



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



# Contents

	Page
<b>Forewords</b>	
<a href="#">Our Partners in Research</a>	3
<a href="#">Professor David Crossman</a>	5
<a href="#">Kevin Stewart, MSP</a>	6
<a href="#">Professor Siddharthan Chandran</a>	7
<a href="#">Professor Craig Ritchie</a>	8
<hr/>	
<b><a href="#">Summary</a></b>	9
<hr/>	
<b>Commitments of the Network</b>	11
<a href="#">Summary of commitments</a>	11
Section 1 <a href="#">Background</a>	13
Section 2 <a href="#">Partners in Research</a>	16
Section 3 <a href="#">Recruitment into Research</a>	20
Section 4 <a href="#">ENRICH (ENabling Research In Care Homes)</a>	22
Section 5 <a href="#">Engagement</a>	25
<a href="#">Engagement with third sector organisations</a>	25
<a href="#">Engagement with Centres of Excellence</a>	29
<a href="#">Engagement with Health and Social Care</a>	30
<a href="#">Engagement with Academics</a>	32
Section 6 <a href="#">Scottish Dementia Brain Tissue Bank</a>	36
Section 7 <a href="#">Delivering Clinical Research</a>	41
Section 8 <a href="#">The Future</a>	43
<hr/>	
<b>Annex</b>	44
<a href="#">Abbreviations</a>	

## Our Partners in Research

*“Living with a neurodegenerative auto-immune condition like Multiple Sclerosis (MS) is like living with a big uncertainty in life. Not knowing when a bad day could spin you around. I have had MS for over 21 years and in these years, I have had my ups and many of my downs. I know that I have my disease modified drugs with me and thanks to continuous MS research, I can take these medications.*

*“At first these were injections and now they are tablets thanks to research. This might seem a small thing, but for a patient living with a chronic disease, having a life without injections is a big change. The drugs certainly will not cure me, but I see it as an insurance policy, as hope, in that taking these medications my life gets this protective coating where I carry on living another ‘normal’ day. Ongoing research in any neurological condition is vital, I have seen this with MS and it creates immense hope and support for many loved ones that we are with and around us.*

*“I have been included in several research studies for MS and it gives me positivity to know that our views are included and that there may be new treatments on the horizon.”*

**Abhishek Behl, Person living with Multiple Sclerosis**

*“Having nursed my late mother who died of Huntington’s disease (HD), having inherited the gene which causes HD myself, and having three beautiful daughters who each have a 50% chance of inheriting the condition, research is vital to me, my family and the entire HD community. Whilst services provided by Scottish Huntington’s Association are a lifeline in the now, we all long for a treatment for the future that will change the nature of this disease completely and offer us and our future generations a better quality of life.*

*“Despite the brutality of the disease, the HD community is strong and resilient – the knowledge that research is ongoing keeps us hopeful. I therefore welcome the NRS Neuroprogressive and Dementia Network’s new strategy and know the Huntington’s disease community will get behind it in any way possible as we strive to find a viable treatment for HD.”*

**Gillian McNab, Huntington’s disease family member**

*“I have early-stage Alzheimer’s Disease which affects aspects of my cognition, especially my eyesight, but not my episodic memory. I feel that the portrait of dementia that is generally painted is often misleading, and that the symptoms of the associated diseases are more complex than often supposed. People living with these neurodegenerative conditions are best placed to identify their concerns and to therefore influence research.*

*“We all, of course, want cures – but we also need help in our everyday lives. If research could find ways to help me cope with the challenge of not being able to see the black zip on my dark coloured suitcase, it would literally open up opportunity!”*

**Partner in Research member**

*“In the two years I have had MND it’s stripped me of every part of my independence. I have gone from working full time and living alone with my dog to living with my mum, needing carers four times a day and not being able to work.*

*“I need help with absolutely everything, from washing and dressing to feeding. I wear a ventilator at night because my breathing isn’t strong enough when I’m flat on my back. It’s so devastating. There needs to be a breakthrough to find some form of treatment, and hopefully one day a cure.*

*“We have progressed so much with so many other illnesses, like cancer and HIV, you can now treat them, there are options. For MND there are not any options and I feel it has been left behind.*

*“It takes such a long time to find something, and it has to go through so many stages if it is a new drug, for example. But MND does not wait.”*

**Partner in Research member**

# Professor David Crossman

Chief Scientist for Health  
Scottish Government



*"I am pleased in my role as Chief Scientist for Health within the Scottish Government to support this strategy.*

*The conditions that come under the remit of the Network are always challenging to patients and their loved ones and can often be life-changing.*

*Recent advances in the diagnosis, treatment, and management of these conditions have been possible because of research, and in particular the willingness of patients to participate in clinical trials.*

*The NRS Neuroprogressive and Dementia Network has played a key role in enabling many of these clinical trials to take place in Scotland, thereby offering patients from across the country, and living with different conditions, the opportunity to participate in research.*

*Looking forward, I am optimistic that, as our knowledge increases, patients will benefit both from earlier diagnosis, and from highly personalised, evidence-based approaches to treating and managing their conditions.*

*The NRS Neuroprogressive and Dementia Network will continue to ensure that patients here are well-placed to participate in high quality and innovative clinical studies. It is through this work that advances will continue to be made for the benefit of patients and those close to them."*

# Kevin Stewart MSP

Minister for Mental Wellbeing  
and Social Care  
Scottish Government



*“As Minister for Mental Wellbeing and Social Care, I am pleased to support this research strategy, which will complement the first Dementia Clinical Research Strategy that was published earlier this year.*

*These strategies show the expertise of Scotland’s research communities in the areas of neuroprogressive conditions and dementia and the determination of those researchers to make a difference for the people of Scotland – and beyond. Progress in these key areas require sustained global action and collaboration, and I am proud to see Scotland playing its part in that global endeavour.*

*We continue to provide funding support for clinical research into these important areas and, more recently, into Brain Health Scotland which is developing its first national strategy and with whom we are working to develop new clinical approaches to brain health as a way of detecting dementia risks at the pre-symptomatic stage.*

*I have a strong focus as Minister to listening extensively to the public and to people with lived experience of dementia and neuroprogressive illnesses and so I am particularly gratified that this strategy has a major focus in maximising the meaningful participation of research participants across care settings.*

*I look forward to continuing to support this important agenda, which complements other extensive action across the Scottish Government and with partners, including our Dementia COVID-19 Recovery Plan and our consultation on the National Care Service.”*

