



NEUROPROGRESSIVE
AND DEMENTIA

Neuroprogressive and Dementia Network

Annual Report 2022/2023

Covering Period: 01/04/2022 – 31/03/2023

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Report Published On: 24/04/2023



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Neuroprogressive and Dementia Network

Dementia is one of the foremost public health challenges worldwide. As a consequence of improved healthcare and better standards of living more people are living for longer. This means in Scotland that the number of people with dementia is expected to double between 2011 and 2031.

At the same time, neuroprogressive diseases including Motor Neurone Disease, Parkinson's disease, Huntington's disease, and Multiple Sclerosis are increasingly understood to have commonality in underlying causes, patient experience, symptoms and their management.

To advance understanding of the diseases and new treatments, interdisciplinary research is crucial. Supported by the NRS Neuroprogressive and Dementia Network a wide range of research studies are conducted within the NHS and Care Home settings including research into the underlying mechanisms and causes; prevention; new symptoms; disease-modifying treatments and better care

OUR MISSION

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



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We support researchers from across a range of disciplines and deliver this research across Scotland in a wide range of healthcare settings, including primary and community care, mental health services and acute hospitals. Research capacity in Huntington's disease and Motor Neurone Disease is also being increased with 3-year Clinical Research Fellowships being jointly funded with CSO.

This report has been compiled by measuring what we have achieved compared to our targets that we set in the 2022-2027 strategy.

Headline Achievements

In the 2022-23 financial year, the NDN has maintained a complex and changing portfolio, with 62 unique studies being supported across 8 health boards, in multiple locations.

We have supported academic research studies such as TOPHAT (Ondansetron in Parkinson's and Lewy Body Dementia) and Chief PD (Cholinesterase Inhibitor to prevent falls in Parkinson's Disease) as well as larger commercial studies with pharmaceutical companies such as Roche, Biogen, Abbvie, Novo Nordisk and Merck, which has meant that we have been able to support participants from all over Scotland to take part in high quality research into some of the most impactful medical issues we face today.

We have expanded our portfolio to include NDN staff working on Future MS2 in collaboration with the Ann Rowling Clinic which is a natural progression from staff working with people with Motor Neuron Disease in the MND-SMART trial.



NDN infrastructure has been used to support ENRICH Scotland by having the network manager as a co-chair of ENRICH enabling the financial overview and management of ENRICH Scotland' staff and budget to be used in the most productive way.

We delivered a successful hybrid conference in September 2022 in Edinburgh University grounds that was well attended. The feedback from this was that the format and range of speakers brought together provided a balanced and well-rounded look at the state of neuroprogressive research in Scotland today.

We were involved in the planning, evaluation and launch of the second wave national rater programme coordinated by NIHR.



Partners in Research

Over the last year, the NRS Neuroprogressive and Dementia Network's 'Patient and Public Involvement' group has been co-developed into Partners in Research. The network has reshaped their strategy going forward including funding a Partners in Research Lead to coordinate this aspect of our work and bringing meaningful involvement of people with lived experience of neuroprogressive conditions and dementia to the centre of the Network's activities. A key part of this has been providing a platform to share their stories and have their voices heard, before focusing on the more research-centred activities.



Partners in Research worked with Palgrave Publishers to write a book entitled "**Challenging Assumptions Around Dementia: User-led research and untold stories.**" Partners in Research will be hosting a book launch on the 1st September 2023 where co-authors will share their experience of writing the book together.

We received external funding from The Royal Society of Edinburgh to work with Partners in Research on a co-production strategy for research in Scotland. A core team of people with lived experience of dementia have been holding workshops with healthcare professionals, and people who are working in the field of dementia or neuroprogressive diseases, to explore different peoples understanding of research and co-production.

Over the next few months, we will be holding workshops which focus on ethics in research, as well as exploring the role of research for third sector organisations. It has been a challenge to bring together so many groups of people, particularly at a time of where people are still rebuilding post-covid-19 and there is a concern of research-fatigue. By

developing the work with our core team, we can do our best to make involvement valuable, and manageable within the wider context of commitments people are currently facing.

Over the next year our focus will be on developing research proposals led by people with lived experience. To do this we will offer support and training for our Partners in Research to develop their activities and review, design and collaborate on research submissions.

As part of both the Co-production Research Strategy and the research development opportunities, we will explore how research ethics systems could work better for research involving people with lived experience of neuroprogressive conditions or dementia.

Our main area of improvement going forward will be in building stronger ties with people affected by non-dementia neuroprogressive conditions including Parkinson's, Huntington's, Multiple Sclerosis, and Motor Neurone Disease. We are reaching out to the 'patient and public involvement' leads for the different organisations that support people with neuroprogressive conditions. We are keen to explore what meaningful involvement will look like and the types of activities that people would like to see.



Recruitment



Access to the NDN's primary recruitment tool 'Permission to Contact', has been widened with it being accepted as a study in own right on national Join Dementia Research (JDR) site. We have also developed online access for 'Permission to Contact' which we expect to go live before the end of April 2023.

Recruitment to studies remains a challenge and our involvement in JDR, Permission to Contact and other local recruitment drives for specific studies is our best hope in recruiting to time and target.

The NDN national administrator has worked closely with Alzheimer Scotland staff to maintain and update Scottish studies on the JDR database. We are keen to work more closely with JDR as we have found through regular staff meetings with JDR staff, raising awareness of the service at the conferences we organise and encouraging researchers to engage with JDR as a recruitment pathway we are able to support people from a wide variety of backgrounds and ability levels to take part in meaningful research.

