Alzheimer Disease Centers' Guidelines Committee for External Advisory Committee Visits and Progress Reports

(AKA THE MORRIS METRICS)

THIS AD HOC COMMITTEE was formed on August 30, 2017, by Dr. Nina Silverberg and Dr. Cerise Elliott of the Alzheimer Disease Centers (ADCs) Program of the Division of Neuroscience, National Institute on Aging (NIA). The Committee's charge was to identify the basic organization and conduct of an annual External Advisory Committee (EAC) visit to review a particular ADC's progress and plans. This Committee also is charged with recommending the type of information to be presented at an EAC Meeting. It is anticipated that the Committee's recommendations will be useful regarding the content of each ADC's annual Progress Reports that are submitted to the NIA and for the Progress Report/Preliminary Findings section of the Research Plan for new and competing renewal applications for the ADCs. Of note, the Committee's recommendations are meant to be just that — recommendations that are developed in the spirit of enabling effective communication across the Centers Program but in no way are mandatory. Given the diversity across the Centers Program, each ADC can decide whether to incorporate none, some, or all of the recommendations.

Purpose of an ADC

An ADC should "foster research on the nature of Alzheimer disease and related dementias (ADRD) and serve as major sources of development of more effective approaches to prevention, diagnosis, care, and therapy. ADCs are expected to contribute to the development of shared resources that support ADRD-relevant research, collaborate and coordinate their research efforts with other programs and investigators, and disseminate research findings for the benefit of the community". (NIA's NOT-AG-17-016).

Each ADC is required to have an EAC that meets annually to review the ADC's progress toward its stated goals. The EAC's charge is to "evaluate the ADC's programs, research progress, effectiveness of communications within the ADC, interactions with the National Alzheimer's Coordinating Center (NACC), and any other activities for which outside expertise is required or desirable" (RFA-AG-16-018). A member of the NIA extramural program staff traditionally attends the EAC Meetings, either in person or remotely. The EAC's report of its Meeting is sent to the NIA as well as to the ADC Director. (Note: Discretion is permitted regarding the scheduling of EAC Meetings. For example, if an ADC's new budget period begins in May and its EAC typically meets in June, the ADC Director and EAC Chair, in consultation with the NIA, may forego the EAC Meeting that year due to insufficient progress to evaluate. Although the EAC members typically visit the ADC in person, in some circumstances it may be that alternative formats, such as video conferencing, are appropriate.) Generation of the EAC report can be the responsibility of the EAC Chair with review and input by the EAC members. Another approach is for the ADC, often represented by the ADC Director and/or

Administrator, to incorporate the EAC's feedback into a draft report that then is circulated to the EAC Chair and members for review to ensure that it captures the feedback appropriately.

EAC Membership

The EAC should have members with the requisite expertise to evaluate specific components of a particular ADC. In general, this means that the EAC should have at least one expert in the functions of the mandated Cores of an ADC: Administration, Clinical, Data Management and Statistics, Neuropathology, and Outreach, Recruitment, and Engagement. (Note: this last Core transitioned in 2017 from an Outreach, Recruitment, and Education Core to the Outreach, Recruitment, and Engagement Core to accommodate the new Research Education Component, which addresses professional and research education). ADCs with additional non-mandated Cores (e.g., Imaging) also will require one or more experts in that area. An individual EAC member may have experience relevant to more than one Core (e.g., Administration and Clinical).

The Chair of the EAC should be an established leader in ADRD research. Typically, the Chair is a current Director of another ADC. The EAC Chair and the Director of the ADC being reviewed ideally should interact in formulating the agenda for the EAC Meeting. A sample EAC Meeting agenda is provided in Table 1. Both the Chair and the ADC Director are responsible for maintaining the schedule (so that EAC members can attend the entire Meeting and still make their flight connections or other transportation arrangements).

Suggested Content for an EAC Meeting

Given that the EAC's role is to provide a "friendly" evaluation of an ADC's effectiveness and accomplishments (as opposed to the more formal NIA review panel's evaluation of an ADC's initial or renewal application), it is appropriate for an ADC to invite the EAC's advice concerning three general areas:

1) Progress toward stated goals, both for the ADC as a whole as well as for each of its components
2) Current problems encountered by the ADC
3) Current and future plans for the ADC

It may be helpful for the ADC to provide relevant material to the EAC members in advance of the EAC Meeting. Examples of such material could include: 1) for each Core and Component, the Specific Aims pages from the most recent ADC application; 2) the Summary Statement from the most recent ADC application; 3) the most recent NIA Progress Report (particularly Sections B2. Accomplishments) for the ADC; 4) a copy of the Minutes from the most recent EAC Meeting; and 5) specific questions (if any) that the ADC would like the EAC to address concerning any challenges it is facing. These materials and questions usually are developed by the ADC Director and Administrator with input from the ADC as a whole. The Administrator typically plans the Meeting and arranges travel and reimbursement (including honoraria for EAC member, often $500-

$1,000 per Meeting). The ADC may find it beneficial to have a practice session to preview the planned presentations prior to the EAC Meeting.