## Professor Siddharthan Chandran

Director of the Centre for Clinical Brain Sciences, Edinburgh Neuroscience, the Euan MacDonald Centre, and the Anne Rowling Regenerative Neurology Clinic, University of Edinburgh



*“Disorders of the ageing brain are a major and growing public health threat. Scotland, enabled by the pioneering NRS Neuroprogressive and Dementia Network, is ideally placed to spearhead the clinical research that is essential to improving the outcomes of people living with these devastating conditions.*

*Recognising that a range of disorders share common underlying disease pathology characterised by neurodegeneration, the Network has widened its research portfolio beyond dementia and plays an important role in delivering a globally ground-breaking UK-wide trial for Motor Neurone Disease (MND). This is called MND-SMART, the first adaptive and multi-arm platform trial for people with MND that is led from Edinburgh.*

*MND-SMART is a pathfinder for how as a community we might increase the opportunities for people diagnosed with a range of neurodegenerative conditions from multiple sclerosis to Parkinson’s to the dementias to participate in clinical research and specifically trials. We need to move to a new default, where opportunities for research and clinical trials are offered to all people diagnosed with presently incurable and progressive neurodegenerative conditions.*

*The Network is an essential element of realising this ambition. It is a perfect time to regroup and promote innovative practice as the COVID-19 pandemic has shown what is possible through collaboration and partnership. The focus on research inclusivity, regardless of geography, has become a more feasible prospect thanks to remote appointments and risk adapted strategies now approved by regulators.*

*For the first time we are seeing patients from Orkney and Shetland being recruited to clinical trials, specifically in this case MND-SMART, and the logistics to facilitate this being led by the Network team in Aberdeen. They have also included a patient whose first language isn’t English, further testimony to the focus on inclusivity.*

*It is a very exciting time for clinical research and trials in neurodegeneration and I look forward to continuing to work with the Network in the years ahead.”*

# Professor Craig Ritchie

Chair of the Scottish Dementia Research Consortium,  
Director of Brain Health Scotland, and Professor of  
Psychiatry of Ageing, University of Edinburgh



*“As chair of the Scottish Dementia Research Consortium I am delighted to relay the consortium’s support of this important Network initiative. Elements within this strategy are of vital importance to all our work including equity of access to research from all parts of Scotland, irrespective of a person’s location, socio-economic status, gender, ethnicity, or race.*

*To achieve this will need substantial and aligned work across many actors in research communication, design, and delivery. In this strategy, the NRS Neuroprogressive and Dementia Research Network carves out their large and important role within this research ‘ecosystem’.*

*It is well known, and referenced throughout this document, how much has been achieved by the Network in recent years which sets an incredible foundation on which we can collectively build. Scotland continues to grow its life sciences portfolio and power through pooling initiatives like SULSA and SINAPSE and fundamental research within the Dementia Research Institute, we lead the world in cohort studies for brain health and ageing and have a leading role to play in care home research and data sciences.*

*Our clinical trials portfolio has room to grow, especially in the preclinical and prodromal space where prevention or disease modifying studies are increasingly at the front of sponsors’ development plans. Scotland is better placed than many countries in the world to deliver on this growth.*

*To fulfil our collective objectives means working closely with the new Brain Health Services in NHS Scotland and NHS Boards more broadly, aligning with the recently published Scottish Brain Health and Dementia Research Strategy, using tools like Join Dementia Research to aid participation in studies, having all clinical staff talking about the importance of research, and delivery of trials in all parts of Scotland for all (potentially) eligible participants.*

*There is a rich tapestry of organisations and people involved in discovery, design, and delivery of knowledge, cohorts, and trials in Scotland for neurodegenerative diseases under the umbrella of SDRC, we influence well above our weight, and the critical role of the Network will be assured and expand secondary to the successful delivery of their strategy. It has full SDRC and Brain Health Scotland support.”*

# Summary

In **Section 1** we are pleased to **look back over the last decade** and see how far things have come in terms of research activity in Scotland. Most importantly, it is great to see the **positive effects** of inclusion in research on the lives of people living with neuroprogressive conditions and dementia. There is still a long way to go, both in terms of discovering disease-modifying treatments or preventative strategies for these conditions and how best to support and care for people affected.

**Section 2** sets out our commitments to move from a place where research is something that is done *to* people with a condition towards a place where research is done *with* them. We are making a commitment to **involve, engage with, and support** people with lived experience of neuroprogressive conditions or dementia and explore how we achieve **involvement of our partners in research** in all facets of our Network.

**Sections 3 and 4** are all about including everybody. **Section 3** focuses on how to offer everyone the opportunity to **engage in research** including those who live in **remote and rural areas** in Scotland, including the islands. In a similar vein, **Section 4** outlines our commitment to include those who live, work, and have loved ones in **care homes** in research.





**Section 5** describes our commitment to **engage** with the **third sector**, the vibrant **current research landscape**, **clinical services**, **students** in healthcare, and **supporting our own staff** to realise their potential as well as acting as an **expert resource in clinical research** to all these sectors.

In **Section 6** we outline our plan to **increase** the number of donors signed up to the **Scottish Dementia Brain Tissue Bank**, including those who live in remote and rural locations and hard to reach populations, ensuring our database harmonises with other databases out there to facilitate being part of international research projects.

**Section 7** describes how we will continue to build on our reputation in **delivering high quality clinical research** to our Scottish population in all disease areas on our portfolio and **increase the numbers** of people able to access research while **nurturing the next generation** of researchers.

Finally, **Section 8** speaks to **the future**: It is exciting to think where we will be a decade from now and the whole Network is delighted to be at the heart of clinical research in Scotland. **We look forward to taking this journey with you!**

## Section 2 – Partners in Research

---

1. Funding a Partners in Research Lead to coordinate this aspect of our work
2. Obtaining external funding to bring together everyone in Scotland interested in involving people with lived experience in research
3. Bringing meaningful involvement of people with lived experience of neuroprogressive conditions and dementia to the centre of the Network's activities
4. Engaging with all the groups and individuals working in this area across Scotland to collaborate on meaningful involvement of people with lived experience of neuroprogressive conditions and dementia in research
5. Supporting our Partners in Research to develop their activities and support them to review and comment on research submissions
6. Exploring how research ethics systems could work better for research involving people with lived experience of neuroprogressive conditions or dementia

## Section 3 – Recruitment

---

7. We will forge closer links with Join Dementia Research (JDR) through regular Scotland-wide meetings including staff from Alzheimer Scotland
8. Ensuring everyone in Scotland with or at risk of a neuroprogressive condition or dementia is offered the opportunity to participate in research
9. Exploring how people in remote and rural locations or on the islands can be involved in research

## Section 4 – ENRICH (Enabling Research In Care Homes)

---

10. Increasing the number of care homes willing to be approached by researchers, while increasing the number of research opportunities in Scotland for people living and working in care homes

## Section 5 – Engagement

---

11. Working with Alzheimer Scotland to foster local links between Network staff and Alzheimer Scotland Dementia Advisors / Link Workers to support them to have confident conversations about research with the people they work with. We hope to expand this to charities working in other disease areas in due course
12. Engaging with the charitable sector to promote research engagement, research recruitment, and to enhance our Partners in Research group
13. Continuing and strengthening our collaborations with the vibrant research landscape in Scotland
14. Engaging with doctors and nurses in training to offer clinical research experience, aiming for as many as possible to complete training in Good Clinical Practice
15. Working with clinical services to offer research opportunities widely
16. Offering support to Network staff to undertake academic work and training
17. Acting as an expert resource in research processes

## Section 6 – Scottish Dementia Brain Tissue Bank

---

18. Increasing the numbers of donors by offering the possibility of signing up to the Scottish Dementia Brain Tissue Bank as widely as possible
19. Maintaining the high quality of clinical data collected and harmonise with other datasets
20. Continuing to explore the possibility of including as much of the Scottish population as possible

## Section 7 – Delivering Clinical Research

---

21. Continuing to build our reputation in delivering cutting edge clinical research in neuroprogressive conditions and dementia across Scotland
22. Increasing the number of people with these conditions taking part in research

## Section 8 – The future

---

23. Nurturing the next generation of Investigators so that excellent research can continue in Scotland, and we can have an impact on cause, cure, and care

## Section 1 - Background

Unlike many other research networks, the CSO-funded **Scottish Dementia Clinical Research Network (SDCRN or the Network)** was not built from established academic centres but was set up in 2008 with the intention of spreading a culture of research across Scotland and improving recruitment from both urban and rural areas.

Leadership of the network was shared with **Professor Peter Connelly (Consultant Old Age Psychiatrist, NHS Tayside)** as Chair, **Professor John Starr (Professor of Health & Ageing, University of Edinburgh)** as Director with key academic responsibilities, and **Dr Emma Law as Network Manager**.



**Professor Peter Connelly**



**Professor John Starr**



**Dr Emma Law**

## SDCRN to NRS NDN

For many years the Network had staff in every mainland Health Board in Scotland.

In 2012 we were welcomed into the European Alzheimer's Disease Consortium linking researchers across Europe and providing an environment to expand resources.

During 2015 the Network expanded its portfolio to include neuroprogressive and neurodegenerative diseases including:

- Motor Neurone disease
- Parkinson's disease
- Huntington's disease
- Multiple Sclerosis
- Creutzfeldt-Jakob disease

The transition in the Network responsibilities from dementia-only to a more comprehensive portfolio was completed by 2016 with the SDCRN being renamed the **NRS Neuroprogressive and Dementia Network (NDN)**.



At the same time the Network was expanding its remit, there was a substantial increase in the number and complexity of studies in the dementia field, mainly driven by a move by the pharmaceutical industry to explore compounds which may be effective in tackling the pathological changes of Alzheimer's disease before clinical symptoms become fully manifest.

*“Setting up a Network of clinical researchers across Scotland, united by the same desire to promote Scotland as a key centre at the forefront of clinical trials, was a huge undertaking. Many who joined us had no experience of working in research. Not everything went smoothly, but everyone persevered. We learnt much along the way, gaining new skills in familiar and unfamiliar illnesses, and became confident in our ability to attract and deliver clinical trials. None of this would have been possible without the commitment of our high-quality staff, but more importantly the commitment of those people who kindly volunteered for the studies we ran in the knowledge that they might not benefit directly but that what they did could benefit others for years to come.”*

**Professor Peter Connelly**

## Staffing

---

Staff turnover was low and new staff were absorbed well into the team. Testament to this is the fact that many of the staff from the early days are still working with the Network.

Participation in more complex studies in differing diseases led to a substantial increase in the level of experience among all staff. Because of the intensity of studies, we had to move away from our previous comprehensive coverage of Health Boards in Scotland with staff being more concentrated in the major centres where these more complex studies are undertaken.

Sadly, in December 2018 Professor John Starr died very suddenly. John was a highly skilled geriatrician and experienced academic. He worked closely with Professor Ian Deary over two decades as Chief Investigator of the Lothian Birth Cohorts of 1921 and 1936<sup>1</sup>, the latter of which is currently being followed up in a sixth wave with participants in their mid-80s. He mentored and supported countless clinicians and researchers and inspired love and gratitude in them.

From 2011 he was Director of the Alzheimer Scotland Dementia Research Centre at the University of Edinburgh. In addition to his medical and scientific skills he was a gifted linguist, graduating with a PhD from the University of Edinburgh in 2013 entitled “A Quantitative Analysis of the Aramaic Qumran Texts”<sup>2</sup> which he completed in his spare time. His thesis was later published in the prestigious T&T Clark Library of Second Temple Studies series<sup>3</sup>.

He was ordained as a Lay Reader in the Scottish Episcopal Church shortly before his death. He continues to be greatly missed and his input to the genesis and development of the Network is widely recognised. For example, in 2021 he was posthumously awarded the Marjorie Warren Lifetime Achievement Award by the British Geriatrics Society.

---

<sup>1</sup> <https://www.ed.ac.uk/lothian-birth-cohorts>

<sup>2</sup> <https://era.ed.ac.uk/handle/1842/8947>

<sup>3</sup> <https://www.bloomsbury.com/uk/classifying-the-aramaic-texts-from-qumran-9780567683137>

Professor Connelly's outstanding contribution to clinical research and practice was acknowledged by his being awarded the lifetime achievement award in older people's mental health by the Faculty of Old Age Psychiatry of the Royal College of Psychiatrists in 2021.

In 2021, Professor Peter Connelly stepped down as Network Champion., to be replaced by Dr Tom Russ. Tom is a Consultant Old Age Psychiatrist in NHS Lothian and succeeded John Starr as Director of the Alzheimer Scotland Dementia Research Centre.



**Dr Tom Russ**

## Collaboration

---



The Network is deliberately and explicitly collaborative. We seek to work with everyone who shares our aim of ensuring everyone with a neuroprogressive condition or dementia has the opportunity of taking part in research.

