The Neurodegeneration Initiative

Delivering the Objectives of the Dame Barbara Windsor Dementia Goals Programme

BARBARA Foundational Participation Call for a Proof-of-Concept Study

1. Executive Summary

Purpose
This Foundational Participation Call is designed to identify a small number of cohorts to work with the Neurodegeneration Initiative in a proof-of-concept phase to establish BARBARA, a federated platform linking UK dementia cohorts.

Who should apply
Cohorts with stored blood samples, appropriate consent for data sharing, and the ability to re-contact participants.

Key dates
Call opens: 12 January 2026
Call closes: 6 February 2026

Funding available
Up to £2.2 million to support Proof of Concept (PoC) activities.

Benefits
Financial support, funded biomarker analyses, and early positioning within BARBARA.

2. Introduction

The Dame Barbara Windsor Dementia Goals Programme (DGP) is a national initiative established to accelerate progress in dementia research, diagnosis, and treatment. The Programme aims to build the scientific, clinical, and data infrastructure required to support more clinical studies, providing accurate detection, biomarker-enabled precision medicine, and the development and delivery of more effective therapies.

The Programme supports:

- Creation of trial-ready populations and scalable recruitment pathways to improve the success of clinical trials;
- Development and validation of biological and digital biomarkers for early detection, diagnosis, stratification, and monitoring;
- Innovative translational research that advances understanding of neurodegeneration;
- Adoption of new technologies and approaches that can improve outcomes and access for people living with dementia and their families.

By investing in these foundations, the DGP seeks to transform the UK's capability to detect, treat, and ultimately prevent dementia.

3. The Neurodegeneration Initiative

The Neurodegeneration Initiative (NI) is a public–private partnership established to deliver the objectives of the DGP. The NI aims to build the infrastructure and translational pathways needed to accelerate biomarker-enabled clinical trials, improve access to treatments, and support real-world evidence generation through scalable, secure and interoperable platforms.

4. About BARBARA

BARBARA — named in honour of Dame Barbara Windsor — stands for **Brain Ageing Registry for Biomarkers, Access to trials, Research and Adoption**.

BARBARA is **not** a new registry, but it is intended to be a dynamic, federated platform that connects existing UK dementia cohorts, registries, and population health resources, while respecting data ownership, governance, and local control.
Through a federated portal, BARBARA aims to:
- accelerate recruitment into dementia trials,
- improve trial success by enabling precision stratification, and
- generate longitudinal, real-world evidence on disease progression and treatment response and health system implementation.

Given its scale and ambition, the development of BARBARA will necessarily be iterative and delivered in multiple stages, with different partners joining at different points as the programme evolves.

To support this ambition, we will be working in close partnership with the Dementia Trials Accelerator (DTA) in line with Government intent. The DTA provides a foundation stone for the DGP and is already working with a number of cohorts across the UK to: a) provide a 10,000 strong participant cohort with up-to-date blood based biomarkers and cognitive testing b) build a secure, UK-wide data platform to speed recruitment and feasibility; to accelerate recruitment into late-stage clinical trials for dementia.

In addition, we will be establishing a Health Informatics Steering Committee comprising of external members to work with already existing national and international data platforms to deliver this future work.

This Proof of Concept (PoC) is intended to deliver within 2026, and therefore the number of cohorts that will be appropriate for selection will be necessarily small. There will be a requirement to provide access to blood samples and/or to clinical participants that could be recontacted across the UK within 2026.

We will be working with the programme People's Forum to gain input from the public and people with lived experience.

BARBARA is intended to grow over time. The Neurodegeneration Initiative anticipates that many additional cohorts and resources will join the programme as it expands beyond this initial

PoC. In order, to deliver the full ambition for BARBARA over the next two-three years we will be working with a comprehensive and diverse set of cohorts and data sources across the UK to ensure access to data. There will therefore be subsequent rounds of calls to identify and collaborate with future partners, providing opportunities for all relevant cohorts in neurodegenerative diseases. This PoC is intended to be the foundational step of BARBARA.

Please contact The NI for any specific query related to your application.

5. Purpose and Scope of this Proof of Concept (PoC)

This Proof of Concept (PoC) represents an early step in building BARBARA, designed to test the feasibility of the end-to-end workflow required to enable research, including logistical and ethical considerations, de-risk future scale-up, and establish practical working models with a small number of initial partners.

The PoC is designed to:
- test feasibility across real-world cohorts,
- de-risk future scale-up, and
- establish practical, repeatable working models with a small number of initial partners.

What the PoC will demonstrate
The PoC will demonstrate the feasibility of:
- identifying and accessing data and participants across multiple cohorts for future clinical trial recruitment;
- accessing stored blood and plasma samples to enable additional biomarker and genetic analyses (including pTau217 and related biomarkers); and
- enabling secure, federated access to participant-level cohorts and biological samples from a small number of sites.

Scope limitations
- The PoC is **limited to research in Alzheimer's disease (AD) and non-AD dementias**, with a focus on people with a diagnosis or risk to develop dementia.
- Disease-specific cohorts primarily focused on other neurodegenerative conditions (e.g. Parkinson's disease, Motor Neuron Disease) are out of scope for this call, but may be included in future BARBARA phases.

