Chapter 28

Dementia Review Procedures

Background and Overview

The Dementia Review Committee assigns consensus cognitive diagnoses in accord with the procedures of the Framingham Heart Study (FHS). The Dementia Review committee consists of neuropsychologists and neurologists including Stephanie Cosentino (CU), Stacy Andersen (BU), Larry Honig (CU), Megan Barker (CU), Sandy Auerbach (FHS), and William Kriesl (CU).

Procedures for Dementia Review

Identifying cases for dementia review – Dementia reviews will be conducted for LLFS participants who demonstrate the presence of diagnostic triggers at ANY time including:

1) CDR >0
2) Cognitively impaired by the NACC-based algorithm (case_status = 1);
3) If CDR and algorithm are missing, report of a cognitive problem by an informant defined by endorsement of any item between #1 and 7 on the Dementia Questionnaire

Dementia Report from DMCC – Once the list of potential dementia participants is created (based on retrospective review of CDR, algorithm status, and DQ), the DMCC will:

- provide a list of the participants whose charts will need to be retrieved for dementia review at each site, and
- create a report for each participant (*Neuropsychology Summary)*. This report includes information entered into REDCap during in-person and follow-up phone calls, which is then used to create analysis datasets.
- Using these datasets, the DMCC extracts necessary information to aid with the dementia review process. These reports will be available for download at the sFTP site: **/LLFS_#/DementiaReview/ (where # is NY, BU, or PT).**

Dementia Review Documents for each participant – Prior to the bi-weekly dementia review calls, each site will create a dementia review document for each participant to be presented on the call. These files must be uploaded to WUSTL Box by close of day on the business day prior to the call, to allow LeAnne time to distribute the link to the dropbox. See following section (‘**Preparing Documents for Review’**) for details on the preparation of the files. During the Dementia Review call, the Dementia Review Form (Long or Short version, depending on participant’s cognitive status as determined on the call) will be finalized based on the adjudication. After the call, each form will be entered into REDCap by staff at the site presenting that case.

Procedures for uploading files: Due to our security policy to protect HIPPA information, review documents are distributed to the adjudicators in a password-protected dropbox. Any persons wishing to upload files should contact the DMCC Project Manager, LeAnne Kniepkamp (l.kniepkamp@wustl.edu) and request to be added as an editor on the "LLFS Dementia Review Records" WUSTL Box. If new adjudicators or staff need to be added to the distribution list for Box, they should contact LeAnne.

After access is granted, completed review documents can be uploaded to the folder created for the upcoming call. LeAnne will transfer these files to the password-protected dropbox at close of day one day prior to the call, and then distribute the box's link and password to the adjudicators and relevant staff the morning of the call.

Adjudication During Dementia Review Panel Calls – Files will be downloaded and reviewed by the Dementia Review committee members. A representative (usually the person who prepared the case file) will give a short presentation that covers the mains points of each case. Following this, the committee will adjudicate the case and decide on a classification of "Normal Cognition", "Normal Cognition with Concerns", "Mild Cognitive Impairment" (MCI) or "Dementia". Discussion of the case and completion of the Dementia Review Form (Long Form or Short Form) will occur during the call. The Dementia Review Form will be entered into the REDCap data system after the call and a hard copy will be added to the participant's chart after data entry.

Preparing Documents for Review

Each document will include

1) the Neuropsychology Summary report from the DMCC
2) scanned pages from the participant's chart
3) a Dementia Review Summary containing information synthesized from both these sources and the participant's other files.

These separate files should be combined into one PDF labelled "[ParticipantID]_[Site]_DR_DementiaReviewSummary" and uploaded to the relevant folder on Box. For further details on the preparation of this summary, please see below. The example below is offered only as an example of how one field site (CU) prepares this summary. There may be some variability across sites in how the information is ordered. Should the ordering of an item in this MOP conflict with established practice at your institution, site-specific instructions are to take precedence over the suggestions below. The goal of the template is simply to codify the information that should be contained within a completed DR summary, not establish rules for its layout.

Dementia Review Template

The heading of the review should contain basic demographic information about the participant, including: Participant ID, Site (at which they were enrolled, not necessarily where the summary is being prepared), DOB/DOD, age (either at death or at the time of review if they are still alive), sex, highest level of education (in years or highest level completed), and occupation or former occupation if retired.

The 'Synthesized Summary' of the template should contain an overview of the relevant data available for each visit or follow-up. This includes information about the participant's cognitive status, physical functioning, and significant medical events, as well as informant reports and any other data that might be useful in the determination of the participant's cognitive profile. The Synthesized Summary should take the form of a table, listing all dates of contact in chronological order, with key details to the right of each date. Here is an *example*:

Algorithm Status: V1 = 0/V2 = 1

V1 (Jan 2009) [Age 96]	Notes about V1 test scores, relevant medical conditions, CESD score, physical functioning
AFU1 (Jan 2010)	TICS (40/51), no DQ due to high TICS score, ADL summary
AFU2 (Jan 2011)	TICS (20/51), notes about DQ findings, new relevant medical conditions, no change in ADLs, relevant update to medication inventory
AFU3 (Jan 2013)	TICS (20/51), notes about DQ findings, new relevant medical conditions, new limitations on ADL form
V2 (Jan 2016) [Age 103]	Notes about V2 test scores, changes in cognition, summary of DQ findings, CDR score [including individual domain scores e.g. "1 for memory, 0.5 for orientation, etc."], relevant update to medication inventory
AFU4 (Jan 2017)	TICS refused, CDR score, notes about DQ findings
DPI (March 2018)	Participant deceased January 2018. Info from DPI, addendum.

Include any DQ information in this section, especially examples or quotes from the informant which elaborate on the participant's problems. If a DPI is available it should be entered into the table as if it were the last follow-up, and should discuss cause of death, factors leading up to death, and any physical impairments endorsed by the informant.

The 'Chart Summary' should include any other contributing factors and health-related / medical issues (not necessarily cognitive) (e.g., head injury, stroke, developmental disorder, Parkinson's disease, etc.). Age of diagnosis should be included, as well as whether the condition is current or resolved. Past and present use of tobacco/alcohol should be described after medical conditions. If the medication history includes mdications directly relevant to the dementia review (e.g. donepezil, memantine, etc) then these should be listed. The person preparing the summary should use judgment to decide whether to list additional medications; for example, medications

pertaining to vascular issues or incontinence may be deemed relevant, but multivitamins are unlikely to add any relevant information. If the person preparing the summary is unsure, they should err on the side of inclusion rather than exclusion.

Prior to V3, medical records were only obtained following death of the participant, and even then, medical records may be unavailable. Beginning with V3, effort will be made to acquire neuro-related medical records. The 'Medical Records Summary' should only be completed if medical records are available. Otherwise write 'N/A'. If medical records are available, best judgment should guide what is included and what is omitted. Of particular relevance are:

- cause of death–If multiple lines are filled, include all information. Causes are listed from most immediate to most underlying, and it is often more relevant, for example, that a patient suffered from end-stage ALS than that their terminal mechanism was respiratory failure.
- past medical history–especially if a condition described in the medical record is, in the patient's self-reported medical history, vague, improperly dated, or entirely absent.
- abnormal findings on psychiatric or neurological exams–only if it seems relevant to the goal of the review. Motor symptoms corroborating a stroke endorsed in the summary, or psychiatric evaluation noting clinical depression, would be more important to record than newly acquired delirium secondary to fatal sepsis. Again, if the person preparing the summary is unsure, they should erro on the side of inclusions rather than execlusion.
- cranial imaging –usually too technical to summarize. If an imaging description or analysis is available, simply note the imaging type and location in the Medical Records section, and include the relevant page(s) in the scans attached to the summary. Care should be taken on the call to direct adjudicators to these scans.

