Dementia DataHub

Annual One-Year Research Pilot Awards

Request for Proposals – Year 2 Cycle

Posted July 10, 2026

The Dementia DataHub

The **Dementia DataHub** (DDH, dementiadatahub.org) is the first interactive, open data interface to provide national, state, and county-level dementia surveillance for the U.S. Built with funding from the National Institute on Aging (R01 AG075730) and launched in September 2024, the DDH reports statistics on diagnosed prevalence, incidence, and related health outcomes and costs among Medicare beneficiaries. The system serves researchers, policymakers, public health professionals, advocacy organizations, and the public.

Purpose and Scope

Over 5 million Medicare beneficiaries have a documented diagnosis of Alzheimer's Disease or Related Dementias, with millions more who may have dementia but lack a diagnosis in their claims record. The DDH was created to make this information visible, accessible, and useful. Surveillance data only realizes its value when researchers use it to ask questions that improve our understanding of the health condition and the systems that serve people living with it.

These pilot awards (up to $40,000 total costs), supported through R33AG094611, exist to support that next step. We are looking for early-stage investigators and nontraditional researchers with well-defined questions grounded in the DDH's public use data. Some projects will be answerable using public use files (PUFs) themselves (described below in *Available Data Sources*). Others will use analyses of the PUF files to develop testable questions that require restricted Medicare claims. Both approaches are equally appropriate for this mechanism. The strongest proposals will answer a focused question well in one year, not attempt a broad survey of everything data might reveal.

Is This For You?

If you have a research question about dementia that could be informed by county-level surveillance data or Medicare claims, and you can complete a focused project in one year, this mechanism was designed for you. We provide the data access, programming support, and technical guidance. You provide the question.

A pilot award is also an opportunity to develop preliminary findings and demonstrate feasibility for a larger independent grant application, such as an NIH R21 or R03, using DDH data. We encourage applicants to think of this mechanism as a standalone project and a foundation for future funded research.

Public health professionals who want to use DDH data to inform state or local planning, policy, or programming are encouraged to apply. Your proposal does not need to follow an academic research framework; simply describe your question, your approach, and what you will produce.

Out of scope. Projects that do not engage with DDH public use files or the surveillance mission of the system are not appropriate for this mechanism. Unfocused exploratory analyses that test

large numbers of associations without a theoretical framework will not be competitive. Projects requiring sophisticated statistical modeling or machine learning to be executed inside the CMS Virtual Research Data Center (VRDC) are unlikely to be feasible within available resources (see *Available Data Resources* below for details on what VRDC programming can support). Projects requiring primary data collection, clinical trials, or data sources not held by the DDH are not eligible. Projects designed to influence legislation or support lobbying activities are not eligible for funding under this mechanism; applicants proposing policy-oriented deliverables should ensure compliance with NIH lobbying guidance for awardees.

Applicants should understand that DDH data reflect *diagnosed* dementia in Medicare claims, which differs from true dementia prevalence in the population. Rates of diagnosis given the same symptoms almost certainly vary by place, demographics, and time. A competitive application will grapple with this distinction and its implications for the proposed research. For more information, see Case Definitions and Outcome Measure Definitions on the DDH website.

Applicants are encouraged to consider how their proposed research aligns with NIA's Unified Strategy for Advancing NIH's Mission and the AD/ADRD Research Implementation Milestones. While alignment with these priorities is not a formal scoring criterion, NIA retains final approval of all funded projects and will consider alignment with current research priorities in that determination.

Process and Key Dates

Request for Proposals Release: **July 10, 2026**

Pilot Applications Due: **September 28, 2026**, by 5pm Eastern Time

Question deadline: **July 24, 2026**

> Questions should be submitted to dementiadatahub@norc.org.

Nonbinding Letter of Intent Due: **August 14, 2026**

> Prospective applicants are encouraged (but not required) to submit a brief letter of intent by August 14, 2026 to dementiadatahub@norc.org. The letter should include the applicant's name, institutional affiliation, and a brief description (one paragraph) of the proposed research topic. Letters of intent are nonbinding and will not be used in the review process. They help us anticipate the number of submissions and allow us to provide early feedback to applicants whose proposed topics may fall outside the scope of this mechanism.

