

Reporting on the UK Biobank Study pilot and its opportunity for enhancing neurodegenerative disease research

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A comprehensive Brain Health Study protocol can be successfully delivered within UK Biobank research centres, with >90% completion rates across assessments. However, large-scale implementation will require more effective approaches to identifying and recruiting participants with neurodegenerative conditions.

BACKGROUND

UK Biobank is a prospective cohort study of 500,000 UK volunteers. Participants are now entering older age (mean age 74 years).

To complement the extensive genetic, biomarker, imaging and questionnaire data already available, the Brain Health Study (BHS) was designed to assess the feasibility of collecting additional data that could help further characterise and subtype neurodegenerative conditions.



The aim of the pilot study was to evaluate the feasibility of recruiting participants with neurodegenerative disease diagnoses and cognitive concerns and conducting a comprehensive brain health assessment in a UK Biobank research centre.

METHODS

A brief survey was sent to ~24,000 UK Biobank participants living within 20 miles of the Stockport research centre.

Participants were considered for invitation to a BHS visit if they self-reported:

- a diagnosis of Alzheimer's disease, Parkinson's disease, mild cognitive impairment (MCI), vascular dementia, or unspecified dementia; and/or
- subjective cognitive complaints.

The study visit lasted ~3 hours and included assessments of:

- cognition,
- a brain MRI,
- a blood sample,
- a smell test,
- study partner questionnaires, and
- 7-day cardiac monitoring.

Feasibility outcomes included response rates, attendance, acceptability and successful completion of study assessments.

RESULTS

Recruitment

Participant characteristics	Total	By email	By post	% Female	Mean age (SD)
Sent eligibility survey	24,103	20,604	3,499	54.3	73.2 (7.9)
Responded to eligibility survey	9,031	8,613	418	56.6	72.2 (7.6)
Reported diagnosis	151	142	9	45.7	76.9 (6.3)
Invited to attend BHS	206	185	21	45.6	75.1 (6.9)
Attended BHS	57	54	3	35.1	73.8 (6.8)

Participation

Icon	Count (%)	Description
	40 (70%)	Attended with study partner
	44 (77%)	Had previously attended a UK Biobank imaging assessment
	32 (56%)	Reported any diagnosis*
	14 (25%)	Reported memory clinic referral (without diagnosis)
	11 (19%)	Reported other subjective cognitive complaints (without diagnosis)

*included Parkinson's disease (n=15), MCI (n=10), and dementia (n=9)

Feasibility of data collection

The study protocol was successfully delivered. Over 90% of study measures were completed. Few operational issues were encountered. Acceptability was high.

CONCLUSIONS

The BHS protocol was feasible to implement within an existing UK Biobank research centre and achieved high completion rates across all assessments.

Recruitment was challenging, with relatively few participants with diagnosed conditions identified and a modest uptake among those invited.

The findings support the planned rollout of the BHS while highlighting the need for alternative recruitment approaches, including using electronic health records and existing UK Biobank data sources.

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www.ukbiobank.ac.uk/the-uk-biobank-brain-health-study/

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