The EAC can advise an ADC in addressing challenges and problems that are encountered by ADCs. For example, if an ADC might benefit from stronger institutional support, the EAC's report can include a recommendation for such support to provide the ADC with increased leverage with the institutional leadership. The EAC also can advise regarding current and future plans for the ADC, including changes in scientific directions. The ultimate measure of any ADC's success lies in its scientific contributions. Hence, for the reporting period being reviewed by the EAC, the ADC should provide an overview of the key research findings emanating from the Center and the projects it supports. Ideally, the EAC Meeting can include at least brief reports of the scientific progress by relevant ADC faculty and their ADC-supported research projects. New scientific initiatives being considered by the ADC also should be presented for the EAC's input.

Progress Toward Stated Goals

There is no single method to ascertain "progress". Items common to all ADCs (e.g., ability to follow the desired number of active participants in the Clinical Core) help an EAC gauge an ADC's effectiveness, but over-reliance on a checklist approach can obscure other relevant information. For example, recruitment goals for a particular ADC as regards individuals with Alzheimer disease (AD) dementia may not have been met in the previous year because the ADC had instead focused on increased recruitment of individuals with frontotemporal dementia to better meet the needs of investigators using ADC resources. Nonetheless, certain metrics can be useful for an EAC to evaluate "progress toward goals".

A. ADMINISTRATION CORE

1. Demonstrate the "centerness" of the ADC that unites its Cores and investigators with a common vision and purpose. This could include an overarching scientific theme around which the ADC's research is organized, although a central theme is not a requirement for an ADC. Also, "centerness" reflects the cohesiveness and integration of all components of the ADC to enable it to achieve its goals. One simple metric might be how frequently the leaders of the ADC's components meet with the ADC Director and Administrator. Another metric is the concordance of the numbers reported by various ADC components, such as whether the number of deaths and subsequent autopsies reported by the Clinical Core are consistent with those reported by the Neuropathology Core.
2. Demonstrate the value of the ADC to its academic institution. Is the ADC recognized as the program that fosters and facilitates ADRD research at the institution, or would ADRD research at that institution continue successfully if the ADC were to disappear? One example of a metric to demonstrate the value of the ADC to its institution is the number of departments utilizing ADC resources or collaborating with ADC investigators.

3. Describe any changes in the scientific focus of the ADC in comparison with its original stated aims.
4. Discuss leadership changes (if applicable) for any Core or other ADC component and how they were addressed, as well as the addition of any new faculty and their role within the ADC.
5. Review the succession planning for the ADC Director and other key ADC leaders, as applicable.
6. Describe the ADRD research that is supported by the ADC
    a. The number and type of NIH grants, as well as those from other funding agencies, that leverage ADC resources
    b. The number of requests for access to ADC research participants, their data, and their biospecimens for use in investigator-initiated research (see Table 2). Describe the process wherein such requests are evaluated and fulfilled (if approved) and methods for tracking the impact of this resource sharing (e.g., publications, new grants, or assay development).
    c. Scientific productivity as measured by peer-review publications that were directly supported by the ADC; publications that were indirectly supported by the ADC should be listed separately. [Note: "Direct support" typically indicates that ADC resources are integral to the resultant manuscript, whereas "indirect support" applies to the situation where an ADC investigator may be an author on a manuscript but ADC resources were not utilized in the study.] Productivity also includes new grants that are supported by the ADC, research collaborations, and novel assays (see Table 3).
    d. Number of applications for the most recent ADC pilot grant process, including the departments at the ADC's institution represented by the pilot applications. Indicate if additional pilot grants are awarded using funds (e.g., philanthropy) outside of the ADC's NIA funds (see Table 4).
    e. The success of previous pilot grant awardees, as indicated by the ability of the awardee to obtain external funding for the research initiated by the pilot award. Publications that derive from the pilot award also are very useful to cite but the selection by the ADC of applications for pilot grant funding that later secure external funding is the key metric.
7. Describe any operational or financial synergies with other grants, projects, or centers, both inside and outside the institution, and philanthropy directed to the ADC. The NIA award for an ADC may not cover all of the costs necessary to fulfill its full research mission, including the conduct of federally funded clinical trials or other programs that do not fully reimburse the attendant costs, so it is increasingly important to demonstrate institutional support (including philanthropic support) that enables the ADC to optimally function.