Application requirements:

1. **Cover page** with name, affiliation, project title, contact information, disclosures, and a brief statement describing how the proposed research relates to Alzheimer's Disease and Alzheimer's Disease-Related Dementias (AD/ADRD)
2. **Research Plan** Up to 3 pages, single-spaced, excluding references; 11-pt. Arial font, minimum 0.5" margins on all sides. See Suggested Research Plan Outline below.
3. **Biographical Sketch** for all investigators, using the latest Common Form and Supplement (see instructions)
4. **Mentor Letter** (required for students and post-doctoral researchers; see Eligibility)
5. **Budget and Justification** (1-page summary; see Budget Requirements)
6. **Proposed Milestone Schedule** (1 page; adapt the standard schedule below to your project)

7. **Technical Appendix** (optional, 2 pages maximum). For projects requiring restricted Medicare data, applicants may include supplementary material such as RIF variable lists, data specifications, or other technical details that support the research plan.
8. **Human Subjects Statement** (1 page maximum). Describe whether the proposed research involves human subjects, and if so, the status of IRB review at the applicant's institution. If the research qualifies for an exemption, state the applicable exemption category. This statement is required to facilitate NIH prior approval of the subaward.

Page limit note. The 3-page limit applies only to the Research Plan. The following items are separate documents and do not count toward the page limit: cover page, biographical sketch, mentor letter, budget and justification, proposed milestone schedule, technical appendix, human subjects statement, and references.

Scientific Review: **October through November 2026**

Applications will undergo an initial review for completeness and adherence to submission guidelines. Eligible applications will each be assigned to at least two members of the review committee, comprising qualified investigators and advisory board members, and scored using the rubric below. The full committee will convene to select awardees based on scores, budget, and programmatic considerations including the breadth of research objectives and disciplinary diversity among funded projects.

Announce Awardees: By **December 4, 2026**

Award Start Date: Between **January 1 and February 1, 2027**

Technical support. Each awardee will be paired with a DDH research staff member who will help refine the research question and analytical specifications, and with a VRDC programmer who will implement data analyses through NORC's existing research DUAs. The awardee will work collaboratively and iteratively with their paired staff throughout the project year.

Eligibility

We invite proposals from students, early-stage investigators (e.g., post-doctoral researchers, assistant professors, and others who have not received major NIA funding and meet NIH criteria for Early Stage Investigators), clinicians, public health professionals, and nontraditional researchers who wish to use DDH data for research. Applicants from for-profit institutions are ineligible. Individuals with conflicts of interest are ineligible.

Students and post-doctoral researchers must include a letter of support from a faculty mentor or research advisor confirming institutional support, the mentor's willingness to provide guidance throughout the project, and the availability of any institutional resources needed to complete the work. Faculty do not need to include such a letter.

Funding Information

Direct Funding Amount: We anticipate funding 1 to 4 one-year pilot grants this cycle, dependent on meritorious submissions. A total of $40,000 is available to fund all awards in this cycle; the number and size of individual awards will be determined based on the quality of submissions and the review committee's assessment of how to maximize the value of the portfolio.

Support: Each awardee receives a paired DDH research scientist who will advise on the project and coordinate VRDC programming time (up to 50 hours of programming time per awardee). This staff member will be a NORC researcher funded separately through NIH grant no.

R33AG094611. Awardees gain indirect access to 100% Medicare Research Identifiable Files (RIF) through NORC's existing data infrastructure. Obtaining independent access to CMS RIF data would typically require nine or more months of administrative processing and approximately $45,000 in new project fees. This mechanism eliminates that barrier entirely.

Award Documentation: Pilot awardees will receive a letter from the DDH PI documenting the total value of the award, including technical support, suitable for inclusion in tenure and promotion materials.

Award Structure: Each award will be structured as a cost-reimbursement subaward, contingent on NIH prior approval.

