixed?	It looks like it just needs to be fixed as the language was edited recently for the motor domain (change in motor domain vs decline in motor domain). I'll make a note to make this edit on the form!
B9	Will it create an error if the person completing the A1 is told no decline in cognition via patient but then during the B9 the patient states yes to decline with the provider. will this discrepancy create an error?	Good question. There should probably be a consistency check here.
B9	Will it create an error if the person completing the A1 is told no decline in cognition via patient but then during the B9 the patient states yes to	Yes, NACC is still writing data quality checks, but likely there will be an alert to confirm whether the inconsistency between forms is correct or not

Form	Question	Answer
	decline with the provider. will this discrepancy create an error?	
B9	And 9i says 'behavioral symptoms.' I assume it should be 'cognitive symptoms'?	Yes, typo! Marked to edit
B9	If someone is considered "Impaired, not MCI or dementia" or "subjective cognitive decline" should we say that they are experiencing meaningful impairment in cognition?	Impairment refers to psychometric deficits or possibly informant or clinician documentation
B9	Are coordinators expected to fill out these last few forms? These are usually filled out by the doctors.	Form B9 is to be completed by the clinician (usually a physician or nurse practitioner)
B9	We see people annually or biannually so what if the change happened more than a month ago? It may be clinically significant but wouldn't be captured then? Like hallucinations they are not necessarily present consistently so we may miss them if they happened more than a month ago?	The CTF discussed this at length - section 3 is meant to capture neuropsych symptoms that occurred in the last month, independent of when they were last evaluated in the ADRC
B9	Am I missing something or is the form no longer catching exactly which cognitive, behavioral ,or motor symptoms manifest initially? (e.g. memory was the first cognitive symptom, anxiety the first behavioral symptom, and/or tremor the first motor change)? that would seem like important data points	It's meant to be captured under each section. There's a section that says, age of onset, approximately age of onset, of cognitive and impairment, or age of onset of the psychosis, behavioral changes, etc. So that's meant to try to get at what features came on first. We thought about doing that for every single symptom, but thought that would be just too much. Section 5 at the end, indicate the predominant domain that was first recognized, so I think this is where we're trying to capture the initial clinical presentation. So to John's question, you are not missing anything. We simply have somewhat changed how we're doing this. So we're asking you at the end of the form, to tell us what was the predominant presentation at the beginning, but not necessarily their predominant symptom.
B9	but it doesn't say specifically what symptom is first? it was easily done on the old form	Correct. It doesn't say specifically what symptom is first. We've had to make judgment calls. There are lots of important information that we understand we're not going to be collecting, but

Form	Question	Answer
		our sense was that in the interest of not excessively burdening participants and clinicians, it made sense to take this approach. And if people are followed longitudinally, you'll know whether they had the symptom at 1 point, and then they didn't another, vice versa, that didn't have the symptom prior visit. Now they do so once they're in the system, there'll be a better way to capture which symptoms, and or physical features came on first and then the date or age of onset is supposed to capture. You know what happened before they became part of the clinical visit.
B9	Are there going to be cross-visit errors/alerts where version 3 answers are being compared to version 4 answers? (General question)	The CTF had talked about whether within the pilot studies we would do some kind of cross comparisons and try to link and see if diagnoses change. We worked with UDSv3 at baseline, and made the changes from there, and we thought the pilot would be too much to do all that within a small pilot, otherwise it would take a long time to implement this. So we decided to give the pilot be focused on feasibility and implementation, guidebook clarification, and that we will promote analyses across the conversion from UDS 3 to 4 and look for trends in diagnoses. So again, some of the diagnostic criteria have been clarified. Some have been teased apart, so people who may have been grouped in other things may be labeled as subjective cognitive decline now. So again, we'll be looking at some of those changes, but it it'll be a larger undertaking than just doing some pilots.
B9	Aren't B3, B8, D1a and D1b also completed by a physician or nurse practitioner?	Each form identifies at the top whether it should be completed by a clinician or another trained research or health professional.
B9	how much time do you expect these new forms to take for your speedy providers and then for your slowest providers?	One of the goals of the UDSv4 Pilot which is launching this week is to determine the timing for these new/updated UDSv4 forms (vs UDSv3). Also, expect that timing depends on the participant as well as the provider.
B9	Just to clarify, there has been some discussion regarding clinicans (MDs, nurse practitioners) completing the forms. Does this mean that the	All forms clarify in the top instructions who should complete the form. B9 is to be completed by a clinician which would include neuropsychologists.