8. If the ADC is within a year or so of its deadline for submission of its renewal application, the plans (to the extent that they are developed) for the renewal should be presented to the EAC.

9. The ADC should describe how it has responded to the EAC's recommendations from previous meetings.

B. CLINICAL CORE

1. The Clinical Core and its cohort(s) are the quintessential components of an ADC. The EAC agenda should allot sufficient time (i.e., more than for other ADC components) for the presentation and discussion of the Clinical Core and its "bread and butter" functions.

2. In general, the cohort should reflect the diversity that characterizes the population served by the ADC. The size and characteristics of the cohort(s) should be justified by the science that the cohort supports. For example, should an ADC support studies that examine the interaction of cerebrovascular disease and neurodegeneration, the individuals in the cohort should be enriched with cardiovascular risk factors. Alternatively, if investigators at a particular ADC are examining aspects of preclinical AD (i.e., cognitively normal individuals who are positive for one or more molecular biomarkers of AD), then the cohort may recruit and follow a disproportionately high percentage of cognitively normal older adults compared with persons with symptomatic AD. A focus on preclinical AD also implies that the participants in the cohort are both eligible for and willing to complete lumbar puncture (LP) (to obtain cerebrospinal fluid [CSF]) and/or positron emission tomography (PET) using tracers for amyloid and/or tau so that their biomarker status can be characterized. In this way, the research studies supported by the ADC determine the composition of the Clinical Core cohort(s). It is preferable that the ADC establish its scientific theme(s) prior to recruiting its cohort. Themes may evolve over time and, if so, the cohort will need to evolve as well to address the new directions.

   Regarding cohort size, ideally the number of cognitively normal and symptomatic participants should be sufficient to allow the specific aims of the projects utilizing the cohort to be addressed as determined by power calculations. This stipulation extends to under-represented groups (URGs) included in the cohort. (The specific URGs included in the Core's cohort largely depend on the demographics of the ADC's catchment area; for example, in some regions of California the dominant URG may be Latino but in others it may be Asian or African American. In any event, sufficient numbers of individuals from the URG should be included to permit comparative analyses). Because the Clinical Core budget is finite, enrolling and following an adequate number of participants may mean that the Core can only follow one symptomatic group (e.g., AD dementia) rather than to try to follow participants across a range of dementing disorders. The decisions the Core

makes in regard to the size and composition of the cohort should be made clear to the EAC. Describe the demographic and clinical characteristics of the active cohort (i.e., all participants who are being scheduled for baseline and follow-up assessments) to ensure that those characteristics are "matched" across clinical groups (e.g., show that cognitively normal controls are roughly equivalent in age to affected individuals) (see Tables 5a and 5b).

Finally, differentiate and describe any additional cohort(s) beyond the active Clinical Core cohort. The Clinical Core cohort represents individuals who are followed longitudinally with Uniform Data Set (UDS) protocol and whose data are submitted to NACC, but ADCs may follow select individuals whose data are not assessed with the UDS and/or are not submitted to NACC. Collaborations with other ADCs and with non-ADC programs that address ADRD also should be described.

3. The Core should describe to the EAC the characteristics of the recruitable pool of potential participants and those who already are enrolled (e.g., geographical area; recruitment from the community or from a clinic) as well as the sites where participants are accessioned and followed. Consider possible biases or problems these pools may introduce into the cohort (e.g., may be difficult to recruit cognitively normal participants from a memory disorders clinic). Describe the recruitment strategies, as developed by the Core and other ADC components (e.g., Outreach, Recruitment, and Engagement Core) with special consideration on individuals from URGs. Beyond the UDS, any other assessment instruments should be described as well as the data collection methods. Describe how the data flow into the central database, as well as the efforts made by the Core to ensure the quality and consistency of the data across Core clinicians and staff (e.g., training and certification procedures for new faculty and staff, consensus conferences, clinicopathological case reviews, etc.)

