

# NHS Lothian: Neuroprogressive and Dementia Network Team Strategy 2025 – 2027

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**Version:** 1.0

**Date:** 18 Sept 2025

**NHS**

**Lothian**

NHS RESEARCH SCOTLAND

**NEUROPROGRESSIVE  
AND DEMENTIA**

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## Introduction

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The Neuroprogressive and Dementia Network (NDN) Team in NHS Lothian was established in 2015 following the successful expansion of the Scottish Dementia Clinical Research Network. The core Lothian NDN team is comprised of a team of Clinical Studies Officers supported by a team of clinicians with an interest in clinical research, with a shared purpose of delivering of high-quality clinical research for people living a neurodegenerative condition. People with neurodegenerative conditions are passionate about supporting the development of a translational research programme specific to their needs. They have a powerful desire for a local research programme and are very generous with their support. We will continue to build on our strong record of patient and public involvement and create multiple opportunities for our patient community to engage and participate. In addition, education and training for colleagues is vital to promote safe trial conduct, professional development. retention and wellbeing.

## Vision

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To facilitate the delivery of cutting edge, meaningful and inclusive and innovative clinical research for every person affected by a neurodegenerative disease in Lothian.

## Areas of Focus

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Our team works to address the priority areas identified in the national NDN strategy (2022-27) and NHS Lothian R&D strategy (2022-27).

- Delivering Clinical research
- Partners in Research
- Recruitment
- Engagement
- ENRICH Scotland
- Scottish Dementia Brain Tissue Bank
- The Future

## Objectives

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### Delivering Clinical research

1. Increase participation in clinical research for those affected by neurodegenerative diseases.
2. Have clearly defined metrics of success (recruitment and income).
3. Foster links with academia and industry to grow our commercial portfolio.

### Partners in Research

4. Collaborate with patients to ensure that they are involved at every step of their research journey.
5. Engage with underserved communities and groups.

### Recruitment & Engagement

6. Raise the profile of the Lothian NDN team and our clinical research expertise with national and international organisations and committees to maximise clinical research opportunities.
7. Engage with local clinical services to embed clinical research as part of routine clinical care.
8. Actively engage with charity and third sector organisations to enhance opportunities for promoting clinical research opportunities.

### ENRICH Scotland

9. Support the activity of the ENRICH programme.

### Scottish Dementia Brain Tissue Bank

10. Increase number of donors by offering the possibility of signing up to the Scottish Dementia Brain Tissue Bank.
11. Maintain high quality clinical data and harmonise with other datasets.
12. Explore the possibility of including as much of the Lothian population.

### The Future

13. Develop our skilled and educated team, underpinned by clear pathways for professional development and career progression.
14. Encourage and develop the next generation of clinical researchers and investigators to advance their clinical research careers.
15. Develop, grow and sustain successful collaborations with the University of Edinburgh.
16. Maintain financial sustainability by growing our commercial portfolio.

## Plan

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### 1. Increase participation in clinical research for those affected by neurodegenerative diseases.

1. Increase the number of academic, investigator-led and commercial observational and interventional studies that test potentially disease-modifying therapies and symptomatic treatments.
2. Promote use of research registers (i.e. Permission to Contact and NeuroCARE) in all relevant clinical settings and specialties to maximise research participation opportunity and diversity.
3. Attend and support external patient facing meetings and public events.
4. Engage with charities (e.g. Alzheimer's Scotland, Parkinson's UK, Cure Parkinson's, PSP Association, Lewy Body Society, Scottish Huntington's Association) to promote 'Permission to contact', active clinical studies and our work.
5. Participate in networks to promote the NDN Lothian team (e.g. UK PD CSG, NIHR RDN, SDRC).
6. Engage with individual clinicians and clinical teams across Lothian (neurology, old age psychiatry and medicine of the elderly) to highlight active research studies and embed research activity within teams.
7. Maintain public facing NHS Lothian NDN team website.
8. Promote team and study activity via NRS NDN 'X', Facebook, and the national NDN team meetings and newsletters.

### 2. Develop our skilled and educated team with clear pathways for professional development and career progression.

Education and training for colleagues is vital to promote safe trial conduct, professional development, happiness and wellbeing.