Form	Question	Answer
	licensed neuropsychologists are not meant to complete the B9? Of course with the idea that the neuropsychologist would use the physician/nurse practitioner information from the neuro exam for section 4 (motor symptoms).	
C2/C2T	The GDS will likely not be enough to fill in the delay	That's probably true, and we also recognize centers have some of their own unique tests and methods, but the principle is to avoid direct interference as much as possible.
C2/C2T	I think there are several Spanish versions of the CERAD memory test floating around. Has it been established which version will be used?	There is a Spanish Translations group working on UDSv4 and they will provide their recommendation for the CERAD
C2/C2T	So MINT cannot be administered in RAVLT delay period?	We would prefer to not have tests in the same domain that would potentially interfere. But there may be site-specific issues or constraints, so this is meant as guidance for best practice.
C2/C2T	Are any additional non-verbal tests appropriate for the delay? We usually administer the Rey-O, GDS, WAIS-R Blocks, and sometimes the Pareidolia and sleep questionnaires during our AVLT delay. Is that acceptable?	That would be fine. As long as you can fit it within the 20-30 minute delay
C2/C2T	For the telephone versions, why are category fluency used in the delay of these verbal learning tests?	We'll review and correct or provide additional guidance as necessary.
C2/C2T	I though it was said that we should not use verbal tasks in between delays	We'll review and correct or provide additional guidance as necessary.
C2/C2T	The order shown at the end had verbal fluency during the delay. Could you please clarify because that is different from the suggested order shown earlier.	The order shown earlier was for the in-person/video (C2) version.
C2/C2T	Will the database allow us to enter either of the new tests? We use the HVLT in our visits, just brainstorming how to reduce duplicating tests.	Yes
C2/C2T	Do sites have to choose a single test, CERAD vs RAVLT, to complete for all participants? Or is it possible to complete 1 test or another on a case-by-case basis?	Your center will not be limited to a single test, you can do this on a case-by-case basis!

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C2/C2T	Do most centers only use REDCap for documentation or do they also chart in an EMR?	Since data collected for ADRCs is research data, I believe most centers use REDCap or a related research database. If a participant is also a clinic patient, they may have information also recorded in the EMR.
C2/C2T	tcog says to put verbal fluency in RAVLT delay but the in person says not to put verbal fluency in delay. I think that's what the question was referencing	We'll review and correct or provide additional guidance as necessary.
C2/C2T	I want to make sure I am understanding the order of test implementation. After the RAVLT learning sites are allowed to administerer their site specific measures in that delay?	Correct, as long as you can fit it within the 20-30 minute delay and it doesn't interfere.
C2/C2T	The order shown for the in person visit had the MINT towards the end, can the MINT be administered before the RAVLT?	We would prefer to follow the prescribed order. But there may be site-specific issues or constraints, so this is meant as guidance for best practice.
D1a	My group is working with adults with Down syndrome in our ADRC — would all of these individuals be coded as “other cognitive impairment” due to intellectual disability, or can we mark them as unimpaired if they haven’t experienced AD-related decline?	Yes, guidance on the form states for those with longstanding cognitive impairment (e.g. Down Syndrome) that does not represent a decline from their usual functioning, consider checking Question 5b for a diagnosis of “Cognitively Impaired, Not MCI/dementia”. I'd also like to remind everyone that the Down Syndrome Module is available for participants with Down Syndrome, with forms specific to this population: https://naccdata.org/data-collection/forms-documentation/dsm
D1a	For "affected domains", should this be based on clinical symptoms, neuropsych testing, or either?	Clinician judgment is key - when in doubt, use your clinical judgment based on the information that is available to you, including history, past interactions with the participant, cognitive data, or if biomarker data is known and influencing your decision, then make that judgment and record how it was made.
D1a	MBI, Cognitive impairment not MCI or dementia...are there more details or trainings available on these new terms?	Yes, the Clinical Task Force has hosted several webinars and the topics were on "MBI" and "cognitively impaired, not MCI" (which is a term that was on UDS3). These webinars are recorded and available to review. You can find links to the recordings about 2/3 down the page:

