

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

This document's purpose is to identify the basic organization and conduct of an annual External Advisory Committee (EAC) visit to review a particular Alzheimer Disease Research Centers (ADRCs) progress and plans.

These guidelines are developed in the spirit of enabling effective communication across the Centers Program and in no way are mandatory. Given the diversity across the Centers Program, each ADRC can decide whether to incorporate none, some, or all the guidelines.

Purpose of an ADRC EAC

Each ADRC is required to have an EAC that meets annually to review the ADRC's progress toward its stated goals. The EACs charge is to "conduct and provide annual evaluations of the programs of the ADRC, research sharing and progress, the effectiveness of communications within and outside of the ADRC, interactions with National Alzheimer's Coordinating Center (NACC), National Central Repository for Alzheimer's Disease and Related Dementias (NCRAD), and Standardized Centralized Alzheimer's and Related Dementias Neuroimaging (SCAN) at Laboratory of NeuroImaging (LONI), and any other activities for which outside expertise is required or desirable." ([RFA-AG-24-001](#)).

EAC Membership

The EAC should have members with the requisite expertise to evaluate specific components of a particular ADRC. In general, this means that the EAC should have at least one expert in the functions of the mandated 7 Components of an ADRC: Administration, Clinical, Data Management and Statistics, Neuropathology, Outreach, Recruitment, and Engagement (ORE), Biomarker, and Research Education Component. ADRCs with additional non-mandated Cores 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). Typically, Centers have between 5 and 9 EAC members. Committee members are not allowed to be reviewers of the competitive application.

The Chair of the EAC should be an established leader in ADRC research. Typically, the Chair is a current Director of another ADRC. The EAC Chair and the Director of the ADRC being reviewed ideally should interact in formulating the agenda for the EAC Meeting. A member of the NIA extramural program staff should be invited to each EAC Meeting. It is acceptable to have ad hoc EAC members for particular purposes. Changes in standing membership should be discussed with the NIA program officer.

The EAC meeting may be conducted either in person or remotely, but in person is preferred. In certain circumstances, like mid-cycle assessments, a shorter remote or hybrid EAC might be more

suitable. In the remote format, presentations can be pre-recorded and shared with the EAC beforehand, along with pertinent background information. This ensures a well-prepared and comprehensive evaluation process with more time for discussion.

Suggested Content for an EAC Meeting

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

- Progress toward stated goals, both for the ADRC as well as for each of its components
- Current challenges encountered by the ADRC (e.g., institutional support)
- Current and future plans for the ADRC (e.g., changes in scientific direction)

The ultimate measure of any ADRC's success lies in its scientific contributions. Hence, for the reporting period being reviewed by the EAC, the ADRC should provide an overview of the key research findings emanating from the Center and the research it supports. Ideally, the EAC Meeting can include at least brief reports of the scientific progress by relevant ADRC faculty and their ADRC-supported research projects as well as REC scholars or developmental project recipients.

Progress Toward Stated Goals

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

Nonetheless, certain metrics can be useful for an EAC to evaluate "progress toward goals".

Meeting Preparation

Options for organization of the meeting: a full-day session (with dinner at the end) or two half-day sessions (with a break for dinner and an early morning start). When planning the agenda, dedicated specific slots for discussions should be scheduled. Each Core should have the opportunity to present their work and have time for questions from the EAC. It's essential to allocate more time for the Clinical Core, recognizing its potential need for more extensive discussion. To accommodate potential overruns, incorporate "buffer time" in longer breaks.. However, if the Center is addressing a mission-critical issue, a different approach may be necessary, such as discussing the primary "meta" issue together while providing "bread and butter" details for each Core in advance, possibly through recorded presentations. The conclusion of the EAC meeting should allow private discussions between the EAC members and NIA Program staff, followed by feedback sessions for the ADRC Director and leadership.

A sample EAC Meeting agenda is provided in Table 1. Both the Chair and the ADRC Director and Administrator 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).