1. Ensure team culture reflects values of NHS Lothian and promotes wellbeing.
2. Encourage and support professional development and learning via formal and informal learning opportunities.
3. Develop induction packs with required research training for new NDN Lothian team members.
4. Succession planning within the team.
5. Identify individual career progression and development pathways.
6. Promote teaching by becoming a placement site for student nurses and medical students.
7. Ensure that all registered nurses within NDN Lothian are practice supervisors and practice assessors to support student nurses.
8. Regular learning events as a team.
9. Support costs of study leave attendance.
10. Regular team meetings.

### 3. Support and develop the next generation of clinical researchers and investigators to advance their research careers and grow local investigator capacity.

1. Offer interested clinicians the roles of sub investigator and training such as the NIHR Associate PI Scheme
2. Outreach to doctors in training to highlight the value of clinical research and research opportunities in modern medical careers.
3. Support the NIHR Principal Investigator Pipeline Programme (Research nurses and midwives).

#### 4. Raise the profile of our team and our clinical research expertise and capacity.

As a relatively small team in a large organisation, it is vital that we raise our profile both locally and nationally. This will help us attract research studies to our site.

1. Participate in national committees and networks, e.g. UK PD CSG, NIHR RDN, SDRC.
2. Maintain public facing NHS Lothian NDN team website.
3. Promote team and study activity via the NRS NDN 'X' and Facebook accounts and the national NDN team meetings and newsletters.

#### 5. Engage with clinical services to promote and embed clinical research as part of routine clinical care.

Joining up routine clinical care with access to clinical research is a key ambition of this strategy. Clinical services are provided by neurology, old age psychiatry and geriatric medicine across all localities within NHS Lothian supported by Community Mental Health Nurses, Parkinson's Nurse Specialists and allied healthcare professionals. While this allows care to be provided close to patient's homes, it can make it more challenging to recruit to clinical research. We will also engage with clinical management teams to highlight the value of clinical research.

1. Maintain a register of local clinical teams.
2. Identify and support clinical research champions within in each service.
3. Make it easier for patients to be involved without adding to clinical time burden, e.g., promote Permission To Contact and NeuroCARE.
4. Engage with clinical teams across localities, contribute to teaching and local team meetings.
5. Engage with clinical management teams to support clinical research activity.

#### 6. Collaborate with patients to ensure that they are involved at every step of their research journey.

People with neurodegenerative conditions are passionate about supporting the development of a translational research programme specific to their needs. They have a powerful desire for a local research programme and are generous with their support. We will continue to build on our strong record of patient and public involvement and create multiple opportunities for our patient community to engage and participate.

1. Raise awareness of the 'Partners in Research' programme in Lothian and through local charities and third sector groups.
2. Link in with local disease-specific groups (e.g. Edinburgh Parkinson's Branch, Edinburgh Research Interest Group to promote active clinical studies.
3. Work with local community charities and third sector groups to promote 'Partners in Research'.
4. Collaborate with the national NDN team to develop a plan for underserved populations to ensure equity of opportunity to research being led by Emma Law (see appendix.
5. Create links with GP practices and local healthcare providers to share research participation opportunities.
6. Promote professional development opportunities for colleagues to learn about effective public and patient engagement.

## 7. Develop, grow and sustain successful collaborations with the University of Edinburgh.

The UoE is a key academic partner. All members of our team hold substantive or honorary contracts with the University of Edinburgh. Within UoE there are considerable opportunities for synergy and growth.

1. Ensure new team members have honorary UoE status.
2. Highlight our capability and capacity to colleagues in CCBS and the wider Edinburgh Neuroscience community.
3. Work with colleagues in Anne Rowling Regenerative Neurology Clinic, Edinburgh Clinical Research Facility, ACCORD, Edinburgh Imaging Facility, Edinburgh Dementia Prevention and the Alzheimer's Scotland Dementia Research Centre.

## 8. Foster links with industry to grow our commercial research portfolio.

We will proactively engage with industry, NRS Feasibility teams and Contract Research Organisations (e.g. PPD, Quintiles, Roche) to be a visible, responsive and effective trial site.