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Form	Question	Answer
		https://naccdata.org/nacc-collaborations/uds4-updates
D1a	Since almost everyone will have an MRI, but not all will have CSF/PET, won't item 9c mislead database researchers by lumping them....	The purpose of this question is to identify when biomarker information was used to determine the clinical syndrome - not the preferred method, but at times it is unavoidable - D1b will capture which biomaker information was available and used to determine the etiology in more detail.
D1a	For Clinical Syndrome (Section 2)- is the standard and preferred methods to make the determination without biomarkers?	That is correct, this diagnosis should be done using clinical information and cognitive/neuropsychological testing, ideally without reference to biomarker data.
D1a	Is MDD considered present even when in full remission (since MDD never becomes absent. It just goes into partial or full remission. That was a point of confusion previously for us)?	The form asks to note if the MDD is present (Y/N), primary, contributing, or non-contributing. Thus, if someone is effectively treated, MDD may be present, treated and, thus, non-contributing.
D1a	Does a CDR of 0.5 global with only 0.5 in memory really count as "functional impairment" that excludes SCD ?	This is a good question. SCD is a clinical judgment rather than purely based on any cut offs.
D1a	I'm confused, certainly MCI and MBI are not mutually exclusive	Correct, these are not mutually exclusive. MBI can occur if you have MCI, but not if you have dementia.
D1a	For subjective memory complaint, my understanding from the presentation was that there is no cut point, and diagnosing is based on clinician's judgment of how serious and worrisome is the complaint raised by a participant. Am I right?	Yes, this is correct.
D1a	In the behavioral component did we think about chronic UTI causing these symptoms?	Consistent with standard of care in clinical practice, these diagnoses should be made after any causes of delirium is ruled out.
D1a	Can you improve instruction criteria for MBI to reduce confusion. Currently says not explained by another DSM-V condition, but of course Minor and Major Neurocognitive d/o are in the DSM-V	Yes - we can clarify that point. Thank you!

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Form	Question	Answer
D1a	With the clinical core criteria for MCI, can someone be "average" on all cognitive tests but still show decline across time?	**Andy:** That is really another rather widely accepted definition of MCI, and probably something we could introduce better clarification of in the D1a guidebook, but, overall, I think if it's a reliable decline over time within a participant, most would consider that consistent with most definitions of MCI. **Jeff:** There are practices at local sites, and our goal is to encourage a little more uniformity. But if you have have your own practice for making that judgment, then local standards are respected.
D1a	I'm confused about the answer to the MDD questions...I thought section 3 was not meant to be a recapitulation of the health history. So, if the participant ever met criteria for MDD but has no current depression, MDD should still be listed as present, and non-contributing? What about for treated sleep apnea?	Let's say a participant in their thirties had major depressive disorder, was treated, and they never had a relapse (i.e., nothing ever happened). That's not necessarily someone for whom we're we're looking to record this on Form D1a. However, a participant who had major depressive disorder in their forties, who still has some partial symptoms/partial remission that might be contributing, then we would want to know that as well as the judgment as to whether it's contributing to any cognitive disorder.
D1a	My understanding is MBI is sort of behavioral variant of some sort of neurodegenerative process but not making them to be dependent. Is that right?	Right now I'm agnostic about when an MBI phenotype or which phenotype would be an early indicator of the neurodegenerative process, and that's partly why we're trying to capture information about it so that we can make judgments around that. it certainly could turn out that a lot of cases of MBI are the result of "A or B or C" neurodegenerative process; but, maybe it, won't and they might be related more to aging.
D1a	Just to clarify my affected domains question, if the participant voices strong memory complaints/symptoms but neuropsych testing only shows executive dysfunction, what do we mark for question 6, section 1?	We will clarify in the Guidebook in D1a section "Affected Domains - Dementia and MCI)" if "impaired" refers only to cognitive testing results or participant complaints and clinical judgment as well