4. Describe the process for seeking autopsy consent, both antemortem and at time of death. Provide the true autopsy rate (number of autopsies divided by number of deaths of all ADC participants, not simply those who preconsented for autopsy) over a relevant timeframe (see Table 6). Ensure that these numbers correspond with what is being reported in the Neuropathology Core.

5. Provide information as to how participant burden is monitored and addressed. One relevant metric may be the "completion rate": the number of active participants who complete specific components of the assessment protocol (e.g., annual UDS clinical and cognitive assessments; structural brain imaging; amyloid PET scan) divided by the number of active participants who are eligible for that component (e.g., the individual is due for his/her annual UDS assessment) (see Table 7). Discuss whether completion rates vary by participant subgroup. For example, do individuals from URGs in the cohort complete biomarker studies, participate

in clinical trials, and have similar autopsy rates as non-Hispanic whites? A related metric is the attrition rate, which is the percentage of individuals in the cohort who had at a minimum a baseline UDS assessment but no longer participate in the ADC assessment protocol (the main reasons for attrition are refusal, relocation, and death). Describe plans to address remediable factors that contribute to less than optimal completion and attrition rates.

6. The productivity noted in Administration Core above for the ADC as a whole can be expressed in Core-specific terms: how many peer-review publications and research projects use Core data and how many investigator requests does the Core support? How many funded research projects developed from studies using Core resources? If the Core is involved in clinical trials, the recruitment, enrollment, and retention information should be provided for the specific trials being supported by the Core.
7. If applicable, describe how consent for LP, neuroimaging, and other biomarker procedures is accomplished and how these procedures accommodate special circumstances, such as may be encountered in URGs.

C. DATA MANAGEMENT AND STATISTICS (DMS) CORE

1. Discuss the database structure, describing the data input and outflow from the Cores and projects. Describe the quality control procedures for the data.
2. Discuss rules for accessibility to the data.
3. Demonstrate that Core members are integrated into study design and data monitoring of projects, not simply given the data for analysis at study conclusion. The involvement of Core members from the outset of a project results in sounder and more statistically appropriate studies and also allows statisticians to become familiar with the scientific rationale and with the methodology of the study. Investigators should seek the statisticians' input and adopt their recommended rigorous statistical approaches to ensure unbiased scientific conclusions. One metric for the degree to which DMS personnel are involved in the design and conduct of studies is their inclusion as authors/co-authors for resulting publications.
4. Is there sufficient time and effort provided to database managers, programmers, Information Technology specialists, and faculty statisticians and their support staff (e.g., masters level statistical data analysts; students) for the work involved?
5. Promote methodological development by the statisticians that results in new or improved analytic approaches and that also advance their academic careers.
6. Describe audit trail procedures to record changes or corrections of data submitted to the DMS Core (and eventually to NACC).
7. Discuss how the DMS Core interacts with other Cores to promote ADC functions,

such as the recruitment and retention of participants and tracking of research visits (see E. below).

D. NEUROPATHOLOGY CORE

1. Report the number of brain or whole body autopsies versus the number of deaths in individuals who have one or more ADC assessments in the Clinical Core.
2. Report the number of brain or whole body autopsies from sources other than the Clinical Core and justify why such autopsies were accepted, including an assessment of the accompanying clinical data.
3. Be prepared to report on the protocol for dissection, tissue blocks obtained, and staining. Describe whether both frozen and fixed tissues, as well as postmortem CSF, are available from these cases.
4. Provide some indicator of the quality of the postmortem brain tissue as regards molecular studies. Although no metric is perfect, commonly used indicators include postmortem interval, the RNA Integrity Number (RIN), and tissue pH.
5. Provide clinicopathological correlations for the brain autopsies using consensus neuropathologic guidelines. For example, for all ADC participants who came to autopsy and were diagnosed with AD dementia during life, how many had intermediate or high neuropathologic AD change? To aid in the clinical diagnostic process, some ADCs conduct a retrospective dementia interview (essentially, the Informant component of the UDS clinical assessment) with a family member shortly after the participant's death to capture any relevant diagnostic information that may have developed in the participant after their final ADC evaluation. (Note: Such information may be presented in the Clinical Core)
6. Describe the specimen inventory process and database that tracks specimen input and output from the Core and to whom specimens are provided. Describe the number of requests for biospecimens and by whom, as well as indicating whether resources are sufficient to meet the needs of investigators. Indicate what cost recovery mechanisms are used when ADC resources are insufficient. Ideally, link the provided specimens to resulting publications, funded research, and collaborations.
7. Describe the process by which the Core (most often in conjunction with the Clinical Core) provides a report of the neuropathologic evaluation to the next-of-kin of the decedent, and include the mean turn-around time for report generation.