The 'Neuropsychology Summary' should consist of a table laid out similarly to the Synthesized Summary, with dates listed in the leftmost column, the specifics of that data collection point in the center, and an additional rightmost column containing normalized scores (z-scores) (availabe for in-person visits only). Note that the z-scores may be included in the 'Synthesized Summary' section if that tis the preference of the individual site. Performance on testing, the specific nature of errors, confounding factors, and any notes made by the interviewer should be listed in the central column for all neuropsychological measures available (TICS only for phone follow-ups, full battery for in-person visits). Note that all errors on TICS and in-person cognitive testing should be described in detail in this section. For all testing possible (specifically, all quantitative tests administered at visits minus FAS and HVLT) raw scores should be comapred to NACC normative data, and the resulting z-scores recorded in the rightmost column of the Neuropsychology Summary table. HVLT scores may be compared to other normative data if available.

The 'Behavioral Observations' should include

- comments on both conditions of the Clocks test
- comments from the interviewer / tester
- any confounding factors not noted in the Synthesized/Neuropsychology summaries

- any notes from the staff member preparing the review that will give the adjudicators a clearer picture of the participant
- comments / descriptions of neuropsych testing errors that were not recorded elsewhere

Scanned Documents: All written output from the participant at V1 (MMSE sentence, MMSE pentagons, DSST), V2 (MMSE sentence, MMSE pentagons, DSST, all 4 trails items, Clock command, Clock copy), and V3 (same as V2, if available) should be scanned. When scanning documents to be circulated, all identifying information (e.g., names, acrostics) needs to be redacted by using Adobe to place a black box over the information.

Composing Files for Upload: The separate pieces of the final file (the summary document, scanned pages, medical records if applicable, and "Neuropsychology Summary" Redcap output) should be combined into a single PDF in the order listed (1. Dementia Review Summary, 2. Scans, 3. REDCap output). A consistent numbering system should be applied to the top right corner of every page in the combined PDF, and drawings should be labeled, for example 'V1 Pentagons', 'V1 Sentence', 'V2 Trails A Page 1' etc. in the upper left corner of the scanned pages. Medical records should be labeled, also in the upper left corner, with what information is relevant on the page, for example "PMH depression" "date and description of stroke" "head CT summary", etc. Once the file has been properly combined and labeled, it should be uploaded to WUSTL Box as described above.

Dementia Review Forms Cheat Sheet

Subjects ID Number/Date of Review/Adjudicators/Review Number

- Mostly self-explanatory
- Adjudicators are anyone who speaks on the call, or anyone in the room for in-person adjudication.
- Review number refers to how many times this particular participant has been brought up for review; for all retrospective reviews, this box will always be 1.

Last Documented Normal/Baseline Cognitive Status and Degree of Certainty (DoC)

- Only applicable if participant declines from normal cognition after V1. If they have any degree of cognitive impairment at V1 then Last Normal is unknown.
- If participant becomes cognitively impaired or demented between follow-ups, or if the date they became MCI/demented is uncertain, then Last Normal is the last data point when they were truly known to be normal. Last Normal and Earliest Documented Date of Cognitive Impairment don't have to be two consecutive data entries.
- If Last Normal is "U = Unavailable" then DoC is "N=N/A" (this is true for all dates with DoC ratings).
- Degree of Certainty can be at most 3 if the date is a follow-up, unless there is extremely compelling informant information or a specific event (e.g., TBI, stroke) with corroborating information (these instances are rare). Levels 4 and 5 are used only for visits where a full complement of neuropsychological testing is available.

Cognitive Impairment/Cognitive Decline

- If you're filling out this form (i.e., the long form), then they're cognitively impaired. Put a 1 in the Cognitive Impairment box.
- Cognitive Decline is almost always "2 = Yes, Duration Greater Than 6 Months." Option 1 may be used in the following (rare) circumstances: 1) brain injuries /illness resulting in documented cognitive decline followed by death within 12 months; 2) if the first evidence of cognitive impairment occurs at a recent visit (that is, less than 12 months ago) but the participant is still alive.

Date of Cognitive Impairment Onset/DoC and Earliest Documented Date of Cognitive Impairment

- Distinction between these two is often case-by-case.
- If the Date of Last Normal is Unknown (that is, the participant is MCI/Demented at V1), then most often the Date of Cognitive Impairment Onset will be Unknown as well, and the Earliest Documented Date of Cognitive Impairment will be V1. However, in some cases the Last Normal may be Unknown, but the committee doesn't think there is enough

evidence to call the participant MCI at V1 – in these cases, the Date of Onset and Earliest Documented Date of Cognitive Impairment will be a later visit date, and should usually be the same as one another.

- If there is a date of Last Normal entered, then the Date of Cognitive Impairment Onset and the Earliest Documented Date of Cognitive Impairment should always be the same. For example, if the participant is visibly normal at AFU5 and visibly impaired at AFU6 then Date of Onset and the Earliest Date of Cognitive Impairment would be set to AFU6 and a confidence rating assigned based on the information available at AFU6.
- On the other hand, for example, if they're visibly normal at AFU3 then no information is available until they are visibly impaired at AFU6, Date of Onset is coded as Unavailable and Earliest Documented Date is set to AFU6.
- The visit/follow up split for the DoC still applies here; up to 3 for follow ups, 4 and 5 only for visits with full neuropsychological testing.
- If the cognitive impairment is due to a specific injury/event (e.g., stroke, car accident, hospitalization, fall), and we are highly confident that the injury/event is the primary or only cause of impairment, then the date of that injury/event should be used as Date of Onset. If only the month and year are known (common for stroke due to the way the DQ is set up) the 15th of that month is used as the exact date.
    - N.B. This "approximation rule" is true for all dates on the form. If you know the month but not the date, enter the 15th. In rare cases where we only have the year, we enter June 30th as the date.

MCI Subtypes

- If participant moves straight from normal cognition to dementia, code MCI subtypes as "D = Don't Know".
- If MCI onset is during a FU year (i.e. the only neuropsych is the TICS) nothing can be assigned beyond amnestic vs. non-amnestic. Further subtype division to be coded as Don't Know, and specific subdomains to be coded as N = N/A.
- If information needed to code a particular subdomain is missing (e.g. no pentagons available for V1, so no information available to assess visuospatial skills) then code it as Don't Know. "0 = no" is only used when enough information is available to reasonably call the impairment absent for any specific subdomain.
- The Language subdomain was re-added in recognition of the subset of participants whose cognitive profiles suggest a language deficit, despite the lack of a standard language test (e.g. naming). Due to this, the assignment of the language subtype must be, to a greater degree than the other subtypes, a product of clinical consensus.
    - The main factor in assigning a language deficit is Animal Fluency. As this test places demands on both executive and language systems, performance on Animals should be judged in the overall context of the participant's deficits. If Animals is the only test below normal limits (especially if other linguistic tasks, like Verbal Fluency or the MMSE sentence, are low or abnormal) this should be recorded as the Language subdomain impaired. If, however, the participant exhibits a dysexecutive cognitive profile, then poor performance on Animals can b

- interpreted as a manifestation of executive problems rather than a separate language difficulty; in this case the 'language' domain could either be 'don't know' or 'absent' based on clinical consensus.
- If there is any ambiguity about the presence or absence of a language deficit for a particular participant, err on the side of choosing "Don't Know" rather than "No", as the lack of a dedicated task makes it impossible, in theory, to declare a language deficit absent.

Dementia

- Date of Diagnosis is the first instance of data entry where the participant is deemed demented. This is true regardless of the severity of impairment at that follow-up.
- DoC still follows visit/follow up rule.
- If the participant is adjudicated as MCI only, code 0 for Probable Dementia Present, still code Dementia Subtype (as "09-Cognitive Impairment – No Dementia"), and code N/A for "Severity of Dementia Subtype at Last Assessment." Still code "Date of Last Assessment", as this variable can be used independently of a severity rating.