Budget Requirements

A total of $40,000 is available to fund all pilot awards in this cycle. Individual award amounts will depend on the number of funded projects and the proposed budgets of selected applicants. The award must cover all costs to the awardee's institution, *including any institutional overhead or indirect costs*. No additional funds will be provided beyond the award amount.

Applicants must submit a budget describing how they plan to use the requested funds and providing a total cost estimate. A brief narrative justification is sufficient; a detailed line-item breakdown is required. Once awarded, payments will be made as cost reimbursement based on invoicing.

NORC programming, technical, and statistical support are project-funded and should not be included in the applicant's budget.

Priority Research Areas

- **Surveillance of dementia diagnoses**
- **Health utilization differences**
- **New claims-based diagnostic indicators**
- **New treatments, diagnostics, and adverse events**
- **Economic questions**
- **Novel public health applications**
- **Creative uses of DDH data not listed above.**

Applicants are encouraged to link DDH public use data to other publicly available data sources to investigate questions that neither source could answer alone. Published examples of this approach include linking DDH county-level prevalence data to EPA drinking water lithium concentrations (Hwang et al., 2026, *Environmental Pollution*) and to social infrastructure indicators such as the density of museums, recreational facilities, and civic organizations (Goldman et al., 2025, *Alzheimer's & Dementia: BSEA*).

Available Data Resources

Pilot awardees will have access to two categories of data: DDH Public Use Files (PUFs) that are available by request, and restricted 100% Medicare Research Identifiable Files (RIFs) accessible through NORC's existing data infrastructure.

DDH Public Use Files

To obtain PUF data, contact **dementiadatahub@norc.org** or use the data request form on the dementiadatahub.org website. Applicants should request and review the PUFs before preparing their proposals. All PUF data are presented as count data subject to CMS cell suppression rules: no cells with fewer than 11 beneficiaries, and no cells from which a count below 11 can be derived through combination with other released cells. The codebooks contain definitions, suggested citations, and notes on using files across years. Additional documentation is available on the DDH website under the Resources tab. Read the codebooks carefully.

Annual Files (2020, 2021, 2022). Three annual files are available, one per year, containing the following indicators for all Medicare beneficiaries (fee-for-service and Medicare Advantage combined, as well as separately where suppression allows):

- *Primary indicators:* Diagnosed ADRD prevalence, ADRD incidence
- *Secondary indicators (among prevalent cases):* Mortality, COVID-19 infection, hospitalization rate, hospital discharges per 1,000, short-stay long-term care rate, long-stay long-term care rate, and all-cause payments (FFS only)

Annual files are stratified by age group, race and ethnicity, and sex, at the national, state, and county level.

Pooled Summary File (2020–2022) *(anticipated).* We anticipate releasing a pooled file aggregating three years of data to reduce suppression and support analysis at finer geographic levels. Applicants who have worked with the annual files will recognize that cell suppression limits what can be observed at the county level and within demographic subgroups; the pooled file is designed to address this. It will contain the following measures calculated as 2020–2022 sums: beneficiary counts, ADRD prevalence rate, ADRD incidence rate, ADRD mortality rate, and COVID-19 cases among those with an ADRD diagnosis. Stratification will include:

- National and state-level results by age group, race and ethnicity, and sex
- County-level results by one demographic group at a time
- Hospital Referral Region (HRR) and Hospital Service Area (HSA) results for beneficiaries aged 65 and older
- Results for the combined FFS and MA population, and separately where suppression allows

The pooled file uses coarser age groups (65–79 and 80+) to further reduce suppression.

Pooled Comorbidity File (2020–2022, FFS only) *(anticipated).* We also anticipate releasing a pooled comorbidity file for FFS beneficiaries aged 65 and older. This file will summarize the presence of selected comorbidities among all beneficiaries and among those with dementia, using both the “highly likely plus likely” and “any ADRD” case definitions. Comorbidity indicators were developed using the Chronic Conditions Data Warehouse (CCW) ever-diagnosed flags and include: Parkinson’s disease, epilepsy, diabetes, chronic kidney disease, hypertension, depression, and stroke. Stratification follows the same structure as the pooled summary file.