Once a date and meeting format is chosen, meeting materials and questions should be developed by the ADRC Director and Administrator with input from the ADRC as a whole. ADRCs should plan accordingly so that the EAC report is received in time and included in the RPPR. Plan to allocate 30-60 days to provide sufficient time for the EAC to compile and finalize the report. The Administrator typically plans the Meeting and arranges travel and reimbursement (including honoraria for each EAC member, often \$500-\$1,000 per Meeting). Each Center decides the amount of the honorarium and if they will provide different amounts for remote vs in person meetings.

The ADRC should provide relevant material to the EAC members and NIA Program Officers in advance of the EAC Meeting. Examples of such material could include:

1. Meeting Agenda – ample time should be provided for discussion; most EAC meetings run behind schedule.
2. The PowerPoint slides decks that will be presented. In general, each Core presentation (other than Clinical Core) should be for 10 minutes (with 10 or fewer slides) and should include the Core's Specific Aims.
3. NIA Summary Statement from the most recent ADRC application.
4. The most recent NIA Progress Report (particularly Sections B2. Accomplishments) for the ADRC.
5. The prior year's EAC report (including listing all EAC members) with a response to their recommendations. Ensure that the last year recommendations by the EAC have been specifically addressed.
6. Specific questions (if any) that the ADRC would like the EAC to address concerning any challenges it is facing; and Specific questions/issues that the Center would like to be discussed during the meeting. The EAC's role is that of a "friendly" reviewer so be straightforward about progress towards stated goals, current challenges, and future plans. Overall goal should be to get constructive feedback. Having these questions in advance helps to achieve that goal.
7. Biosketches of any new key personnel proposed to be added.

The ADRC may find it beneficial to have a practice session to preview the planned presentations prior to the EAC Meeting.

A. Administrative Core

1. Demonstrate the "centeredness" of the ADRC that unites its Cores and investigators with a common vision and purpose. This should include an overarching scientific

- theme around which the ADRC’s research is organized. Also, “centeredness” reflects the cohesiveness and integration of all components of the ADRC to enable it to achieve its goals. This can be demonstrated, e.g., by stating how frequently the leaders of the ADRC’s components meet with the ADRC Director and Administrator, or by the concordance of the numbers reported by various ADRC 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 ADRC to its academic institution through institutional commitment. Centers often ask their Dean or Provost to attend and discuss the importance of the ADRC. Is the ADRC recognized as the program that fosters and facilitates ADRC research at the institution, or would ADRC research at that institution continue successfully if the ADRC were to disappear? Sample metric: the number of departments utilizing ADRC resources or collaborating with ADRC investigators.
 3. Describe any changes in the scientific focus of the ADRC in comparison with its original stated aims.
 4. Discuss leadership changes (if applicable) for any Core or other ADRC component and how they were addressed, as well as the addition of any new faculty and their role within the ADRC.
 5. Review the succession planning for the ADRC Director and other key ADRC leaders, as applicable.
 6. Describe any changes to the ADRC website and how it has facilitated awareness among the public as well as researchers about the resources available at the ADRC.
 7. Summarize the ADRC research that is supported by the ADRC:
 - a. The number and type of NIH grants, as well as those from other funding agencies, which leverage ADRC resources.
 - b. The number of requests for access to ADRC 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 ADRC; publications that were indirectly supported by the ADRC should be listed separately. [Note: “Direct support” typically indicates that ADRC resources are integral to the resultant manuscript, whereas “indirect support” applies to the situation where an ADRC investigator may be an author on a manuscript, but ADRC resources were not utilized in the study.] Productivity also includes new grants that are supported by the ADRC, research collaborations, and novel assays (see Table 3).

- d. Number of applications for the most recent ADRC Developmental Project selection process. Indicate if additional pilot grants are awarded using funds (e.g., philanthropy) outside of the ADRC's NIA funds (see Table 4).
 - e. Development Project review process and next batch of projects proposed, Center-level collaborations with other studies/entities/etc.; success of previous developmental projects, as indicated by the ability of the awardee to obtain external funding for the research initiated by the developmental project. Publications that derive from the project also are very useful to cite.
8. Describe any operational or financial synergies with other grants, projects, or centers, both inside and outside the institution, and philanthropy directed to the ADRC. The NIA award for an ADRC 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 ADRC to optimally function.
 9. If the ADRC 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.
 10. The ADRC should describe how it has responded to the EAC's recommendations from previous meetings.
 11. Report any major findings coming out of the ADRC research and any local or national media attention.