A portfolio of commercial and non-commercial studies is supported by the network. Working closely with industry is an important part of keeping the NHS at the forefront of modern treatments and research. It helps provide clinicians early access to the latest treatments and technologies for diagnosing and treating disease, whilst offering more opportunities for people living with dementia and neuroprogressive conditions to take part in cutting-edge research.

It should be noted that no individual profits are received by the network for working with industry. Commercial research is funded by pharmaceutical or medical technology companies and helps to generate further research capacity and cover study related and overhead costs.

## Section 2 – Partners in Research

### Commitments

1. Funding a Partners in Research Lead to coordinate this aspect of our work
2. Obtaining external funding to bring together everyone in Scotland interested in involving people with lived experience in research
3. Bringing meaningful involvement of people with lived experience of neuroprogressive conditions and dementia to the centre of the Network's activities
4. Engaging with all the groups and individuals working in this area across Scotland to collaborate on meaningful involvement of people with lived experience of neuroprogressive conditions and dementia in research
5. Supporting our Partners in Research to develop their activities and support them to review and comment on research submissions
6. Exploring how research ethics systems could work better for research involving people with lived experience of neuroprogressive conditions or dementia

The Network has, and continues to be, very active in Patient and Public Involvement (PPI). At its peak our PPI group had almost 200 members with approximately 50 involved in research activities each year.

PPI group members are hugely valuable to the network and contribute in many ways. For example, reviewing study protocols, patient information sheets, leaflets, and grant/fellowship applications, taking part in focus groups, planning and speaking at conferences.

The PPI group were consulted about, and have been involved, in several publications, including:

- Law, Starr & Connelly (2013) Dementia research – what do different public groups want? A survey by the Scottish Dementia Clinical Research Network. *Dementia* **12**: 23–8.<sup>4</sup>
- Darling & Parra (2013) Involving patients and the public in research. *Nurse Researcher* **20**(6): 21-25.<sup>5</sup>
- Law, Russ & Connelly (2013) What motivates patients and carers to participate in dementia studies? *Nursing Older People* **25**(9): 31-36.<sup>6</sup>
- Law, Russ & Connelly (2014) What motivates patients and carers to participate in dementia studies? *International Journal of Geriatric Psychiatry* **29**(1): 106-7.<sup>7</sup>

We strongly believe that the active inclusion of people with lived experience of a health condition in the design, development, and execution of research is essential. For this reason, we intend to bring people with lived experience of neuroprogressive conditions and dementia to the centre of the Network's activities. We have started this with our reinvigorated PPI group who named themselves "Partners in Research" and have ambitious plans to develop this in the future.

We are funding Dr Rosie Ashworth (**Commitment 1: Funding a Partners in Research Lead**) as our Partners in Research Lead to coordinate this work and are excited to announce external funding has been obtained from the Royal Society of Edinburgh (**Commitment 2: Obtaining external funding**). This will help begin the process of bringing together everyone in Scotland interested in involving people with lived experience of dementia or neuroprogressive conditions in research.

---

<sup>4</sup> <https://doi.org/10.1177/0142723711420309>

<sup>5</sup> <https://doi.org/10.7748/nr2013.07.20.6.21.e341>

<sup>6</sup> <https://doi.org/10.7748/nop2013.11.25.9.31.e503>

<sup>7</sup> <https://doi.org/10.1002/gps.3990>

On signing up to be a Partner in Research, we present a number of potential activities that people may have interest in, including:

- providing testimonials
- participating in meetings, groups related to Partners in Research, or other projects
- reviewing research literature and proposals
- involvement in conference events, either speaking or manning a stall

As well as the proposed activities, we will be building on the suggestions of our Partners in Research (**Commitment 3: Bringing meaningful involvement of people with lived experience**) to make sure that the activities we have to offer suit their preferences. For instance, a book proposal and training package (including certification) are both concepts that we hope to build on with the group.

*"Having taught in 3 secondary schools in Scotland for nearly 36 and retiring as the Head of Science Department. I was quite devastated when I was diagnosed with early onset of Alzheimer - Cognitive Impairment about 2 years ago. Alzheimer affecting mainly my short-term memory, confusing words and small tasks.*

*I took the advice from Doddie Weir's book 'My name is Doddie' when he was diagnosed with MND. He wrote that, if he can't beat it, he might as well join them and do something about it. I can see the value of co-production work.*

*I took on his advice and started connecting with numerous groups to do with dementia research, as a Community Researcher; to use my experience as someone living with dementia to influence research, working closely with professional and academic people:*

- *I have been and still am a Community Researcher with the Creating Better Live? An Evaluation of the Life Changes Trust – University of Stirling. Support of Academic staff.*
- *Connecting with Age Scotland – About Dementia as a member of their various Subgroups.*
- *Deepness Group – I organised the first ever Dementia Conference – a Conference organised by People Living with Dementia.*
- *Partners in Research – co-authoring a literature review on co-production and patient and public involvement.*

*I gained a lot by being a member of these organisations and as a Partner in Research, through working with the academic staff and other members of the teams – Carers, Young Carers & People Living with Dementia. It is a good platform for sharing experiences, exchanging ideas & very good debates."*

**Mike Cheung**  
Partners in Research group member

There are already several organisations doing excellent work in this area, such as the **Scottish Dementia Working Group**<sup>8</sup>, the **National Dementia Carers Action Network**<sup>9</sup> (NDCAN), and the **DEEP Network (Dementia Engagement and Empowerment Project)**<sup>10</sup>. We are keen to build on our existing relationships with these organisations and others, as well as engaging with organisations working with people with lived experience of neuroprogressive conditions. In the first instance, this will be through the relevant charities.

We aim to bring together all organisations across Scotland (**Commitment 4: Engaging with all the groups and individuals working in this area across Scotland**) led by and / or involving people living with dementia and neuroprogressive conditions to agree a national consensus how meaningful involvement can be put at the heart of research into these conditions. We plan to collaborate with groups of people with lived experience, third sector, and academic and NHS organisations to develop a unified approach to co-produced work and PPI.

We envisage a series of consensus meetings and focus groups which we hope to start in early 2022. We do not want to duplicate or overlap with excellent work which is already happening and so feel that this consultation and collaboration is likely to lead to the best results for every organisation and person with an interest in this area.