1. Use effective social media platforms.
2. Timely completion of feasibilities.
3. Develop relationships with key industrial partners to ensure national visibility.
4. Ensure timely feedback from sponsors, CROs following expression of interests.
5. Respond to sponsor and CRO feedback to better understand the needs of sponsors and CROs to further grow the commercial portfolio.

## 9. Actively engage with charity and third sector organisations to enhance opportunities for promoting clinical research opportunities.

1. Engage with key charity partners, including Alzheimer's Scotland, Parkinson's UK, Cure Parkinson's, PSP Association, Lewy Body Society to highlight our capability and capacity, promote permission to contact and advertise active clinical studies relevant to their membership.
2. Attend and support external patient facing meetings and public events.

## 10. Ensure the financial sustainability of the team to deliver clinical research in Lothian.

1. Embed Edge as the activity and financial tracking platform for all clinical studies (where appropriate) and ensure team are trained in correct use to accurately record all trial activity.
2. Regular meetings with management accountant team.

## 11. Metrics of success.

1. Number of people participating in NDN research studies.
2. Number of active and completed clinical studies for each condition.
3. Number of academic and investigator led studies.
4. Number of commercial studies and income generated to ensure financial sustainability of the team.
5. Staff retention and wellbeing.
6. Number of public-facing events and presentations.
7. Number of registrations with 'Permission to contact' and NeuroCARE.
8. The above will be presented via our Annual Report and NDN Annual Meeting presentation.

## Appendix 1. Clinical Research Activity

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### Open to Recruitment (2025/26)

#### **TOPHAT: Trial of Ondansetron as a Parkinson's HALLucinations Treatment**

**Type:** CTIMP. UK Multicentre. Phase 3 study  
**Sponsor:** University College London  
**CI:** Prof Suzanne Reeves, UCL  
**Funder:** Parkinson's UK  
**PI:** Dr Gordon Duncan

#### **COBALT: COmBining memantine And cholinesterase inhibitors in Lewy body dementia (PDD and DLB) treatment Trial**

**Type:** CTIMP. Multicentre Phase 3  
**Sponsor:** Cumbria, Northumberland, Tyne and Wear NHS Foundation Trust and Newcastle University  
**CI:** Prof John-Paul Taylor, Newcastle University  
**Funder:** NIHR – Health Technology Assessment  
**PI:** Dr Gordon Duncan

#### **CAN-PDP: CANNabidiol for Parkinson's Disease Psychosis**

**Type:** CTIMP. Phase 2A  
**Sponsor:** Kings College London and the South London & Maudsley NHS Foundation trust  
**CI:** Prof Sagnik Bhattacharyya, KCL  
**Funder:** Parkinson's UK  
**PI:** Dr Gordon Duncan

#### **ENROLL-HD: A Prospective Registry Study in a Global Huntington's Disease Cohort**

**Type:** Observational  
**Sponsor:** CHDI Foundation, Inc  
**CI:** G. Bernhard Landwehrmeyer  
**Funder:** CHDI Foundation, Inc.  
**PI:** DR Peter Foley

#### **HEALTHE-RND: European eHealth Care Model for Rare Neurodegenerative Diseases: Development of HD-specific outcome measures**

**Type:** Observational  
**Sponsor:** Galen Research  
**CI:** Dr. Ramona Moldovan  
**Funder:** EU Joint Programme – Neurodegenerative Disease Research (JPND-research)  
**PI:** Peter Foley

## Closed to Recruitment – in follow up (2025/26)

### **EVOKE/EVOKE+: Investigating Semaglutide in People with Early Alzheimer’s Disease**

**Type:** CTIMP. UK Multicentre. Phase 3 study  
**Sponsor:** NovoNordisk  
**CI:** Dr Najj Tabet  
**Funder:** NovoNordisk  
**PI:** Dr Tom Russ

### **DFP: Deep and Frequent Phenotyping; Combinatorial Biomarkers for Dementia Experimental Medicine**

**Type:** Observational  
**Sponsor:** University of Oxford  
**CI:** Prof Vanessa Raymont  
**Funder:** DPUK  
**PI:** Dr Catherine Pennington

