

ON-FIRE

Open Network for Frontotemporal dementia Innovation Research

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Background

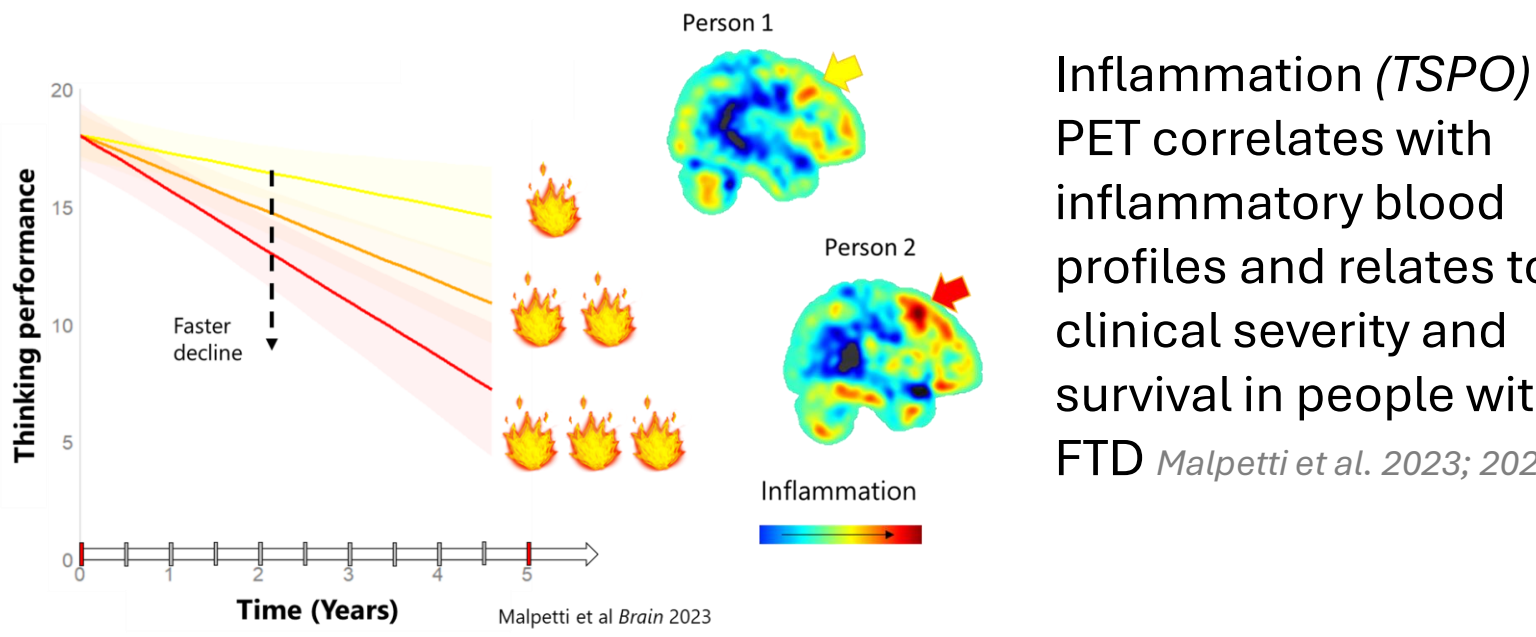
Open Network for Frontotemporal dementia Innovation Research (ON-FIRE) is a UK-wide network of researchers across more than 40 sites, collecting longitudinal cognitive, clinical and lifestyle data alongside blood samples in people with frontotemporal dementia (FTD) and related disorders.

Objectives

1. To establish a **national network** and **collaborative platform** for blood biomarker discovery in FTD; recruiting participants across the whole UK, in different healthcare settings.
2. To “**fingerprint**” **inflammatory blood profiles** in FTD, from **diverse participants** with “real-world” variation in clinical phenotype and ethnic, genetic and socioeconomic backgrounds.
3. To create an **open international resource** for **FTD research**, making data and samples available for researchers through safe and secure access and use agreements.

Development

From inflammation...



Defining and validating **inflammatory blood profiles** and their clinical meaning requires a **large, diverse and representative** cohort only achieved through **multicentre efforts**

...to **Innovation**

Creating an **international resource** for FTD research, **beyond inflammation** research

Recruiting people with sporadic FTD from across the UK, complementing existing multicentre genetic FTD initiatives

Diverse and well-characterised cohort

Clinical, cognitive, lifestyle and blood data, blood samples

Platform for sub-studies and trial recruitment

Design

Recruitment



Trials Platform

Helping get the UK ready for clinical trials in FTD

- Informed consent
- Agree or disagree to...
- Genetic feedback
 - Known FTD-related genes
 - Future contact
 - Medical research and clinical trials

Creating a well-characterised, diverse database of people interested in participating in clinical trials

Sub-studies

Optional protocol extensions for sites and participants

- Immunophenotyping**
Screening against chronic and acute inflammatory events
Mass and flow cytometry on fresh pBMCs, frozen pBMCs stored
- Dried blood spot cards**
Validating against venous blood markers
Central coordination and trialling underway
Site-wide roll out Sept 2026
- Digital cognitive testing**
Ignite launching Aug 2026
13 app-based cognitive tasks, translated into multiple languages
Octal joining Sept 2026
11 tablet or desktop cognitive tasks, or 5-task mobile version
- Brain imaging**
Future goals to offer PET and MRI sub-studies, with participant-referral from sites without imaging infrastructure

Database and Biorepository

Access to data and samples for researchers internationally available through access requests*

Participant view > P-00304



P-00304

Age at Visit: 43
Male
Patient Participant

Visit 2

Visit 3

Baseline visit

Data overview: Baseline visit		Available Data/Samples	
	Cognitive testing		MoCA, ACE-r
	Participant questionnaires		Demographics, Lifestyle
	Informant questionnaires		CBI-r, FRS, FTLD-CDR
	Medical history		Diagnoses, Medications
	Blood biomarkers		CNS, Inflammation, Genetics
	Blood samples		Plasma, Serum, RNA, DNA, pBMC
	Imaging		MRI, CT, PET
	Sub-studies		Ignite, Immunophenotyping

* Database and biorepository currently in data/sample collection phase. Whole genome sequencing (WGS) to be performed in batches of n=150, with the first batch being currently arranged. Core central nervous system (CNS) and inflammation panels to be applied in similar-sized batches. Remaining samples to be retained for requested use. Database to be made available to researchers, by request, after Phase 1 (N=300) completion, and following quality checks and data cleaning.

Core protocol

Baseline, 12- and 24-month follow-ups

- Blood sample, cognitive test, medical history, lifestyle and informant questionnaires