Dementia Subtype

- 00-None: Not used due to existence of Short Form.
- 01-AD Without Stroke: Clinical AD presentation with either no recorded history of stroke, or a terminal stroke only. Note that "recorded history of stroke" means that neurological signs need to be documented – if a stroke is documented without neurological signs then it doesn't count. For example, someone might have a family report of a stroke, but we would still code "AD Without Stroke" if there are no neurological signs reported.
- 02-AD With Stroke: AD presentation with a documented, detailed description (including neurological signs) of a non-terminal stroke that DOES NOT include a definite suggestive temporal profile of cognitive decline. In other words, the underlying degenerative process is assumed to be AD, and the stroke is unrelated to the cognitive impairment, it is just a coincidental event.
    - N.B. There is often overlap between this code and coding (Subtype 01+ "30 = Stroke/TIA" in Other Causes of Dementia or Impairment). The dividing line is whether a stroke is simply mentioned, for example in the Medhx or hospitalization records, or whether medical records/neurological signs in the stroke section of the DQ are available. In the former situation the code is Subtype 01+ "30 = Stroke/TIA" in Other Causes of Dementia or Impairment, while in the latter the code is 02.
- 03-Vascular Dementia Without AD: For cases showing obvious signs of vascular dementia: clinically documented and well-described stroke, or multiple strokes, decline in cognitive function following stroke/s, and little or no cognitive impairment *unrelated* to stroke events.

- 04-Mixed Dementia Type (AD+Vascular Dementia): Used for cases that would qualify for Code 03 (cognitive impairment due to stroke), but also exhibit AD-like clinical progression (e.g., impairment prior to the stroke/s, or notable degeneration in function independent of subsequent strokes). In other words, the cause of cognitive impairment is likely to be related to both vascular factors and AD.
- 05-FTD: Rare, assigned by clinical consensus.
- 06-DLB: Rare, assigned by clinical consensus (call Dr. Honig!). The use of this code over "03 = DLB" in Other Causes of Dementia or Impairment should be decided based on whether the impairment fits a primary DLB pattern (code in Dementia Subtype section) or if DLB is likely secondary to a different (primary) cause of impairment (code in Other Causes section). DLB is most often assigned when we have evidence of parkinsonism, hallucinations, REM sleep behavior disorder, and fluctuations.
- 07-Dementia that does not fit any other Category (progressive): Catch-all bucket for cases where dementia is clearly present but an atypical pattern of impairment/absence of information makes a subtype classification difficult. To be used when, despite the lack of clarity in subtype, there is a clear downward trend in the participant's cognition.
- 08-Dementia that does not fit any other Category (non-progressive): Same as code 07, except to be used in cases where clear dementia is present, but participant cognition does NOT appreciably decline over the period of study.
- 09-Cognitive Impairment – No Dementia: Used when participant is adjudicated as MCI but not demented. See "Dementia" section above for full explanation.
- 10-Dementia-Uncertain: Used when participant has dementia but the committee is uncertain about the etiology/subtype.
- D-Don't Know: Interpreted to mean "uncertain if dementia is present." Rarely used; functions as an intermediate step between MCI-only and assignment of a fully-fledged dementia subtype.

Severity of Dementia Subtype at Last Assessment/Date of Last Assessment

- Self-explanatory. Only fill out if a dementia subtype (other than Code 09) has been assigned. Estimate severity at most recent data point, even if no cognitive information is available. Include date of this assessment.