*“I am so grateful to have the opportunity to take part in the MND Smart clinical trials. While I live in hope that I may have a ‘miracle drug’, I also feel very strongly that the only way forward to lessening the impact of this condition is through research.*

*We were overwhelmed by the care and kindness of the Aberdeen team at my initial assessment, who truly went above and beyond to make everything work as smoothly as possible for us, as we travelled from Orkney. It has given me great confidence in the trials and being in easy contact has been very reassuring.”*

**Irene Drever,  
Person with lived experience of Motor Neurone Disease**

*“I think research is really important for HD families because it helps provide hope that potentially life changing treatments could be available for the future.”*

**Person with lived experience of Huntington’s Disease**

---

<sup>8</sup> <https://www.alzscot.org/our-work/campaigning-for-change/have-your-say/scottish-dementia-working-group>

<sup>9</sup> <https://www.alzscot.org/our-work/campaigning-for-change/have-your-say/national-dementia-carers-action-network>

<sup>10</sup> <https://www.dementivoices.org.uk>

In the spirit of co-production, the final areas of focus will emerge in the process of consultation and collaboration, but we have identified some preliminary areas in which we hope our Partners in Research could engage

**(Commitment 5: Supporting our Partners in Research to develop their activities and support them to review and comment on research submissions):**



- **Public engagement** – there are many opportunities to engage with the public as well as people living with dementia about research, to educate, engage, and inform
- **Setting research priorities** – we would like to see people with lived experience of neuroprogressive conditions and dementia informing the direction the Network’s research takes
- **Research ethics** – there is a recognition of the complications surrounding research ethics for projects involving people with neuroprogressive conditions and dementia and all social care research, and we would like to explore how this could be optimised (**Commitment 6: Explore how research ethics systems could work better**)
- **Equitable access** – we strongly believe that everyone should be offered the opportunity to take part in research. We will explore how to engage with hard-to-reach groups, including but not limited to people in remote and rural areas (including the islands), people from minority ethnic groups, and LGBTQ+ people. We have already begun to engage with people on the islands to explore what research participation could look like for them
- **Research and funding** – with appropriate support, we would like to expand the role of our Partners in Research having input to grant and fellowship funding applications, being involved from an early stage with researchers at Universities across Scotland and even, potentially, being co-applicants as an expert based on their lived experience.

## Section 3 – Recruitment into Research

### Commitments

7. We will forge closer links with Join Dementia Research through regular Scotland-wide meetings including staff from Alzheimer Scotland
8. Ensuring everyone in Scotland with or at risk of a neuroprogressive condition or dementia is offered the opportunity to participate in research
9. Exploring how people in remote and rural locations or on the islands can be involved in research

The Network has a history of very successful recruitment to clinical trials. However, we are very far from the situation where everyone with a neuroprogressive condition or dementia is offered the opportunity to take part. Many organisations agree with the importance of offering everyone the opportunity to participate in research. For example, a recent report from Alzheimer’s Research UK and the Royal College of Psychiatrists states that “Psychiatrists are keen to support greater participation in research”<sup>11</sup>. However, we have work to do to get to this level of participation.

The Network makes great use of the UK-wide Join Dementia Research (JDR)<sup>12</sup> and the Scottish Health Research Register (SHARE)<sup>13</sup>. We have recently started meeting regularly with the UK JDR team and Alzheimer Scotland (**Commitment 7: Forging closer links with JDR with regular Scotland-wide meetings including staff from Alzheimer Scotland**) to ensure that the Network is supportive of and makes full use of this valuable resource.



However, our research involves people with all neuroprogressive conditions, not just dementia. Furthermore, it became clear that we needed a GDPR-compliant way to keep research participants’ details on our secure database held within the NHS network at the Health Informatics Centre, University of Dundee.

Our ‘Permission to Contact’ scheme fulfils this function, and we are distributing information and leaflets to services across Scotland, for distribution to people with or without a diagnosis who might be interested in finding out more about research, and what participation entails (**Commitment 8: Ensure everyone in Scotland with or at risk of a neuroprogressive condition or dementia is offered the opportunity to participate in research**).

This is an opt-in system since only people interested in finding out more will return the leaflet. A minimum of information is collected, including permission for the member of Network staff to find out a little more about the person, thus allowing the most appropriate research opportunities to be discussed.

<sup>11</sup> [https://www.rcpsych.ac.uk/docs/default-source/members/faculties/old-age/are-we-ready-to-deliver-disease-modifying-treatments\\_25may21.pdf?sfvrsn=e8d580a\\_2](https://www.rcpsych.ac.uk/docs/default-source/members/faculties/old-age/are-we-ready-to-deliver-disease-modifying-treatments_25may21.pdf?sfvrsn=e8d580a_2)

<sup>12</sup> <https://www.joindementiaresearch.nihr.ac.uk>

<sup>13</sup> <https://www.registerforshare.org>

*"[We] found the form very straight forward to complete, though Donna is having regressive literacy skills and was happy for me to complete on her behalf after discussing each element.*

*"We both found the concept and process a positive experience, and in particular Donna the positive aspect of the potentially helping in any future study."*

**John and Donna Cousins**  
**Permission to Contact leaflet completers**



The leaflet features the NHS Scotland logo at the top left. Below it, the text reads 'NEUROPROGRESSIVE AND DEMENTIA'. A circular inset shows a whiteboard with 'this week:' written on it. Another circular inset shows a woman and a man looking at a document. The main text asks 'Are you affected by a neuroprogressive condition?' and 'Would you be interested in taking part in research?'. Below this, there are three circular images: one of a woman writing, one of two men smiling, and one of a woman looking at a document. The text states: 'We are looking for people who have been diagnosed with a neuroprogressive condition, or for people who have a problem with their memory.' At the bottom, there are social media links for the website, Facebook, and Twitter.



The leaflet features the text 'Interested in taking part in research? Contact details for your local team are overleaf.' Below this, it states: 'NRS Neuroprogressive and Dementia is the leading NHS organisation in Scotland for clinical research into memory impairment, dementia and other neuroprogressive conditions like Parkinson's disease, Huntington's disease and Motor Neurone Disease (MND). We support a wide range of research conducted within the NHS, Scottish universities and in care homes.' It then describes the types of studies they run and the process of participating. It also mentions that information is held at the NHS Tayside and University of Dundee offices. At the bottom, there are two circular images: one of a woman talking on a phone and one of a brain scan. Social media links are provided at the bottom.

The Network also has a responsibility to engage with research organisations – both commercial and academic – to lobby for opportunities for research participation for all groups of people affected by neuroprogressive conditions and dementia. Hopefully in the future the input of our Partners in Research can both guide the areas of interest and add further credibility to this lobbying.