Restricted Medicare Claims Data

Through existing research data use agreements, the DDH project maintains access to 100% Medicare Research Identifiable Files (RIFs), including Part A, Part B, Part D, and Medicare Advantage encounter data, as well as the Master Beneficiary Summary File. These restricted data are housed in the CMS Virtual Research Data Center (VRDC) and can be accessed only by authorized NORC programmers with active VRDC seats.

How awardees access restricted data. Awardees will not touch restricted Medicare data directly. Instead, each awardee will work with a paired DDH research staff member to develop

data and analytical specifications. The DDH researcher will help refine these specifications for feasibility and translate them into programming requests, which NORC programmers will execute within the VRDC. This is iterative. Awardees should expect multiple rounds of specification development and results review over the course of their project year and plan their timelines accordingly.

What the VRDC can and cannot deliver. NORC programmers can extract aggregated counts, tabulations, and basic regression outputs from the restricted files. The VRDC is not suited for running sophisticated statistical models or machine learning algorithms. All results extracted must comply with CMS privacy restrictions: no cell containing fewer than 11 beneficiaries, and no cell from which a count below 11 could be derived through combination with other released cells. These secondary suppression requirements limit the granularity of results that can be extracted. Applicants should account for this when designing their analyses.

Programmer time. NORC will work with each awardee to develop specifications that are achievable within available resources. Programmer time for any single pilot award will not exceed $20,000. The paired DDH researcher will help assess feasibility and scope requests to fit within this allocation. Simple tabulations require less time than complex analytical designs. Applicants should discuss the anticipated complexity of their data needs in their proposals.

Suggested Research Plan Outline

The Research Plan is limited to **3 pages**, single-spaced, excluding references, budget narrative, and appendixes. Use 11-point Arial font with margins no smaller than 0.5 inches on all sides. Figures and tables count toward the page limit; references do not.

The following outline is suggested to help applicants organize their proposals around the criteria used in review. Page allocations are approximate. Applicants may adjust emphasis to suit their project, but should ensure that each section's content is addressed somewhere in the plan.

I. Specific Aims

State the research question or applied use case. Describe the expected product and its public health significance. Be specific: what will this project produce that does not currently exist? If the project has a single primary aim, state it clearly. If there are secondary aims, keep them few and tightly connected to the primary question.

II. Background and Significance

Establish what is currently known, identify what is missing, and explain why this question matters now. This is a good place to demonstrate awareness of what diagnosed dementia in claims data does and does not measure (see *Purpose and Scope*). Cite relevant literature, including prior work using DDH or similar surveillance data where applicable.

III. Engagement with DDH Data

Describe your familiarity with the DDH website and public use files. Explain how PUF-level data inform or motivate the research question. What patterns, gaps, or questions did the PUFs reveal? If this is a PUF-only project, describe the analytical approach to the public use data here. If the project will also require restricted Medicare claims, explain what the PUFs showed that motivated the need for individual-level data.

IV. Approach

Describe the study design, data sources, variables, and analytical methods. If restricted Medicare data are needed, specify the types of VRDC analyses required and their anticipated

complexity (e.g., simple tabulations, stratified counts, regression models). Address feasibility within the 12-month timeline and available resources, including programmer time constraints and CMS cell suppression rules where relevant. Identify potential limitations and how you plan to address them.

V. Expected Products and Timeline

Describe the planned outputs. The primary research product may be a peer-reviewed journal article, but we also welcome non-traditional products suited to the applicant's organizational environment, such as a policy brief for a state or local health department, a data dashboard or visualization, a methods guide for other DDH users, or a report prepared for an advocacy or community organization. Applicants may propose other products not listed here. Whatever the format, **the product should be of sufficient quality to be posted on the DDH website**. Briefly note how this project fits your research or professional trajectory. If you are a student or post-doc, explain what completing this project will enable you to do next. If you intend to use pilot findings as preliminary data for a future grant application (e.g., an NIH R21 or R03), describe that plan here.