### **Effects of Bacillus subtilis PXN21 on blood and gut biomarkers in Parkinson’s disease**

**Type:** Interventional  
**Sponsor:** University of Edinburgh  
**CI & PI:** Dr David Breen, University of Edinburgh  
**Funder:** Reta Lila Weston Trust

## Upcoming in 2025/6

### **Biohaven: A Phase 2/3, Double-Blind, Placebo-Controlled Study of BHV-8000 in Participants with Early Parkinson's Disease**

**Type:** CTIMP. Global Multicentre Phase 2/3 study  
**Sponsor:** Biohaven  
**CI:**  
**Funder:** Biohaven  
**PI:** Dr Gordon Duncan

### **MINDSET 2: Phase 3, Randomized, Double-Blind, Placebo-Controlled, Parallel-Group Study to Evaluate the Efficacy and Safety of KarXT + KarX-EC for the Treatment of Cognitive Impairment Associated with Mild to Moderate Alzheimer's Disease**

**Type:** CTIMP. UK Multicentre Phase 3 study  
**Sponsor:** Bristol-Myers Squibb Company  
**CI:** Prof Vanessa Raymont  
**Funder:** Karuna Therapeutics  
**PI:** Dr Tom Russ

### **FAST: Feasibility and acceptability study of scalable biomarkers of brain health**

**Type:** Blood based biomarker (UK Multicentre)  
**Sponsor:** University of Oxford  
**CI:** Dr Ivan Koychev, University of Oxford  
**Funder:**  
**PI:** Jessica Crossan

### **(PROSPECT-M-UK ExPRESS): Progressive Supranuclear Palsy Cortico-Basal Syndrome Multiply System Atrophy Longitudinal Study (UK)**

**Type:** Observational. UK Multicentre study  
**Sponsor:** University College London  
**CI:** Prof Huw Morris, UCL  
**PI:** Dr Gordon Duncan

### **ASPro-PD: Ambroxol for Parkinson's**

**Type:** CTIMP. UK Multicentre Phase 3 study  
**Sponsor:** University College London  
**CI:** Prof Tony Schapira, University College London  
**Funder:** Cure Parkinson's  
**PI:** Dr David Breen

### **EJS ACT-PD: Multi-arm, multi-stage trial Edmond J. Safra Accelerating Clinical Trials in Parkinson's disease: A Multi-arm Multi-stage Platform Trial for potential disease modifying approaches**

**Type:** CTIMP, UK Multicentre Phase 3 study  
**Sponsor:** University College London  
**CI:** Prof Camille Carrol, Newcastle University & Prof Tom Foltynie, University College London  
**Funder:** NIHR (Lead Funder)  
**PI:** Dr David Breen

## Completed studies up to 2025

### **EXENATIDE-PD3: A randomised, double blind, parallel group, placebo controlled, Phase 3 trial of Exenatide once weekly over 2 years as a potential disease modifying treatment for Parkinson's disease**

**Type:** CTIMP. UK Multicentre. Phase 3 study  
**Sponsor:** University College London  
**CI:** Prof Tom Foltynie, UCL  
**Funder:** NIHR – HTA  
**PI:** Dr Gordon Duncan

### **ROPAD: Rostock International Parkinson's Disease Program**

**Type:** International epidemiological observational non-interventional  
**Sponsor:** Centogene AG Rostock  
**CI:** Prof Peter Bauer  
**Funder:** Centogene AG Rostock  
**PI:** Dr David Breen

### **CHIEF-PD: Cholinesterase Inhibitors to Prevent Falls in Parkinson's Disease**

**Type:** CTIMP. UK Multicentre. Phase 3 study  
**Sponsor:** University of Bristol  
**CI:** Dr Emily Henderson, University of Bristol  
**Funder:** NIHR – HTA  
**PI:** Dr Gordon Duncan

### **ADepT-PD: Antidepressants Trial in Parkinson's Disease - A Randomised Controlled Trial of Escitalopram and Nortriptyline compared to placebo, together with standard psychological care, for depression in Parkinson's disease**