An interesting development arising from the Covid-19 pandemic is the possibility of remote trial delivery which the NIHR is actively exploring<sup>14</sup>. We have some experience of this, having begun remote consultations using NHS Attend Anywhere video consultation software, but this is likely to be an area of great development in the future. **(Commitment 9: Exploring how people in remote and rural locations or on the islands can be involved in research).**

<sup>14</sup> <https://sites.google.com/nihr.ac.uk/remotetrialdelivery/home/remote-trial-delivery-preliminary-guidance-from-the-nihr-remote-trial-deli>

## Section 4 - ENRICH (ENabling Research In Care Homes)

### Commitments

10. Increasing the number of care homes willing to be approached by researchers, while increasing the number of research opportunities in Scotland for people living and working in care homes

**ENRICH**  
**SCOTLAND**  
enabling research in care homes



**ENRICH Scotland** has been supporting a programme of work within the NIHR Enabling Research in Care Homes (ENRICH) framework since 2012 through Emma Law's management and chairing of the group.

Emma was joined by Dr Susan Shenkin as co-chair in 2017. Together they have helped to facilitate the development of care home research interest and capability within Scotland by:

- bringing together a group of people interested in care home research including care home and NHS staff, academics from a wide range of universities in Scotland, the Care Inspectorate, and AHPs, all of whom are assisting in gathering the evidence base required to advance care home practice in Scotland and sharing this widely
- raising the profile of care home research in Scotland via the ENRICH Forum and with the help of NRS communication team
- acting as advocates to promote the care home research agenda with appropriate stakeholders including care-home managers, NHS and academic partners, policy makers, and research funders
- building on the NIHR ENRICH network of care homes and making this uniquely fit for Scottish care homes to join

The pandemic has highlighted the vulnerability of care home residents. However, the opportunity to improve these through research has been very limited due to the lack of an appropriate infrastructure. This now needs to be remedied.

ENRICH continues to be supported by the NDN but we are grateful to the CSO for specific funding for this work which enables us to:

- scope out a future structure for research in care homes by:
  - assessing the number of homes that would be interested in participating in clinical and social research
  - assessing which of the 27 topic-specific NRS Networks or Speciality Groups are interested in doing research in care homes
  - developing the membership of the ENRICH Scotland academic group to ensure wide representation from all relevant disciplines including potential for commercial studies, and a wide range of research and innovation
- involve residents and care home staff more in our meetings. We have not had the time or space to do this so far. We are devising interesting and innovative ways to promote research and ENRICH across Scotland
- provide expertise on ethical governance and consent issues relating to care home research and enable us to improve the quality and quantity of input we have with homes and interested researchers
- ensure research in care homes (and therefore social care more widely) is high on everyone's agenda, which is particularly pertinent in light of the COVID-19 pandemic

ENRICH Scotland is a separate entity from NRS NDN but works very closely with the Network – not least due to the leadership by Dr Emma Law, NRS NDN Network manager, as well as the NRS Ageing Speciality Group and NRS Primary Care Network.

This interdisciplinary collaboration is key to planning and delivering research to benefit people living in care homes, many of whom are living with dementia or other neuroprogressive conditions and syndromes associated with ageing like frailty, immobility and falls, and incontinence.

The future of ENRICH is an exemplar of the need for close and equal collaboration between health and social care: although it currently sits within the NRS infrastructure, social care partners are a key part of the team.

---

*"I should like to express my sincere thanks for all your efforts on behalf of the PROTECT-CH platform (NIHR133443). ENRICH Scotland and the whole Scottish team have been exceedingly proactive in supporting the project, testing how the project will work in the NHS and Care Homes including in identifying issues that were specific to Scotland and others that needed to be addressed across the four nations. They were also exemplary in finding research nurse support to cover the Scottish sites. This was vital to the speed at which the project progressed."*

**Professor Cally Rick**  
Associate Professor of Clinical Trials  
University of Nottingham



*“ENRICH Scotland provided key support for PROTECT-CH, an ambitious clinical trial to prevent COVID-19 infections spreading in care homes. The study in the end was not required due to the success of the vaccine, but ENRICH Scotland enabled us to make sure the study could be implemented in Scotland, contact interested care homes and, most importantly, provided research nurses to support care home staff to recruit care home residents to the study. This infrastructure will be essential for future studies to benefit care home residents, families and staff to receive the highest quality, research-informed, care.”*

**Dr Susan Shenkin**  
Consultant Geriatrician, NHS Lothian



*“The unique and inclusive approach adopted by NRS NDN offers the opportunity which the Scottish research landscape has been longing for. This is the opportunity to holistically respond to the health and social care integration in Scotland and, as a result, to address the existing gaps caused by the historical lack of collaboration between clinical and social research.*

*“ENRICH Scotland is the first example of such work and we are hoping that bringing the care homes community and research community closer together will demonstrate that, in the current climate of joint working in the Health and Social Care sector, it is vital to have the strong integration of research practises and approaches too.”*

**Irina McLean**  
Health and Social Care Research Coordinator  
NHS Research Scotland



*“We are immensely grateful to ENRICH Scotland for promoting our research ‘Necessary discussions: Advance care planning for nursing homes in a COVID-19 outbreak’ across their network. This ESRC-funded study involves developing and testing an online advance care planning intervention for care home staff, and families of residents.*

*“ENRICH Scotland were instrumental in identifying Scottish care homes that subsequently became involved. The network also supported our recent research funding application which aims to improve wellbeing in care home staff and will identify potentially interested care home sites for this if our application is successful. Without the support of ENRICH Scotland, it would be much more difficult to involve care homes in our research.”*

**Dr Anne Finucane**  
Marie Curie Senior Research Fellow  
University of Edinburgh



## Section 5 - Engagement

### Commitments

11. Working with Alzheimer Scotland to foster local links between Network staff and Alzheimer Scotland Dementia Advisors/Link Workers to support them to have confident conversations about research with the people they work with. We hope to expand this to charities working in other disease areas in due course
12. Engaging with the charitable sector to promote research engagement, research recruitment, and to enhance our Partners in Research group
13. Continuing and strengthening our collaborations with the vibrant research landscape in Scotland
14. Engaging with doctors and nurses in training to offer clinical research experience, aiming for as many as possible to complete training in Good Clinical Practice
15. Working with clinical services to offer research opportunities widely
16. Offering support to Network staff to undertake academic work and training
17. Acting as an expert resource in research processes

### Engagement with third sector organisations

Alzheimer Scotland is the major dementia charity in Scotland and has been an active supporter of dementia research in Scotland for many years. We are keen to strengthen these existing links (**Commitment 11: Working with Alzheimer Scotland to foster local links between Network staff and Alzheimer Scotland Dementia Advisors/Link Workers to support them to have confident conversations about research with the people they work with. We hope to expand this to charities working in other disease areas in due course**) and build new links with charities working with and for people with neuroprogressive disease and dementia. These other organisations include MND Scotland, Scottish Huntington's Association, Parkinson's UK, MS Society, Alzheimer's Society, and Alzheimer's Research UK (**Commitment 12: Engaging with the charitable sector to promote research engagement, research recruitment, and to enhance our Partners in Research group**).