AD by NINCDS-ADRDA Criteria/Classification of AD

- For NINCDS Criteria, code Yes if subtype is 01,02, or 04. Code No or Don't Know if subtype is 03, 05, or 06 (check with committee on call). Code N/A if participant not demented (subtype 09). Code Don't Know if subtype is 07, 08, or 10.
- Classification of AD question only filled out if NINCDS Criteria coded Yes. Code 1 = Probable AD if participant's degeneration is well-characterized and fits the typical AD course to some degree. Code 2 = Possible AD if the participant was adjudicated as having AD, but there are highly unusual / unexpected / unexplained cognitive features, or other possible etiologies behind the participant's progressive dementia. This is almost always coded as "1".

Other Causes of Dementia or Impairment

- Self-explanatory for the most part. Most options rarely/never used. Can still be filled even if participant only judged as MCI.
- PD/DLB options explained above.
- Code 27 = Other Etiologies if it seems like an event in the participant's history (that cannot be described by one of the other options in this code bank) contributed to their neurodegeneration (if used, it is most commonly anxiety, specific medications, falls, or other specific incidents).
- Code 28 = Hx of Depression for any mention of depression in the summary that occurred leading up to or during cognitive impairment, or a CESD score indicating depression.
- Circumstances around Code 30 = Stroke/TIA explained above.

Cognitive Status at Time of Death/DoC

- If participant is alive, choose 4.0 = Alive and N/A for the certainty
- If participant is deceased, estimate participant's cognitive status based on information from the DPI, their severity at last assessment, the reliability of that assessment, and the time that has passed since the assessment was made. This is a category where the X.5 option really comes in handy, especially if it was a decent amount of time between last assessment and death.

Consensus CDR Assignment

- In recognition of the at-times inconsistent use of the CDR instrument earlier in the study, it was decided that a consensus CDR be adjudicated by the Dementia Review Committee for all DR cases (retrospective and prospective)
- Scores will be added for V1, V2, and the date of last assessment
- Retrospectively, these assignments can be accomplished in batch form for most participants using the following set of rules.
    - CDR score at last assessment will be the same as the "Severity at Last Assessment" data field
    - Any data point (V1, V2, neither, or both) before onset of MCI will receive a CDR score of 0
    - Any data point at or after onset of MCI, but before onset of dementia, will receive a CDR score of 0.5
    - If a data point is coincident with onset of dementia, that data point will receive a CDR of 1
- These retrospective rules have been found to fit a majority of the test cases they were applied to. The most significant minority of cases where this algorithm fails are those in which 1) V2 occurs between dementia onset and date of last assessment and 2) the severity at last assessment is >1. In this case the V2 CDR must be assigned manually.

- Similarly, if the participant has dementia prior to enrollment in the study, V1 and V2 consesnsus CDRs must be manually assigned if the severity at last assessment is >1.

Prospectively, Consensus CDR scores will be applied as a routine part of adjudication. In most cases this determination will follow the same rules as the retrospective cases, and will thus be a trivial addition to the dementia review process. In the less-common case where ambiguity exists in the assignment of a CDR score at one or more of these time points, the appropriate score will be settled on via clinical consensus during the call on which the case is presented, as with any other DR variable.

Developmental Disorder/Parkinson's

- Very rare that a developmental disorder is present; only code Yes if one has been explicitly documented.
- In most cases code 0 = No.
- PD question self-explanatory. If there is mention of resting tremor but no mention of PD, code as D=Don't know.

Stroke

Stroke or TIA

- Code 1 = Yes if there are neurological signs documented (e.g. weakness, paralysis, slurred speech, etc), or evidence on imaging. Very high burden of proof.
- Code 0 = No if there is truly no indication of anything stroke or stroke-like in the summary.
- Code 2 = Possible if a stroke is mentioned on the med history, DQ, etc. but is not clinically documented in terms of neurological signs / imaging. Even if a stroke is reported consistently multiple times across multiple follow ups, or there is a hospitalization explicitly for stroke, or it otherwise seems extremely likely that this person did indeed have a stroke, we code 2=possible.
- Code D = Don't Know if a stroke is mentioned in only one place (either med history but not DQ, or in hospitalizations but not med history, etc). In other words, there is no corroborating information, only a single mention. If there is corroborating information, then it should be coded as 2 = Possible.
- If this is coded as 0 = No, the rest of the stroke questions are coded as N = N/A
- If this is coded as 2 or D, then Clinical Stroke Documented and Focal Neurological Signs should be coded as D. Suggestive temporal profile should either be D or 0; it will most likely be D, only if you have evidence for the **absence of a temporal profile** then it should be 0.