**Type:** CTIMP. UK Multicentre. Phase 3 study  
**Sponsor:** University College London  
**CI:** Prof Anette Schrag, UCL  
**Funder:** NIHR – HTA  
**PI:** Dr Gordon Duncan

### **START-Up: Stimulation of the Tibial Nerve: A randomised trial for urinary problems associated with Parkinson's**

**Type:** Non CTIMP, UK Multicentre Interventional study  
**Sponsor:** Glasgow Caledonian University  
**CI:** Prof Doreen McLurg, Glasgow Caledonian University  
**Funder:** Parkinson's UK & Dunhill Trust  
**PI:** Dr Gordon Duncan

### **PD COMM: A Multi-Centre Randomised Controlled Trial to Compare the Clinical and Cost Effectiveness of Lee Silverman Voice Treatment Versus Standard NHS Speech and Language Therapy Versus Control in Parkinson's Disease**

**Type:** Non CTIMP, UK Multicentre Phase 3 study  
**Sponsor:** University of Birmingham  
**CI:** Prof Catherine Sackley, King's College, London  
**Funder:** NIHR - HTA  
**PI:** Dr Gordon Duncan

**Investigating skin chemicals as a new way to diagnose Parkinson's disease**

**Type:** Non CTIMP - Observational. UK Multicentre  
**Sponsor:** University of Manchester  
**CI:** Prof Perdita Barran, University of Manchester  
**Funder:** Parkinson's UK  
**PI:** Dr Gordon Duncan

**Psychological adjustment in people with Parkinson's disease and caregivers: the role of coping, illness beliefs and self-compassion**

**Type:** Non CTIMP (observational)  
**Sponsor:** University of Edinburgh / NHS Lothian  
**CI:** Lorna Hodge, University of Edinburgh  
**PI:** Dr Gordon Duncan

**National audit to determine the prevalence of progressive supranuclear palsy (PSP) and corticobasal degeneration (CBD) in Scotland**

**Type:** Survey / observational.  
**Sponsor:** University of Aberdeen  
**CI:** Dr Carl Counsell, University of Aberdeen  
**Funder:** CSO  
**PI:** Dr Gordon Duncan

**DLB Genetics: Detecting Susceptibility Genes for Dementia with Lewy Bodies**

**Type:** UK Multicentre Observational / Genetics Study  
**Sponsor:** Cardiff University  
**CI:** Dr Rebecca Simms, Cardiff University  
**Funder:** Welsh Government / Health and Care Research Wales  
**PI:** Dr Gordon Duncan

**AD Genetics: Detecting Susceptibility Genes for Alzheimer's Dementia**

**Type:** UK Multicentre Observational / Genetics Study  
**Sponsor:** Cardiff University  
**CI:** Dr Rebecca Simms, Cardiff University  
**Funder:** Welsh Government / Health and Care Research Wales  
**PI:** Dr Lewis Killin

## Appendix 2: Current NDN Staff

<b>Name</b>	<b>Role</b>	<b>Profession</b>
Jessica Crossan	Senior CSO	RGN
Bev Goldberg	CSO	RGN
Emma Fleming	CSO	RGN
Marian Montana	CSO	Psychologist
Bernie McInally	CSO	RMN
Gordon Duncan	Clinical Lead and PI	Consultant Geriatrician
Tom Russ	Network champion and PI	Consultant Psychiatrist
David Breen	PI	Consultant Neurologist
Catherine Pennington	PI	Consultant Neurologist
Peter Foley	PI	Consultant Neurologist

## Appendix 3. Underserved Populations living in Lothian

Emma Law, the Strategic Manager for the NDN in Scotland is leading this work and is seeking various groups engagement in our aims of encouraging people to sign up for permission to contact. Progress has been made in Lothian with MECOPP (Minority Ethnic Carers of people Project) based in Edinburgh, Men's Shed Movement, the Cyrenius, The Edinburgh Mosque, and the Gypsy/traveller community. There has been an enormous uptake of Care Homes in Lothian who are signed up to ENRICH (Enabling Research in Care Homes) Scotland. This facilitates one of the unheard and underserved population to be included in research.