Scoring Rubric

Each eligible application will be scored by at least two reviewers on a scale of 1 (poor) to 5 (outstanding) in five categories. Reviewers will provide brief narrative comments for each category.

Category	Weight	Evaluation Criteria
1. Research Question and Public Health Value	High	**5:** A well-defined, theory-driven question or specific applied use case with clear public health utility. The applicant demonstrates genuine engagement with the surveillance mission of the DDH. The proposal grapples with the distinction between diagnosed and total dementia prevalence and considers what that means for the proposed research. **3:** A reasonable question with some relevance to surveillance or public health, but the theoretical grounding is underdeveloped or the connection to the DDH mission is not fully articulated. **1:** The question is unfocused or lacks a theoretical framework. The proposal amounts to an exploratory analysis without a testable hypothesis. No evidence that the applicant has considered what diagnosed dementia in claims data actually measures.
2. Engagement with DDH Data	Moderate	**5:** The proposal demonstrates specific familiarity with the DDH website and public use files. The applicant describes how PUF-level patterns motivate the research question. The project has potential to show the value of the PUFs, to improve the surveillance system (e.g., new indicators or measures), or both. Projects seeking to develop new measures beyond the PUF file should describe how the project benefits the DDH surveillance system. **3:** General awareness of DDH resources, but no description of specific PUF content that motivates the question. The link between PUF exploration and the proposed restricted-data analysis is vague. **1:** No evidence of engagement with the DDH website or public use files. The proposal could have been written without knowing what the DDH contains.

3. Feasibility and Rigor	High	**5:** The question is tractable within 12 months and available resources, including VRDC programmer time and CMS suppression constraints. The analytical approach is well-scoped: a detailed, informed question that can be answered exceptionally well. The applicant has realistic expectations about what restricted claims analysis can deliver. **3:** The project is likely achievable but the scope may be ambitious relative to resources. Some elements need refinement. General but not specific awareness of VRDC and suppression constraints. **1:** The proposed analysis is clearly infeasible: requires sophisticated modeling inside the VRDC, demands programmer time beyond the available allocation, or ignores CMS suppression constraints. The question is too broad to answer well in one year.
4. Investigator Readiness and Support	Moderate	**5:** The applicant has the research background or professional experience to execute the project. For students and post-docs, the mentor letter demonstrates engaged guidance and institutional support. For nontraditional researchers, there is a concrete plan for how findings will be used. The project represents a meaningful step in the investigator's research or professional trajectory. **3:** Relevant background, but the connection between the applicant's expertise and the proposed work is not fully evident. Mentor support is present but generic. **1:** The applicant lacks the background or institutional support to complete the work. No mentor letter where required, or a letter that raises feasibility concerns.
5. Contribution to the DDH Ecosystem	Moderate	**5:** The project will produce durable, high-quality outputs such as a research product (journal article, policy brief, methods guide, or other deliverable suited to the applicant's environment), a research brief for the DDH website, and reusable annotated code. The work broadens the DDH's reach. Results could attract attention to the system or directly improve its content. **3:** Outputs are likely but the project does not clearly expand the DDH's reach or contribute new perspectives. **1:** Unclear what durable outputs the project would produce. No plan for a research product or DDH-quality brief.

Scoring note. Scores correspond to Poor (1), Below Average (2), Adequate (3), Strong (4), and Outstanding (5). The review committee will also consider the diversity of disciplinary perspectives and research approaches across the funded portfolio when making final decisions.

Milestone Schedule

The standard schedule is outlined below. Applicants should propose a project-specific schedule in their application that adapts this framework. The final schedule will be negotiated at the time of award and incorporated into the subaward agreement.

Milestone	Timing	Deliverable(s)
1	Award execution (Month 1)	Finalized research plan and analytical specifications

2	Close-out (Month 12)	• Primary research product submitted or delivered to intended audience. • Research brief for DDH website. • Presentation at virtual capstone meeting

The primary research product may be a peer-reviewed journal article, a policy brief, a methods guide, a data visualization, or another product proposed by the applicant and approved in the milestone schedule. If an awardee encounters obstacles, they should notify NORC promptly. NORC and the awardee will work together to revise the schedule or, if the project is no longer viable, negotiate an early close-out.