6. Eligibility and Requirements

To participate in the PoC, cohorts must be able to meet the essential eligibility criteria below.
- A. **Participant re-contact capability**
- Ability to re-contact at least 500 participants in 2026 for future research and trial readiness activities.
- Access to participants for additional tests (as required) including but not limited to blood samples and digital cognitive test to characterise participants disease stage and clinical outcomes.

AND/OR

B. **Availability of blood samples suitable for biomarker analysis**

- stored blood samples (e.g., plasma, serum, whole blood) exist for a substantial proportion of participants.
- samples are stored under recognised biobanking conditions.
- Baseline phenotypic characterisation of participants

AND

C. **Appropriate consent and governance**

Existing ethical approval and participant consent must support:
- secondary research use of samples and data;
- additional biomarker analyses (including pTau217 and related biomarkers);
- secure data sharing with external partners via a federated platform; and
- compliance with UK regulatory and governance requirements, including:
  - UK GDPR,
  - Health Research Authority (HRA) guidance, and
  - relevant NHS R&D policies.

7. Benefits to Participating Cohorts

Cohorts selected for the PoC will benefit from:
- Financial support to cover PoC-related activities (for example, additional diagnostic scanning and clinical assessments);
- Funded additional biomarker analyses on stored samples, generating new scientific value for the cohort;
- Experience and capability building in federated data access models aligned with future research and life science requirements;
- Early positioning within BARBARA, a growing national platform intended to support:
  - trial recruitment,
  - biomarker validation and adoption, and
  - access to future public-private research opportunities;
- Visibility and engagement with the Neurodegeneration Initiative (NI) and its industry, health foundation, academic, and policy partners.

Please note that participation in the PoC does not restrict cohorts' independence or future collaborations.

8. Financial Contribution
- A total of **up to £2.2 million** is available to support the PoC.

- Funding will be allocated to selected cohorts to cover the costs of PoC-related activities, which may include:
    - sample access and preparation,
    - biomarker analyses,
    - data access and governance work,
    - participant re-contact preparation, and
    - project management and reporting.

- Final budgets will be agreed with each selected cohort following selection.

9. Timeline and Selection Process

Indicative timeline
- **Call opens:** 12 January 2026
- **Call closes:** 6 February 2026
- **Cohort selection and contracting:** by March- April 2026
- **Participant re-contact readiness:** cohorts expected to be ready to support re-contact during 2026

Selection process
- A small number of cohorts will be selected for this PoC.
- Selection will be based on:
    - ability to meet the essential eligibility criteria, and
    - practical readiness to support feasibility testing within the PoC timeframe.

Selection at this stage reflects practical constraints of a feasibility PoC and does not preclude other cohorts from joining BARBARA in later phases.

Please note that if you think that your cohort could be relevant to BARBARA in future rounds, please use the form below to constitute an expression of interest and we will be in touch in future.

10. Submission Process

Submissions should be provided as a single PDF and emailed to:

Dr Siddhartha Ghose
Siddhartha.Ghose@n-di.org.uk

Subject line:
BARBARA PoC – RFP Submission – [Institution Name]

Please include the institution name, contact person, and phone number.

Request for Proposals (RFP) Application Form
Please note that for administrative consistency, this call is issued through an RFP process; it is not a procurement exercise and should be understood as an initial step to identify cohorts to collaborate in the foundational phase of BARBARA.

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(Applicants may copy/paste this into their submission; the information provided should refer to the essential eligibility criteria specified in page 3 of this document)

Submissions should be provided as a single PDF and emailed to:

Dr Siddhartha Ghose
Siddhartha.Ghose@n-di.org.uk

Subject line:
BARBARA PoC – RFP Submission – [Institution Name]

Please include the institution name, contact person, and phone number.

RFP Application – BARBARA Proof of Concept

Institution:
Cohort/Resource Name:
Principal Investigator / Cohort Lead:
Administrative Contact:
Email:
Phone:

1. Cohort Overview (expected 2-3 pages)
- *Brief description, recruitment, participant characteristics, current sample size, projected numbers to 2026.*
  Please include whether your proposal will address how your cohort could provide access to blood samples and/or access to clinical trial participants.

2. Data and Biosamples (High-Level Summary)
- *Types of biological samples and participants characteristics; summary of data domains; cognitive measures; biomarker overview if applicable.*
- *Description of existing data platform and federation.*

3. Ethics and Governance
- *Confirmation of REC approval, approval/ data access committee; consent suitability, recontact ability.*

4. Feasibility and Readiness
- *High-level statement of capacity, data transfer processes, contracting readiness.*
- *Indicative additional resources required to support further re-contact, research and data management for the PoC.*

Please note that costing is not required at this stage of the process. Only once the cohorts to be involved are identified, we will work with each of them on the detailed costing, requirements and resources needed.

5. Optional: Desirable Features
- *Genetics, imaging, digital biomarkers, longitudinal follow-up, etc.*

6. Declaration

I confirm that the information provided is accurate and that our institution agrees to participate in the BARBARA PoC selection process.

Name:
Role:
Signature:
Date: