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NEUROPROGRESSIVE AND  
DEMENTIA NETWORK

Annual Report  
2025/2026

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# Acronyms

**ACCORD** - Academic and Clinical Central Office for Research and Development

**AHP** – Allied Healthcare Professional

**DEI** – Diversity Equality Inclusion

**FAQ** – Frequently Asked Questions

**GCP** – Good Clinical Practice

**NDN** – Neuroprogressive & Dementia Network

**NIHR** – National Institute for Health and Care Research

**PI** – Principal Investigator

**PIPP** – Principal Investigator Pipeline Programme

**PPI** – Patient and Public Involvement

**RCT** – Randomised Controlled Trial

**UKDTN** – United Kingdom Dementia Trials Network

**WTCRF** – Wellcome Trust Clinical Research Facility



# Welcome

We are pleased to present the first annual report from the NHS Lothian Neuroprogressive and Dementia Network (NDN) team. We continue to deliver clinical research studies for neurodegenerative conditions across Edinburgh and the Lothians.

Our work focuses on improving the lives of individuals living with progressive neurological conditions such as Parkinson's Disease, Huntington's Disease, Alzheimer's Disease, Dementia with Lewy bodies, Progressive Supranuclear Palsy, Mild Cognitive Impairment and Vascular Dementia.

In this report, we reflect on the past year and highlight our team's key achievements.

As part of the NHS Research Scotland network and part funded by the Chief Scientist Office, the NDN Lothian team is dedicated to supporting and delivering clinical research

## OUR MISSION

*Deliver cutting edge clinical research in neuroprogressive conditions and dementia across Scotland*



## Strategic update 2025/26

The Lothian NDN team finalised its collective team strategy for 2025–2027. This plan focuses on delivering inclusive, cutting-edge clinical research for people living with neurodegenerative conditions across Lothian. Key objectives include expanding participation in academic and commercial trials, embedding research into routine clinical care, and engaging underserved communities in our studies. Additionally, the strategy prioritises workforce development to ensure long-term sustainability and excellence in research delivery.

# Meet the Team



**Bernie McInally**  
Clinical Studies Officer  
Research Nurse



**Bev Goldberg**  
Clinical Studies Officer  
Research Nurse



**Emma Fleming**  
Clinical Studies Officer  
Research Nurse



**Marian Montanha**  
Clinical Studies Officer  
Research Practitioner



**Jessica Crossan**  
Senior Clinical Studies Officer  
Research Nurse



**Ruth Moss**  
Research Nurse Manager  
Research Nurse



**Dr Catherine Pennington**  
Principal Investigator  
Consultant Neurologist



**Dr David Breen**  
Principal Investigator  
Consultant Neurologist



**Dr Peter Foley**  
Principal Investigator  
Consultant Neurologist



**Dr Gordon Duncan**  
Clinical Lead  
Consultant Physician



**Dr Tom Russ**  
Network Champion  
Consultant Psychiatrist

# Current Studies



## Alzheimer's Disease

**FAST:** An academic observational research study trying to better understand a person's risk for developing Alzheimer's Disease, using digital cognitive assessments and blood tests.



Click on any of the studies or scan the QR code to learn more

## Huntington's Disease

**ENROLL-HD:** An observational registry study trying to speed up the development of treatments for Huntington's disease.



**iMark HD:** An observational academic research study trying to better understand the early stages of Huntington's disease, and how the disease progresses.



## Parkinson's Disease

**ASPRO PD:** An academic CTIMP clinical trial to see if the medicine ambroxol can slow or halt Parkinson's disease progression.



**COBALT:** An academic CTIMP clinical trial to see if the medicines memantine and cholinesterase inhibitors can help improve symptoms for people with Parkinson's disease dementia or Dementia with Lewy Bodies.



**PD Frontline:** A registry study offering online genetic testing for people with Parkinson's disease to check if they may be suited for other Parkinson's disease trials.



**TOP HAT:** An academic CTIMP clinical trial to see if the medicine ondansetron can help people with Parkinson's disease who experience hallucinations.



## Upcoming Studies



**ADAPT:** A large clinical trial assessing whether a blood test measuring p-tau217 can enhance the speed, accuracy and accessibility of Alzheimer's diagnosis in NHS memory clinics. It is a multi-centre diagnostic randomised controlled trial of disclosure of results of plasma p-tau217 to community memory clinic patients and clinicians in the UK. We will be open to this study in 2026.



**EJS-ACT PD:** This study is the world's largest PD trial and is a Multi-Arm, Multi-stage design assessing multiple treatments at once. Current treatment arms are standard of care (placebo), Telmisartan or Terazosin. We will recruit 72 participants over 3 years of the study and will be open Summer 2026.



**MINDSET 2:** This commercial clinical trial will explore whether the medications KarXT and KarX-EC can help improve memory and thinking for people with Alzheimer's disease. We will be open to this study in Summer of 2026.



**PROSPECT-EXPRESS:** This study will obtain clinical data and biosamples for patients referred with parkinsonism and/or gait disorders who may have an underlying diagnosis of atypical Parkinson such as PSP, CBS or MSA. We will be open to recruitment for this study in Summer 2026.



**SANDBOX:** This study will test a new triage pathway for people referred to Memory Clinics. It combines blood tests for p-tau217 and epigenetic markers, digital memory assessments, and AI-based risk assessment to support diagnosis. The aim is to improve accuracy, reduce waiting times, and increase clinic capacity. We expect to open this study in 2026.

## Closed Studies

**CAN-PDP:** A clinical trial to see if cannabidiol can help improve symptoms of hallucinations and delusions in Parkinson's Disease. **Results pending.**

**EVOKE/ EVOKE+:** A clinical trial which found that the medicine Semaglutide does not help slow down memory and thinking problems for people with Alzheimer's disease.

**HealthE-RND:** A research study trying to make it easier for people with Huntington's disease to get care from different health professional. **Results pending.**

# Research Interest Register

The NDN research interest register allows individuals to sign up to take part in research related to progressive neurological conditions.

In Lothian, we are very proud to promote the register, and its advertisement is integrated into clinical care services to help ensure that as many people as possible who may be affected by these conditions are able to engage with research.

TAKE PART IN RESEARCH

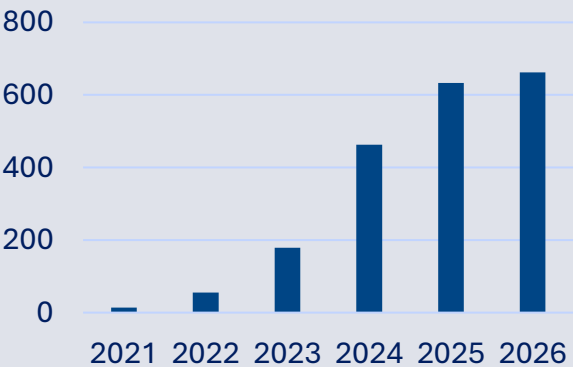
Do you have a memory problem or live with dementia, Parkinson disease, Huntington Disease, Motor Neurone Disease or Multiple Sclerosis?

NHS Research Scotland's Neuroprogressive and Dementia Network are encouraging people to sign up to their research register.





## Annual Sign Ups

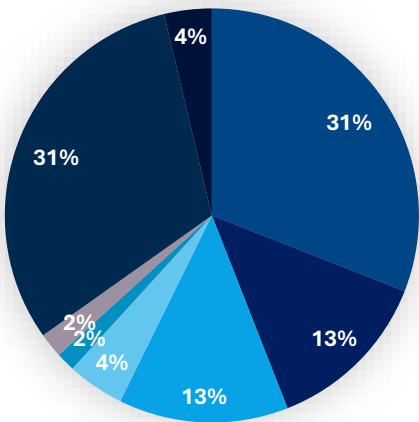


Since 2021, registrations have consistently increased, rising from just 20 sign-ups between April 2021 and 2022 to an average of 150 annually since 2023. We now have 608 registered in Lothian.

Currently, 57% of those registered are male and 43% are female. Ages range from 36 to 99, with the majority falling within the 70–80 age group (n=312). We have broad representation across diagnostic groups, with 68% of registrants having a confirmed diagnosis – most commonly Parkinson’s disease

We are keen to undertake further work across Lothian to expand our reach and better engage the wider community in research. While we currently have a strong and diverse group of participants, there are opportunities to widen participation.

We anticipate that our upcoming work with the Memory Assessment and Treatment Service, alongside Alzheimer’s diagnostic studies, will help to increase both the diversity and overall number of participants engaging with research.



- No diagnosis

Alzheimer’s

DWLB

Parkinson's Disease
- MCI

Vascular

Dementia but not sure

Other

# Successes over the last year

## NHS Lothian become member site of UK Dementia Trials Network!



**UKDTN Clinical Fellow  
Dr Tim Wilkinson**

[The UK Dementia Trials Network \(UKDTN\)](#) is funded by the NIHR and aims to create the UK as a top place to run early phase dementia clinical trials.

In summer 2025, Professor Catherine Mummery and the UKDTN team visited the NDN team at the WTCRF. During the visit, we showcased the research landscape in Lothian. There were presentations from the Memory Clinic services, ACCORD, the Edinburgh Imaging Facility, Clinical Trials Pharmacy, and NDN. Earlier this year, we learned that NHS Lothian has been chosen as a UKDTN member site which makes us the second site in Scotland and the ninth in the UK to join the UKDTN.

The UKDTN aims to make it quicker to start trials, work more closely with industry, support a wider range of participants, and build research skills across the UK. The Alzheimer's Society have invested £3 million to create the first national network of specialist dementia research nurses. We look forward to seeing how the team and studies will grow in NDN with Dr Tim Wilkinson as the UKDTN Clinical Fellow.

## Clinical Trials for Parkinson's: A Companion Guide

In 2025, supported by the [NHS Lothian Charity Fund](#), we held a PPI event exploring clinical trial participation and the needs of people with Parkinson's. Through this and online workshops with our NDN Partners in Research Parkinson's group, we developed the ["Clinical Trials for Parkinson's: A Companion Guide"](#).



Clinical trial research can feel overwhelming: too much information is daunting, too little leaves people uninformed. Our group worked together to present information in a gentle, approachable way, regularly reviewed by people with lived experience of Parkinson's.

We hope the guide gives a clear overview of what a clinical trial involves and reinforces an important message: if a trial isn't right for you, that's nobody's fault.

We're now developing a more interactive online version with FAQs and recommended resources.

## NIHR Associate PI – Dr Katherine Walesby

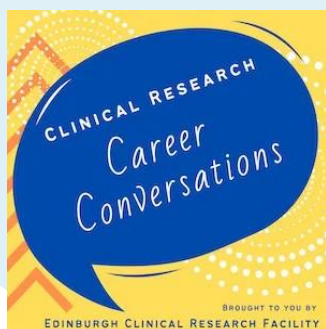
Dr Katherine Walesby is an ST7 in Geriatric Medicine in Edinburgh with a broad research background spanning laboratory medicine, data science, and clinical trials. To develop practical trial delivery skills, she joined the NIHR Associate PI Scheme, becoming involved in the COBALT trial at the Western General Hospital – a multicentre RCT evaluating Memantine in Dementia with Lewy Bodies and Parkinson's Disease Dementia.



Through the scheme, Katherine completed GCP training and joined the study team as a sub-investigator, gaining hands-on experience in recruitment, consent, assessments, and data collection. She has developed insight into randomisation, safety reporting, and data governance, and has presented the COBALT trial locally while signposting patients to research opportunities. She hopes to build on this foundation as a future PI, delivering high-quality research for older people.

## NIHR Principal Investigator Pipeline Programme (PIPP) in Scotland – Jessica Crossan

In March 2025, Jessica joined [the first Scottish cohort of a national programme supporting research delivery nurses in developing the skills needed to become Principal Investigators](#). The programme has equipped her with the knowledge and competencies to progress from research nurse to nurse PI, while highlighting research nursing as an attractive career pathway and providing valuable networking opportunities across NHS Scotland.



Jessica's progression to nurse PI has increased the team's capacity to deliver clinical research, and she is now PI on the FAST (Feasibility and Accessibility of Scalable Tests) study lead by University of Oxford. Her achievement has also inspired fellow colleagues within the Lothian NDN team and Emma has recently joined Cohort 2 of the programme. In January 2026, Jessica also shared her experience on the [Clinical Research Career Conversations](#) podcast.

## Clinical Research Practitioner Registration – Marian Montanha

[When Marian transitioned to research from psychology](#), she found that despite her qualifications and experience, she didn't fill the same "box" that medical or AHP colleagues were able to, when it came to establish what "her role" in research was. [The Academy for Healthcare Science](#) register provides a recognised platform for researchers to demonstrate accountability, commitment to quality, and validation of ability to coordinate complex clinical trials. For Marian, registering as a Clinical Research Practitioner was about establishing a clear professional identity and being a part of creating space for new faces in the industry. Registration bridges the gap between clinical delivery and the multifaceted backgrounds that more researchers are coming from, ensuring they are recognised, regulated and formally valued.

# Clinical Research Delivery Community Strategic Plan – Marian Montanha and Emma Fleming

Parallel to this, the [Clinical Research Delivery Community Strategic Plan](#) launched in December 2025. Developed by Research Nurse Managers Miranda Odam and Rachel O’Brien, the plan was co-designed by a diverse working group - including NDN’s own Emma and Marian - to address operational challenges and staff wellbeing. The group established six strategic themes centred on inclusivity and leadership, which were recently unveiled at The Usher Institute. With monthly meetings ongoing to drive implementation, these combined efforts ensure that NHS Lothian remains at the forefront of both clinical excellence and professional research development. We’re very pleased that Emma and Marian from team NDN are part of this initiative.



**Presenting posters  
at the  
International  
Alzheimer’s  
Conference in  
Bologna, Italy**



**National NDN meeting at  
Edinburgh Zoo**



**Investigator meeting for the MINDSET-2 study,  
in Prague, Croatia**

# Acknowledgments

We would like to express our sincere thanks to everyone supporting the work of NDN Lothian:

- Participants and caregivers involved in our clinical studies
- Clinical colleagues across Lothian
- Clinicians and nurse specialists in Parkinson's Disease
- The Memory Assessment Treatment Service
- ACCORD
- The University of Edinburgh
- The Wellcome Trust Clinical Research Facility
- The Edinburgh Imaging Facility
- Clinical Trials Pharmacy
- The Anne Rowling Regenerative Neurology Clinic

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