There are three ways in which we are particularly keen to work together with the third sector.

**First**, since we plan to have people with lived experience at the centre of the Network's activities, links with charities will be extremely helpful to allow as many people – from as diverse backgrounds as possible – to join our work.

**Second**, we hope that these links will help us with our aim to offer everyone with a neuroprogressive condition or dementia the opportunity of taking part in research.

**Third**, we welcome any approaches from third sector staff or the communities they serve to facilitate communication in both directions. We can benefit from better understanding of the lived experience of specific conditions. Conversely, we can provide education about research for staff and people with lived experience through presentations, information leaflets, or one-to-one or group discussions.

*“We are extremely fortunate in Scotland to have such a high level of collaboration and a committed research community. In recent months we launched a new national Brain Health and Dementia Strategy, laying down the foundations of an overarching ambitious vision for the future. It exemplifies the benefits of the Scottish Dementia Research Consortium and complements the plans outlined in this strategy to build on and develop the significant contribution of the Network.*

*“It is particularly important to note the absolute commitment in this strategy to ensure people with lived experience not only participate in research, but help to plan, shape, and guide it. Alongside empowering tools such as Join Dementia Research, we should move forward with confidence in Scotland’s ability to encourage as great a level of research participation as possible. All of this builds on the commitment and dedication of the leaders who have gone before us, the giants like Professor John Starr whose shoulders we stand on, and whose legacy is intertwined with our future.”*

**Henry Simmons**  
Chief Executive, Alzheimer Scotland



*“Huntington’s disease (HD) is a rare, hereditary, extremely difficult to manage and currently incurable neurological condition that slowly robs people of their ability to walk, talk, eat, drink, make rational decisions and care for themselves. The role of Scottish Huntington’s Association is to battle to ensure HD families get the best care and support, no matter where they live.*

*“But our families need more than this. They need hope of better days ahead. That’s where research comes in. So, we warmly welcome the growing engagement we’ve had from the NDN and congratulate it on its new strategy. And we look forward to working together as we strive to one day turn the hope of a brighter future for HD families into a reality.”*

**Alistair Haw**  
CEO, Scottish Huntington’s Association



*“Parkinson’s UK is delighted to see the new strategy from the NDN, it is really encouraging to see that the Network’s number one commitment is to involve people with lived experience. The new strategy has clear and important goals which include working with its partners in the third sector to get as many people as possible with a neuroprogressive condition or dementia involved in research, with a focus on increasing the number of those from diverse backgrounds involved with the Network’s work.*

*“These commitments and goals align closely with the work being done at Parkinson’s UK and we are looking forward to supporting these aspects of the Network’s work.”*

**Shān Nicholas**  
Interim CEO of Parkinson’s UK



**PARKINSON'S<sup>UK</sup>**  
CHANGE ATTITUDES.  
FIND A CURE.  
JOIN US.

*“MND Scotland’s vision is a world without motor neurone disease. 40 years ago, when our charity was born, there was no treatment available to people diagnosed with MND. We are now closer than ever to finding effective treatments to slow down, or reverse, the effects of the disease.*

*“Today, almost every person living with MND in the UK has access to a clinical drug trial. But we can’t stop. We must keep going. We support the Neuroprogressive and Dementia Research Network’s strategy and look forward to working with them to achieve our goal. Together, we will beat MND.”*

**Rachel Maitland**  
CEO, MND Scotland



**MND**  
**Scotland**  
Supporting people affected by Motor Neurone Disease

*“As the number of people with dementia across the UK grows, the urgency for high quality, impactful research to understand, treat and care for people with the condition continues to build. Many of the Network’s commitments and priorities mirror those of Alzheimer’s Society particularly ensuring that all research involves those with a real-life experience of dementia – as the real experts. We believe this maximises the impact and relevance of dementia research.*

*“We are pleased to see that supporting people with dementia from all backgrounds and geographical locations to take part in clinical trials is a key aim as this is a challenge facing the field as a whole and welcome the engagement sought with the wider third sector. Alzheimer’s Society look forward to working with the Network to achieve these ambitions.”*

**Rich Oakley**  
Head of Research, Alzheimer’s Society



**Alzheimer’s**  
**Society**  
United  
Against  
Dementia

*“We’re delighted the NDN has launched a new strategy with a strong commitment to involve people with lived experience in research in Scotland. At the MS Society, we know people living with MS and their loved ones are experts in their condition. That’s why our research network is made up of people affected by MS, so we can make sure our research strategy reflects the needs and interests of people with MS. We’re driving research into more and better treatments for people living with MS and we look forward to working together with the Network to give people with MS more opportunities to get involved in research in Scotland.”*

**Nick Moberly**  
Chief Executive, MS Society



*“We’re pleased the strategy from the NRS Neuroprogressive and Dementia Network places a clear emphasis on collaboration to improve engagement with research and help make breakthroughs possible.*

*“We look forward to working closely with the Network to help achieve a more inclusive approach to research: one that gives people with a lived experience of dementia and from a range of backgrounds the opportunity to get involved. The strategy’s aspiration to support early career researchers, the next generation of scientists, is a welcome step that will support boosting capacity in the field and help strengthen vital clinical research.”*

**David Thomas**  
Head of Policy, Alzheimer’s Research UK



## Engagement with Centres of Excellence

---

The academic profile of Old Age Psychiatry was increased in 2014 with the transition of Professor Craig Ritchie into his Chair of the Psychiatry of Ageing at the University of Edinburgh, the opening of the **Centre for Dementia Prevention** at the University of Edinburgh<sup>15</sup> (now Edinburgh Dementia Prevention) and increasing preparations for the **European Prevention of Alzheimer’s Dementia consortium**<sup>16</sup> (EPAD) (**Commitment 13: Continue and strengthen our collaborations with the vibrant research landscape in Scotland**).