E. OUTREACH, RECRUITMENT, AND ENGAGEMENT (ORE) CORE

1. Describe the planning and outreach methods for the successful recruitment of participants into the Clinical Core. Similarly, describe retention efforts for

ADC participants. Describe the coordination of the ORE Core's recruitment activities with other relevant Cores, such as the Clinical Core and the DMS Core. For example, the DMS Core can provide a potential sampling frame and/or statistical sampling plan that can guide recruitment strategies. Finally, detail how recruitment and retention efforts are tailored to engage individuals from URGs.

2. Demonstrate the effectiveness of the ORE Core's outreach and recruitment efforts, and discuss how the Core self-evaluates whether a given approach should be discontinued if it is ineffective. If there are collaborative efforts with other programs at the ADC's institution (e.g., Older Americans Independence Center; Resource Center for Minority Aging Research) or other ADCs regarding outreach, recruitment, and retention of participants, or with educational efforts about ADRD for lay audiences, describe them here.
3. Describe the efforts used to encourage participation and retention in biomarker studies (e.g. PET imaging; LP) and autopsy programs.
4. Describe the programming and educational activities for lay audiences, including caregivers. Include the Core's interactions with the local chapter of the Alzheimer Association and other relevant organizations.
5. Describe special programs and efforts to engage participants, including those from URGs, in biomarker and brain autopsy protocols.

F. RESEARCH EDUCATION COMPONENT

1. Describe professional education and training activities that are aimed at developing the future research workforce that will address ADRD, and indicate the professional backgrounds of the trainees to include MDs (e.g., neurologists, neuropathologists, psychiatrists, geriatricians), PhDs (e.g., neuropsychologists, neuroscientists), nurses, and social workers. Review the mentoring program that will support the professional development and advancement of postdoctoral fellows and early-stage faculty.
2. Summarize any multi-disciplinary curricula with structural didactic training to support the career development of early-stage faculty who focus on ADRD.
3. Describe efforts to engage in ADRD research those trainees who are women and/ or are from URGs and to develop and promote these individuals into academic leadership positions, including in ADRD research.
4. Outline evaluation programs to assess the effectiveness of the training and mentoring initiatives, including benchmarks for trainee competency, skills acquisition, research collaborations, presentations, publications, and successful grant applications.

G. IMAGING CORE *(optional; the metrics below are provided as an example that may be appropriately modified to address other optional Cores, such as Genetics or Biomarkers)*

1. Describe which imaging modalities are obtained and detail how well the ADC meets its Imaging Core recruitment goals.
2. Describe how the Core and its Aims integrate with the goals of the ADC as a whole and discuss the Core's interactions with the other ADC Cores and its supported research programs. Similarly, describe the correlative studies of the Core with biofluid, genetic, neuropathological, and other initiatives.
3. Indicate whether Core data are integrated into Clinical Core assessments and also discuss whether and how feedback about individual imaging results are provided to participants.
4. Detail the collaborations of the Core with other projects at the ADC's institution and beyond to indicate whether non-ADC protocols use Core data. Describe how investigators external to the ADC request and obtain Core data.
5. Describe whether Core images are shared with NACC and, if not, whether there are plans for future sharing.
6. Describe policies and methods for access to raw images and processing pipelines and how processed imaging data are integrated into the ADC database.

RESPECTFULLY SUBMITTED on November 30, 2017

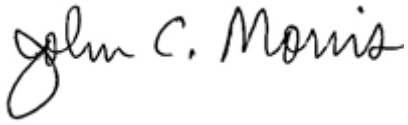

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Table 1. Sample Agenda for Alzheimer Disease Research Center (ADC)
External Advisory Committee (EAC) Meeting
Month/Date/Year

EAC members in attendance: Name/institution; Chair; names/institutions of remaining members. Indicate if any member participates remotely (e.g., by telephone)

National Institute on Aging (NIA) representatives: Names/positions; indicate if these representatives participate remotely (e.g., by telephone). If a NIA representative participates remotely, often it is for the Executive and Feedback sessions (see below).