B. Clinical Core

1. The Clinical Core and its cohort(s) are the central components of an ADRC. The EAC agenda should allot sufficient time (i.e., more than for other ADRC 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 ADRC. The size and characteristics of the cohort(s) should be justified by the science that the cohort supports. For example, if an ADRC focuses on 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 ADRC 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. It is preferable that the ADRC 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.

Number of ATN characterized participants in the cohort, and the method used (e.g., CSF, imaging). Describe how your Center determines ATN and if it is updated at different time points when new data is acquired. Similarly, additional biomarkers collected by the ADRC should reflect the theme of the center as well as interests and needs of the research that leverages the resources of the center.

Describe how sufficient numbers of individuals from the focus URG(s) are included to permit comparative analyses. The goals of the Core regarding the size and composition (URG, stage of disease, risk factors) of the cohort should be made clear to the EAC as well as which biomarkers are to be collected from which participants. 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 the characteristics and usage of the **registry** as well as any **additional cohort(s)** beyond the active Clinical Core cohort (i.e., individuals who are followed longitudinally with Uniform Data Set (UDS) protocol and whose data are submitted to NACC). Collaborations with other ADRCs and with non-ADRC programs that address ADRC also should be described.

3. The Core should describe to the EAC the characteristics of the catchment area and recruitment sources, 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 ADRC components (e.g., Outreach, Recruitment, and Engagement Core) with special consideration of individuals from URGs. Beyond the UDS, any changes in other (non-UDS) 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 status of and any changes to 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 ADRC participants, not simply those who gave provisional consent 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, participant 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 ADRC assessment protocol (the main reasons for attrition are refusal, relocation, and death). Describe plans to identify and address remediable factors that contribute to less-than-optimal completion and attrition rates.

6. The productivity noted in Administration Core above for the ADRC can be expressed in Core-specific terms: how many peer-reviewed 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 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.
4. Demonstrate that DMS personnel are involved in the design and conduct of studies by summarizing their inclusion as authors/co-authors for resulting publications.
5. Demonstrate there is 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.

6. Promote methodological development by the statisticians that results in new or improved analytic approaches and that also advance their academic careers.
7. Describe audit trail procedures to record changes or corrections of data submitted to the DMS Core (and eventually to NACC).
8. Discuss how the DMS Core interacts with other Cores to promote ADRC functions, such as the recruitment and retention of participants and tracking of research visits (see E. below).
9. Describe projects supported by DMS statisticians and support for trainees.
10. Address any needs/questions from the DMS core team for the EAC.

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 ADRC 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. Describe and justify any changes.
4. Provide indicators of the quality of the postmortem brain tissue as regards molecular studies such as 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 ADRC 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 ADRCs 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 ADRC 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 ADRC 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 and retention of participants into the Clinical Core. 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 and how they fit with the needs of the researchers utilizing resources of the ADRC.
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. Describe any collaborative efforts with other programs at the ADRC's institution (e.g., Older Americans Independence Center; Resource Center for Minority Aging Research) or other ADRCs regarding outreach, recruitment, and retention of participants, or with educational efforts about ADRC for lay audiences.
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.
6. Describe the process for evaluating outreach/engagement programs, which may include evaluating metrics related to the total number of participants, feedback forms, number of participants who sign up to receive information or to be contacted by the Center, pre-post event assessments, etc.
7. Describe where efforts & resources are focused (particularly for URGs).
8. Describe the creation of a community advisory board (CAB) and/or participant advisory board (PAB), how members are selected, their role in developing and addressing research questions, frequency of meetings, and how they will facilitate communication of findings and opportunities with the community. Links to webinars are on the NACC ADRC Resources website – <https://nacccdata.org/adrc-resources/adrc-webinars>