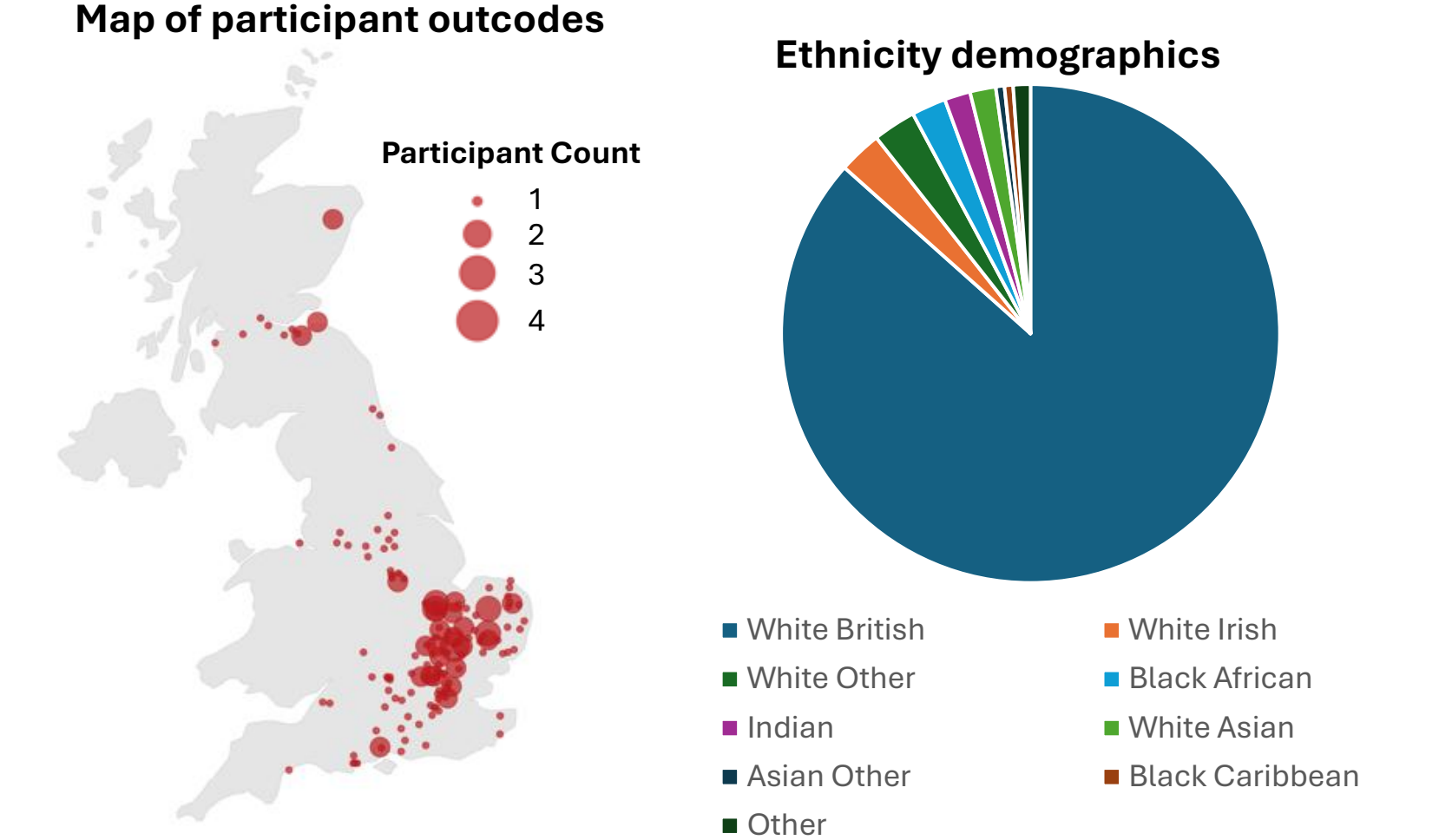
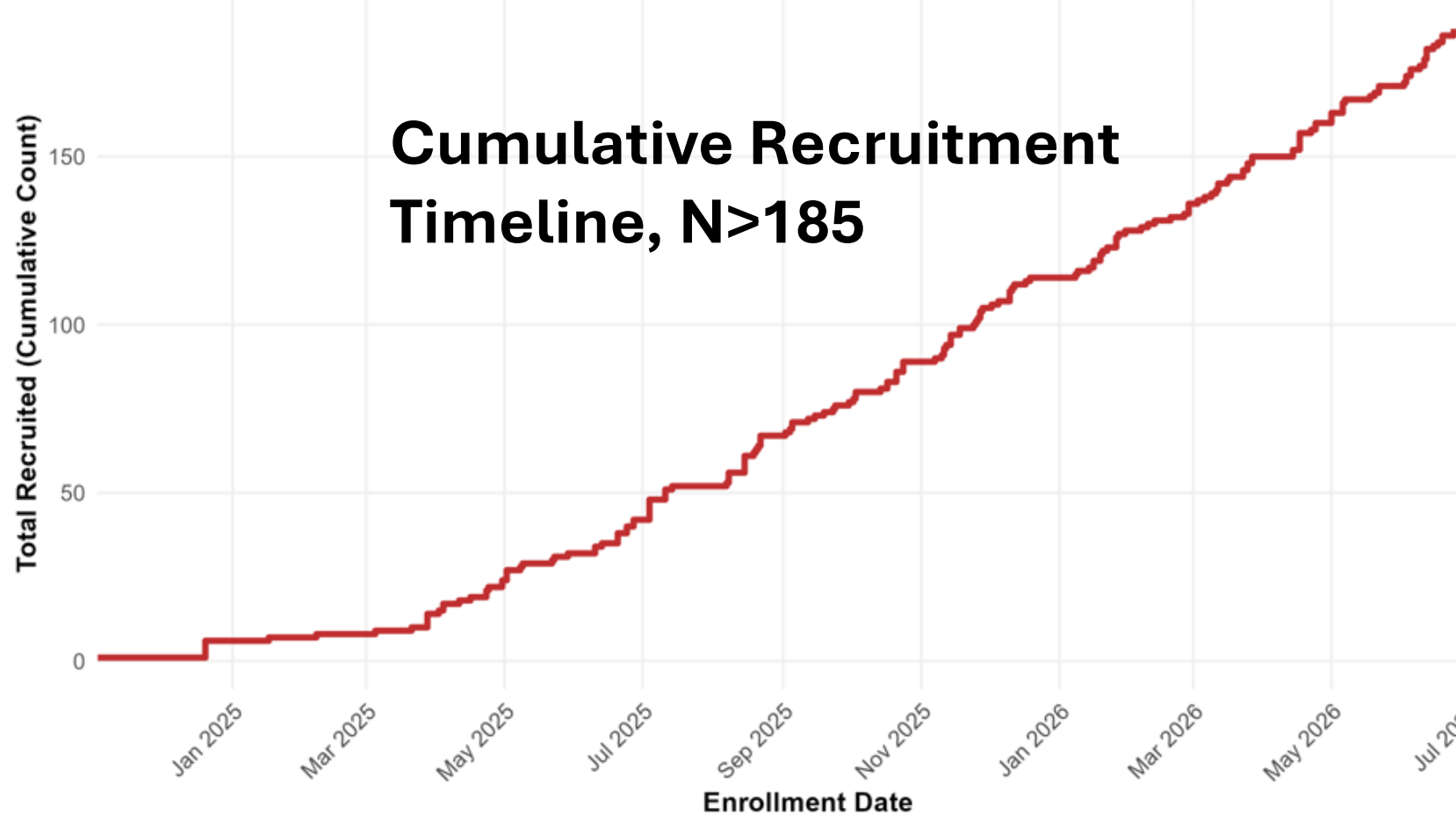
Optional add-ons