AGENDA

		ADC Core Leader (name)	**Presenter** (name)
7:30 am	Breakfast		
8:00 am	Welcome and Introductions[1]	ADC Director	
8:05 am	Overview of ADC; Administration Core	ADC Director	
8:25 am	Clinical Core[2]		
9:00 am	Neuropathology Core[3]		
9:20 am	Data Management and Statistics Core		
9:40 am	Outreach, Recruitment, Education Core		
10:00 am	Break		
10:20 am	Research Education Component		
10:40am	Any optional Core(s) (e.g., Imaging)		
11:00am	Research progress supported by the ADC		
11:30am	General Discussion (e.g.,specific issues that the ADC wishes the EAC to address; new Aims; renewal preparation)		
12:00 pm	Executive Session/working lunch (for EAC members only); NIA may join by telephone		
1:00 pm	Feedback of EAC to ADC Leadership[4]		
2:00 pm	Departures		

Caveat: Each ADC is unique. This Sample Agenda and the subsequent Tables are provided only as guides; each ADC should tailor the EAC Agenda and Tables to meet their needs.

1. Institutional support can be demonstrated when institutional leaders (e.g., Dean of the School of Medicine; Chair of the Department where the ADC is administered) attend at least the Welcome remarks.
2. The Clinical Core should be allotted more time than the other ADC components.
3. In general, each Core presentation (other than Clinical Core) should be for 10 minutes (with 10 or fewer slides), leaving 10 minutes for questions and discussion. If the ADC provides its EAC members with a copy of its most recent Progress Report prior to the Meeting, there is no need to reproduce these Specific Aims with a slide.
4. At a minimum, the ADC Director and Administrator should receive the EAC's verbal feedback. Other ADC leaders may also attend at the discretion of the EAC Chair and the ADC Director.

Final Note: It may be helpful for an ADC to designate one or more scribes who attend and record the entire EAC Meeting (including the Feedback Session). The notes of the scribes may be helpful to the ADC leadership in appreciating the EAC's comments during the Feedback Session. For example, a particular EAC recommendation may have its origin in the questions and discussion that occurred during that component's presentation. In the instance that an ADC prepares the draft of the EAC report, the scribe's notes can be invaluable.

Table 2. Data Sharing for (Reporting Period)

Request Type \ Funding source	Federal	Non-federal	Industry	Total
Data Only (including APOE and Imaging)				
Tissue (including DNA, CSF, fibroblasts, and brain)				
Participant Requests				
Total				

Table 3. ADC Productivity During (Reporting Period)

- XX center-supported publications
- YY studies supported with data, tissue or participants
- ZZ trainees on K awards or other training grants
- XYZ continuing multi-site collaborations (NACC, NCRAD, ADCS, ATRI, ADNI, LOAD, ADGC, GAP, IDEAS)
- Other collaborations
- Externally funded grant awards

Table 4. ADC Pilot Grant Program for (Reporting Period)

- XX applications from YY departments: Genetics, Neurology, Psychiatry, Biomedical Engineering, etc
- List each Pilot Grant #, name/degree/department of awardee, and Pilot Grant title for each application selected for funding by the ADC's Executive Committee
  - Indicate if any Pilots are being funded with resources other than the ADC budget

Table 5a. ADC Active Cohort (N = XXX)

	CDR 0 N=	**CDR 0.5** N=	**CDR 1** N=
Age (y)			
Education (y)			
Male (%)			
African American (%)			
MMSE			
% with *APOE4* allele			

Note: Other variables may be incorporated; for example, some ADCs may wish to replace the MMSE with the MoCA. Also, the summary statistics may include the clinical diagnoses of individuals who are cognitively impaired (see Table 5b).

Table 5b. ADC Active Cohort (N = XXX)

Disorder/Syndrome (D1)	N=
MCI	
Amnestic dementia	
PCA	
PPA	
bvFTD	
DLB	
Nonamnestic multidomain	
Other	

Etiology (D1)	N=
AD	
LBD	
MSA	
PSP	
CBD	
FTLD-MND	
FTLD-NOS	
Vascular	

Note: Data can be pulled from NACC Form D1

Table 6. Autopsy Rate (Reporting Period)

- ADC Participants (everyone with one or more ADC clinical assessment)
  - XX autopsies in YY deaths; XX/YY = ZZ%

Table 7. ADC Participation in Study Procedures

(ever in active participants)

	2015	2016	2017
Amyloid PET imaging			
CSF			
MRI			
Blood for Genetics			

Note: If other biomarkers variables are obtained by the ADC, they also should be included (eg, tau PET imaging; fibroblast collection for generation of induced pluripotent stem cells, etc).