What Happens After You Are Selected

NORC will handle the administrative paperwork. Each award will require NIH prior approval before execution and will be formalized through a subaward agreement between NORC and the awardee's institution. NORC will work directly with NIH on the prior approval and your institution's grants or sponsored programs office to execute this agreement; you do not need to draft it yourself. No funds are released until the agreement is fully executed.

Post-Award Requirements

All presentations and publications resulting from the pilot must acknowledge the funding and technical support provided. Awardees must achieve the milestones in their approved schedule to receive the corresponding payments. A final scientific report is due to NORC within one month of the project end date.

Dissemination. All awardees are required to present their findings at a virtual capstone meeting at the end of the project year. Awardees must complete and deliver their proposed primary research product, whether a peer-reviewed journal article, policy brief, methods guide, data visualization, or other product as approved in the milestone schedule. Awardees will also write a research brief for lay audiences for the DDH website. Annotated code from these projects will be posted on the DDH website alongside the research product and will serve as a training resource for others. NORC may incorporate relevant results (e.g., new outcome measures) into the Dementia DataHub.

Common Questions

Can I apply if I've never used Medicare data before?

Yes. Each awardee is paired with a DDH research scientist and a VRDC programmer who will help you develop analytical specifications and execute the analysis. You do not need prior experience with Medicare claims. You do need a well-defined research question and the ability to interpret the results.

How long does it take to get the PUFs?

We typically respond to data requests within a few business days. Email dementiadatahub@norc.org or use the data request form on dementiadatahub.org and we will send you download links and documentation.

Can my project use only the public use files, without restricted data?

Yes. Projects that use only the PUFs are equally appropriate for this mechanism. Some of the most interesting questions may be answerable by linking PUF data to other publicly available sources.

What if my institution doesn't have a grants or sponsored programs office?

Contact us at dementiadatahub@norc.org and we will work with you to find a path forward.

How small can my budget request be?

There is no minimum. The mechanism is designed to support projects at a range of scales. A well-scoped PUF-only project with minimal personnel costs might request a few thousand dollars. A project requiring significant investigator time and restricted data analysis might request substantially more. Budget what you need.

I'm a student. Can I be the PI?

Yes, but you must include a letter of support from a faculty mentor confirming their guidance and your institution's support for the project.

Can I link DDH data to other publicly available datasets?

Yes, and we encourage it. The DDH public use files contain county-level, state-level, and national data that can be linked to Census data, the American Community Survey, the Behavioral Risk Factor Surveillance System, Area Health Resource Files, CMS geographic variation files, and many other sources. Proposals that combine DDH data with other sources to answer questions neither could address alone are welcome.

What if I can't finish a journal article within the project year?

The primary research product does not have to be a journal article. Policy briefs, methods guides, data visualizations, and reports prepared for specific audiences are all acceptable. Whatever format you propose, the product should be of sufficient quality to be posted on the DDH website. The final milestone requires that you present your findings at the capstone meeting and deliver your product; it does not require journal publication by Month 12.

Can I use this pilot to develop preliminary data for a larger grant?

Yes, and we encourage it. A pilot award is an opportunity to generate preliminary findings, demonstrate feasibility, and establish a working relationship with DDH data that positions you for an independent NIH application such as an R21 or R03. If this is part of your plan, describe it in the Expected Products and Timeline section of your research plan.

Who reviews the applications?

Applications are reviewed by a committee of qualified investigators and DDH advisory board members. Each application is assigned to at least two reviewers and scored using the rubric provided in this RFP. Though the NIH will not review your application, all final decisions must be approved by the NIH, and your application may be subject to renegotiation with the NIH.

Is this opportunity open to applicants based outside the United States?

No, at this time we are only able to offer subawards to applicants based in the U.S. and work must be completed in the U.S. Any international collaborators should be clearly indicated as such in the application.

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