The other neuroprogressive diseases have been added to our Permission to Contact forms to allow staff to contact people who have signed up to this.

Tom and Emma are to visit Shetland in June 2023 to deliver the confident conversations programme to Alzheimer Scotland staff, meet clinicians who work in the field of dementia or neuroprogressive illnesses and work with the people who are affected by these diseases to come up with solutions of how they could best be involved in research.

We started the programme of educating all key Alzheimer Scotland staff in how to have a 'confident conversation' about research. It is agreed that these staff are key to assisting in the aim to offer everyone with a diagnosis of dementia the opportunity to participate in research.



ENRICH



We have increased the number of care homes from less than 100 to 177 by March 2023. We have a monthly newsletter, blog and PPI group 'Rich (Research in Care Homes) Voices'.

With subsequent funding from the Chief Scientist Office, the ENRICH Scotland team plan to:

- Prioritise the support of recruitment of care home residents and staff to relevant studies.
- Maintain and building the network of Research Ready care homes across Scotland.
- Support Research Active care home members of the Lothian and Glasgow City CHIPs with research involvement.
- Build on the success of CHIPs and expand to other health board areas.
- Continue to offer individualised assessment of support to research teams that are considering involving Scottish care home staff, residents and/or relatives.
- Be involved with the Social Care REC Short Life Working Group (SLWG). This group's work is dedicated to the formation of a new Social Care REC within NHS Research Scotland. Developing a REC which will be able to support social care-based research projects is the group's main objective. Supporting research in care homes is



going to be one of the main remits for the new REC. The outcome for the group's work is going to be presented to the Chief Scientist Office in a format of a business case with further research governance recommendations.

- Build the RICH Voices PPI group.

The Challenges of ENRICH include being able to reach all the care homes in all geographical locations using the resources we have. We have tried to employ people in all mainland boards in Scotland, but this proves difficult when there is only 2 hours per week of funding of a member of staff, for the smaller boards.

We are starting to explore how we can improve this by using the resources we have to their maximum potential i.e. increase the funding to Lanarkshire as the Clinical Studies Officer there, has a previous relationship with some of the care homes and staff who work in them and can potentially recruit these care homes to ENRICH.



Engagement

As of February 2023, 115 Alzheimer Scotland dementia advisors / link workers / post-diagnosis support workers have undertaken the Confident Conversations training, building connections between NDN and Alzheimer Scotland to enhance capabilities and confidence in discussing, promoting and enabling participation in research.

We hope to expand this to charities working in other disease areas in due course

We delivered a successful hybrid conference in September 2022 that brought together researchers, charity organisations and those with neuroprogressive diseases in triads, to speak together about how the research landscape has changed, and what benefits the inclusion of more voices in research protocol design have brought about. The talks were delivered in triads of researcher, research participant and charity representative including Multiple Sclerosis, Parkinson's Disease, Huntington Disease and Motor Neuron Disease. This proved to be a popular and successful format.

We had high level representation throughout the conference with Henry Simmons of Alzheimer Scotland as our first Keynote speaker, Dr Rosie Ashworth, lead for the NDN Dementia Partners in Research as our second Keynote and Dianne Gove, Director for Projects in Alzheimer Europe as our final Keynote speaker.



Tom Russ has become the vice chair of the Scottish Dementia Research Consortium (SDRC) and represents the NDN at meetings. We have been able to secure a speaker's slot at their up-and-coming conference.

In 2022/23 we delivered a training session to higher trainees about research, its implications and how to connect locally with the research team and become involved. We aim to deliver this in 2023/24.

We have been asked to attend the Scottish Faculty of Old Age Psychiatrists to deliver a session on the Network and this is a prime opportunity to engage with clinicians.

We have also supported two members of staff to achieve their Master's degrees while working in the NDN. Subsequently, a member of staff working in the Tayside team – Tiffany Stewart - has been accredited as Scotland's first Clinical Research Practitioner.



Alzheimer Scotland Brain Tissue Bank

There was a name change in 2022 from the Scottish Dementia Brain Tissue Bank to the Alzheimer Scotland Dementia Brain Tissue Bank (ASDBTB), which immediately increases the information to a wider audience about what the role and purpose of the sign-up and consequent donation offers for people with dementia.

The ASDBTB is now featured as a study on JDR. The team have been distributing leaflets about both joining JDR and the ASDBTB during the Confident Conversations training days, to enable staff to have another suggestion of how people who may be interested in participating in research, sign up for brain tissue donation. We are exploring if we can include people who live remotely i.e. on the Scottish Islands, could be involved.



Delivering Clinical Research

We have grown in reputation over the years and continue to be approached by major pharmaceutical companies to include the NDN in studies at an early stage.

We have been able to extend our portfolio of Parkinson's disease research in Lothian, Greater Glasgow & Clyde and Tayside. We have been involved in Huntington's research delivery in Grampian, Tayside and Lothian. We are now working on our first Multiple Sclerosis study - FutureMS2 in Grampian and Tayside, with the Ann Rowling Clinic in Lothian.

We plan to expand our outreach work to ensure all these disease areas are included in our newsletters and sign-up forms such as Permission to Contact. The work done in both Confidential conversations work, and our PPI outreach has striven to increase the number of people taking part in research.



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