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Form	Question	Answer
D1b	Was there a particular reason to SPLIT this into two forms?	Yes - Form D1a is the clinical presentation of the person and how they are experiencing these symptoms. Now that we have biomarkers, we are able to separate out the underlying etiology (Form D1b) as there may be numerous pathologies contributing to the participant symptoms. As we move toward more disease modifying therapies, this will become increasingly important.
D1b	If the biomarker results are available but are inconclusive -how should this be documented? (Ie participant had clinical CSF biomarker which are available to consensus but not part of NACC)	They would be listed as "indeterminate"
D1b	What about a verbal APOE4x2 report by patient from 23&me? would this count a fluid biomarker?	We do have a lot of discussions about participants bringing in these results at the ADRCs. We haven't included that on D1b, and APOE is collected elsewhere (e.g., ADGC, NCRAD, locally). This is something we may want to reconsider, but at this point we haven't included that. It can be used to support a diagnosis, and so maybe we should reconsider whether it should be included on this form. As of now, the committee came to the conclusion that's indicated elsewhere, and we can draw on that information, but we want to stay more focused on the fluid and imaging biomarkers.
D1b	Can an FDG-PET scan be consistent with more than one diagnosis (e.g. DLB and AD)?	You can select as many diagnoses as are applicable for each section
D1b	Suggest "Inconsistent" / "consistent" for biomarkers instead of yes/no (although it takes up more form space)	The questions are worded in a way to hopefully be clear, but we we ought to consider "inconsistent" or "consistent." So we will discuss that. Thank you.
D1b	Does the guidebook have a link to CHS categories/images for rating severity of microvascular changes?	Yes, like UDSv3 the guidebook has the CHS categories & images and reference to this paper: Longstreth WT Jr1 , Manolio TA, Arnold A, Burke GL, Bryan N, Jungreis CA, Enright PL, O'Leary D, Fried L. Clinical correlates of white matter findings on cranial magnetic resonance imaging of 3301 elderly people. The Cardiovascular Health Study. Stroke. Stroke, 27(8):1274-82, 1996.

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Form	Question	Answer
D1b	so a patient with a positive amyloid PET scan who is asymptomatic would get a diagnosis of AD (but without a contribution) on D1b?	Correct.
D1b	What about clinical imaging, blood tests, or genetic testing? Should we be using these for the D1b if they are available or should we only be using research data?	If if it's influencing or supporting your etiological diagnosis, then, yes, we want to indicate that here. This doesn't have to be research generated because the purpose of this form is not to say that somewhere in the NACC data there's a biomarker value or a sample to support this indication. The purpose is to indicate that this is information that the team at consensus or the clinician at the assessment is using to to make a diagnosis and to support that diagnosis.
D1b	FDG-PET is notoriously subjective	The fields changing so rapidly. That's why we left this a little broad, as "Yes," "No," or "Indeterminate" because the cut points are going to change, we just wanted to know whether or not it was present (or indeterminate), so that researchers and clinicians will know what data was used in making an etiologic diagnosis.
D1b	I guess we don't know whether we can check more than one box for the FDG-PET interpretation.	Yes, you can check multiple diagnoses
D1b	For the etiologic diagnosis, if there is a possible mixed dementia and/or uncertainty on what is the primary cause of the dementia syndrome, could all listed etiologies be marked as contributing (ex nothing listed as primary)?	If if you're diagnosing a mixed dementia, you would indicate the components of that mixed dementia on D1b, and if you have biomarker support, that should be documented on D1b as well. We would be able to see that you think the participant has mixed vascular and Alzheimer's, or whatever you're diagnosing, but you do need to indicate what you think is the primary etiologic diagnosis/drive of disease.
General	General question - when will the UDS4 forms be finalized for IRB submission? especially for those of us who will be doing the pilot?	Forms are ready and will be distributed shortly. Coding Guidebook will be sent later this month, but isn't participant-facing.
General	Will the Spanish UDS 4 be launched as well? if not how will that impact data collection for this part of the cohort?	Yes, there is a Spanish UDS 4 in progress, but its launch will lag behind the English version. There is an estimated timeline provided on the UDSv4 NACC page: https://naccdata.org/nacc-collaborations/uds4-updates

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Form	Question	Answer
General	So sites with both English and Spanish speakers will need to collect UDS3 and UDS4 data simultaneously?	There will be a lag time during which you will be able to keep collecting UDSv3 on Spanish and Chinese speaking participants until these UDSv4 translations are ready
General	Thank you, this was very helpful! Will there be a place to email questions to be answered after folks start using the forms that can be viewable to all?	Yes, the Clinical Task Force (CTF) has discussed gathering questions collected during the pilot phase to develop FAQs to share with others and refine the UDS 4 Guidebook. Also, the CTF will host drop-in virtual "office hours" where we review common questions and allow teams to bring specific questions to ask someone from the CTF and/or NACC data team
General	Is there a way to send us a form with ALL the new questions. This is super extensive and the questions are even more specific and when we are seeing the participant as providers, we now have to ask so much more detail. Is there a way to stream line this process??	All forms are available on the NACC website, toward the bottom of this page: https://naccdata.org/nacc-collaborations/uds4-updates. We do not have a condensed version of the UDSv4 that only shows the new questions on each form.