- Imaging transfer
- Extended follow-ups
- Sub-studies

Inclusive design

- Translatable tools
- Remote option
- Care home integration

Progress



N, Age (Mean (SD)), and Sex by Diagnostic Group

Diagnostic Group	N (M:F)	Age at baseline	Age at onset	Age at diagnosis	Time to diagnosis
bvFTD	74 (44:30)	64.8 (7.9)	58.9 (8.2)	62.2 (7.7)	3.19 (3.9)
svPPA	29 (18:11)	67.8 (7.9)	61.9 (7.7)	65.0 (8.0)	3.00 (3.1)
nfvPPA	31 (14:17)	75.3 (7.1)	70.5 (7.0)	73.0 (7.2)	2.48 (1.4)
lvPPA	10 (5:5)	72.6 (5.7)	68.8 (5.4)	70.7 (6.2)	1.90 (1.8)
Mixed aphasia	2 (2:0)	72.1 (9.2)	67.5 (10.6)	71.0 (8.5)	3.50 (2.1)
FTD-MND	8 (6:2)	63.6 (12.7)	61.6 (13.0)	63.3 (12.6)	2.00 (2.1)
PSP	4 (2:2)	71.5 (7.4)	66.8 (6.3)	69.5 (7.4)	2.75 (1.7)
CBS	2 (1:1)	72.6 (5.9)	68.5 (7.8)	72.0 (5.7)	3.50 (2.1)
Other	12 (7:5)	66.1 (13.2)	62.9 (14.0)	66.9 (15.2)	1.43 (3.3)
Healthy Control	14 (5:9)	58.2 (16.0)	NA	NA	NA

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Glossary: ACE-r – Addenbrooke’s Cognitive Examination Revised; bvFTD – Behavioural variant FTD; CBI-r – Cambridge Behavioural Inventory Revised; CBS – Corticobasal Syndrome; CT – Computerised Tomography; FRS – Frontotemporal dementia Rating Scale; FTLD – Frontotemporal dementia; FTLD-MND – FTD with Motor Neurone Disease; FTLD-CDR – Clinical Dementia Rating scale with added Language and Behaviour domains; lvPPA – Logopaenic variant PPA; MoCA – Montreal Cognitive Assessment; MRI – Magnetic Resonance Imaging; nfvPPA – Non-fluent variant PPA; PET – Positron emission tomography; PPA – Primary progressive aphasia; PSP – Progressive supranuclear palsy; svPPA – Semantic variant PPA; TSPO – Translocator protein