F. Biomarker Core

1. Describe which biomarkers are obtained and detail how well the ADRC meets its Biomarker Core recruitment goals.

2. Describe how the Core and its Aims integrate with the goals of the ADRC as a whole and discuss the Core's interactions with the other ADRC 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 discuss whether and how **feedback about individual results** are provided to participants.
4. Detail the collaborations of the Core with other projects at the ADRC's institution and beyond to indicate whether non-ADRC protocols use Core data. Describe how investigators external to the ADRC request and obtain Core data and samples.
5. Describe whether Core biomarker data are shared with national initiatives (e.g., NCRAD, SCAN) and in which participants by demographics and diagnosis. If not, whether there are plans for future sharing and any perceived obstacles.

G. Research Education Component (REC)

1. Describe the selection process for REC scholars.
2. Describe 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, e.g., 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.
3. Summarize any multi-disciplinary curricula with structural didactic training to support the career development of early-stage faculty who focus on ADRD.
4. 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.
5. 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.

EAC Committee Reporting

The EAC's report is a required part of the Center's annual Progress Report (RPPR), which is submitted to NIA. Typically, the Center Director & Administrator collaborate to draft the initial version of the report, drawing from comprehensive notes, which is then sent for review and edits by the EAC. The EAC Chair takes responsibility for signing the final report, which is then forwarded to the ADRC Director (cc Administrator) ahead of the RPPR deadline.

Sample Agenda and Tables

**Table 1. Sample Agenda for Alzheimer Disease Research Center (ADRC)
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.

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

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

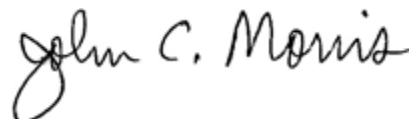
Caveat: Each ADRC is unique. This Sample Agenda and the subsequent Tables are provided only as guides; each ADRC should tailor the EAC Agenda and Tables to meet their needs.

1. Institutional support can be demonstrated when institutional leaders (e.g., Provost; Dean of the School of Medicine; Chair of the Department where the ADRC is administered) attend at least the Welcome remarks.
2. The Clinical Core should be allotted more time than the other ADRC components.
3. In general, each Core presentation (other than Clinical Core) should be for 10 minutes (with ten or fewer slides), leaving 10 minutes for questions and discussion.
4. At a minimum, the ADRC Director and Administrator should receive the EAC's verbal feedback. Other ADRC leaders may also attend at the discretion of the EAC Chair and the ADRC Director.

Suggestion: Provide "buffer time" as meetings always tend to run over time

Final Note: It may be helpful for an ADRC 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 ADRC 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 ADRC prepares the draft of the EAC report, the scribe's notes can be invaluable.

Originally submitted on November 30, 2017



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Chair, EAC Guidelines Committee

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Updated by 2021-2022 Administrator Steering Committee members on August 1, 2023

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Table 3: ADRC 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, LONI, ADCS, ATRI, ADNI, LOAD, ADGC, GAP, IDEAS, SCAN, CLARITI)
AA	Other Collaborations
BB	Externally funded grant awards

Table 4: ADRC Developmental Projects for (Reporting Period)

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

Table 2. Data Sharing for (Reporting Period)

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

Table 5a: ADRC Active Cohort (N = XXX)

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

Note: Other variables may be incorporated; for example, active longitudinal cohort participants with blood draws completed / bio banked. Also, the summary statistics may include the clinical diagnoses of individuals who are cognitively impaired (see Table 5b).

Table 5b: ADRC Active Cohort (N = XXX)

Disorder/Syndrome (D1)	N=	Etiology (D1)	N=
MCI		AD	
Amnesic dementia		LBD	
PCA		MSA	
PPA		PSP	
bvFTD		CBD	
DLB		FTLD-MND	
Nonamnesic multidomain		FTLD-NOS	
Other		Vascular	

Note: Data can be pulled from NACC Form D1

Table 6: Autopsy Rate (Reporting Period)

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

Table 7: ADRC Participation in Study Procedures (ever in active participants)

	Y1	Y2	Y3
Amyloid PET Imaging			
CSF			
MRI			
Blood for Genetics			

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