Clinical Stroke Documented

- This is triggered if the participant receives medical help/sees a doctor for a stroke (does not refer only to strokes documented in medical records!). This can only be coded as Yes (code = 1 or 2) if Focal Neurological Signs is coded as 1 = Yes.
- This is not used if a participant "might have had" a stroke, or an informant "thinks they might have had a TIA back in the 90's, maybe?" Clear neurological evidence of a stroke is required.
- Options are mostly self-explanatory. 3 = Terminal Stroke Only is open to some interpretation, but generally refers to a stroke causing an uninterrupted, unequivocal, and fatal decline, whether it lasts 2 weeks or 6 months.
- If "Stroke or TIA" is coded as 2 = Possible, this category is coded D = Don't Know.
- We code here ONLY the number of strokes that we have neurological signs for. For example, the medical history might say the participant has had multiple strokes, but if we only have neurological signs for one stroke you would code 1 = Yes, One Stroke.

Suggestive Temporal Profile

- Parenthetical definition in the box says it all. This question refers to changes in cognition clearly temporally locked to the stroke.
- If a stroke occurs during an already present decline, but does not appear to worsen that decline, this question is coded as 0 = No.

Focal Neurological Signs Suggestive of Stroke

- Parenthetical definition in the box says it all.
- Information usually only available from the DQ stroke section, rarely from medical records, almost never from other sources
- This question is highly important and has flow on effects – it has to be coded as 1=Yes for the "Stroke or TIA" question to be coded as Yes, and the "Clinical Stroke Documented" question to be coded as Yes.

Stroke Documented on Imaging

- Almost always D = Don't Know, even if other stroke variables are available. Only ever available via medical records.

Imaging

- As with stroke imaging, almost never available prior to V3; in the vast majority of cases, all questions about scans will be coded D = Don't Know and all dates will be U = Unavailable.
- If imaging is available, multiple codes can be entered for one instance of imaging if there are multiple non-exclusive diagnoses

The Short Form

Most sections on the short form are identical to sections of the long form and should be treated the same way; instructions that apply to a given section of the long form also apply to the corresponding section of the short form. The exceptions come at the end of the short form and are described below.

"Normal with Concerns" Box/Text Box

- It is helpful to think of this as an "0.25" on the CDR severity scale. This option is coded "1 = Yes" when a participant is probably not cognitively normal but does not meet criteria for MCI. This situation manifests differently for every participant, and as such is difficult to capture in a set of rules; assignment of Normal with Concerns is the result of a clinical consensus decision. Code "0 = No" if the participant is grossly normal.
- If option 1 is selected, the text box below needs to be filled out with a brief description of the test scores/informant reports/other data points causing concern about the participant's cognition. The information in the field should be specifically about where the participant deviates from normal; the reasons for considering the participant normal (despite these concerns) should be left for the Conclusion box.

Conclusion/Notes

- As noted above, this box is intended as a qualitative description of why the participant was judged to be normal. While reference can be made to the reasoning in the Normal with Concerns box (if filled out) or other scores that deviate from normal, the main point of the conclusion is to summarize the reasoning behind the decision to call the participant normal. This can include things like experimenter error (e.g. the participant was flagged due to a faulty CDR score and is otherwise normal), mitigating factors (e.g. a participant's blindness could have contributed to their impairment on visuospatial testing) or simply a lack of convincing evidence (e.g. a sporadic and mild incidence of poor testing performance that could reflect a participant's lifelong cognition rather than any decline). All of the above are intended as examples only; each Conclusion paragraph should be specific to the participant and the consensus discussion about them.