Craig was one of the Scottish PIs on the Biogen trial which led to the licensing of Aducanumab in the USA and worked with Network staff on delivering this trial in NHS Lothian. More recently, substantial investment by the Scottish Government led to the foundation of **Brain Health Scotland**<sup>17</sup> in partnership with Alzheimer Scotland which aims to reduce the incidence of dementia over the next decade.

Alzheimer Scotland, SDRC, and Brain Health Scotland recently published the first **Scottish Brain Health and Dementia Research Strategy**<sup>18</sup> which the Network endorsed. Its four strategic actions are:

- the development of Brain Health and Dementia Research Boards within NHS Boards / Integration Joint Boards across Scotland
- forming a National Forum for rapid translation of research findings into practice
- conducting a national scoping review of research careers in brain health and dementia in Scotland
- founding a national strategy oversight board

The Network has close links with the National Institute for Health Research (NIHR) in England and Wales and sits on its National Specialty Groups for Neurodegeneration and Dementia. Engaging with the UK-wide research agenda is essential and we welcome the UK Government’s recent Life Sciences Vision and the All-Party Parliamentary Group on Dementia’s report ‘Fuelling the Moonshot: Unleashing the UK’s potential through dementia research’.

---

*“Neurodegenerative conditions and dementia affect the whole of the UK population and so the NIHR Clinical Research Network Dementia, Neurodegeneration, and Neurological Disorders National Specialties Groups have always been pleased to have representation from our Devolved Nations colleagues.*

*“Scotland has been actively involved in the groups throughout and helped enable the NIHR CRN to ensure any strategic and infrastructure programmes of work are designed to also reflect the needs of the whole of the UK where possible.*

Dr Gary Nestor  
NIHR CRN Assistant Specialty Cluster Lead



NIHR | National Institute  
for Health Research

---

<sup>15</sup> <http://centrefordementiaprevention.com>

<sup>16</sup> <http://ep-ad.org>

<sup>17</sup> <https://www.brainhealth.scot>

<sup>18</sup> <https://www.sdrc.scot/wp-content/uploads/2021/07/Scottish-Brain-Health-Dementia-Research-Strategy-2021-min-1-1.pdf>

Other Centres of Excellence we work with include the **Anne Rowling Regenerative Neurology Clinic**<sup>19</sup> and the **Euan Macdonald Centre**<sup>20</sup>, both in Edinburgh, the **National Deep Brain Stimulation Service**<sup>21</sup> for Parkinson's disease in Glasgow, and the **University of Dundee**<sup>22</sup>.

*“We aim to understand at the molecular level, how derailment of pathways controlled by Parkinson's genes such as LRRK2, PINK1 and Parkin cause disease. We collaborate extensively with pharmaceutical companies, clinicians, foundations, and charities and deploy rigorous and innovative methodologies to produce robust data of the highest quality that will advance knowledge of Parkinson's. Our mission is to discover and validate new biology, drug targets and biomarkers to be able to better diagnose and treat Parkinson's in the future.”*

Professor Dario Alessi  
Director of the MRC Protein Phosphorylation Unit  
University of Dundee



University  
of Dundee

## Engagement with Health and Social Care

We have excellent links with NHS services across Scotland, having previously had staff in every mainland Health Board in Scotland. One main way we engage with clinical services relates to research recruitment and our new Permission to Contact leaflets have proved an easy way for services to broach research engagement with patients.

With thoughts to the future, we are keen to play our role in training up the next generation of investigators. Tom Russ sits on the Old Age Psychiatry Specialty Training Committee and is developing recommendations for research training opportunities for doctors training in Old Age Psychiatry across Scotland. This will hopefully involve most or all getting trained in Good Clinical Practice (**Commitment 14: Engaging with doctors and nurses in training to offer clinical research experience**), aiming for as many as possible to complete training in Good Clinical Practice and getting supported experience in clinical research through the Network.

Bringing in our links with academia, there could be mutual benefits with non-clinical researchers getting some exposure to clinical services, and clinicians having research to engage in research in the half a day a week they have allocated for this purpose.

<sup>19</sup> <https://www.annerowlingclinic.org>

<sup>20</sup> <http://euanmacdonaldcentre.org>

<sup>21</sup> <https://www.nhsggc.org.uk/your-health/health-services/deep-brain-stimulation/>

<sup>22</sup> <https://www.dundee.ac.uk/parkinsons>

*“Closer ties with the Network will be mutually beneficial and allow a future generation of Old Age Psychiatrists to meaningfully contribute to the lives of people with neurodegenerative disorders.”*

Dr Rekha Hegda  
Training Programme Director, Old Age Psychiatry  
NHS Education for Scotland



We are keen to offer research exposure to nursing and AHP students and to that end we are linking with Universities and Practice Education Facilitators in local areas to see if we can engage with these students (**Commitment 15: Working with clinical services to offer research opportunities widely**). A useful report by the Council of Deans of Health showcases the value of research placements for nursing, midwifery and allied Health profession students and how they can be successfully set up (Becoming Research Confident, June 2021<sup>23</sup>).

This is already happening in a few of the areas in Scotland (NHS Greater Glasgow & Clyde and NHS Grampian), but we would want to offer this opportunity more widely, firstly to encourage students to consider research as a career choice and secondly to demystify research and encourage students to consider how to engage their patients in research.

*“It is essential for all healthcare professionals to understand the role of research in assessing, evaluating, and improving practice. Research placements allow students to make sense of research ideas, principles and methodologies that might seem alien when only talked about in a classroom.”*

Professor Brendan McCormack  
Lead Member for Research  
Council of Deans of Health



<sup>23</sup> [https://councilofdeans.org.uk/wp-content/uploads/2019/05/CODH.RIPR\\_report\\_v3-002.pdf](https://councilofdeans.org.uk/wp-content/uploads/2019/05/CODH.RIPR_report_v3-002.pdf)

## Engagement with Academics

John Starr was the Network's Director, and his academic credentials were extremely strong. He recruited Tom Russ who completed his PhD with the SDCRN in 2013 with a thesis entitled "**An integrated investigation of dementia risk factors: insights from geography, record linkage, and individual participant meta-analysis**"<sup>24</sup> (**Commitment 16: Offering support to Network staff to undertake academic work and training**).

As a result of this, and because of several excellent research staff involved with the Network, there has been a long history of academic publishing. At the time of writing, there are **42 Network-affiliated articles available on PubMed**<sup>25</sup> from 2012 onwards with a broader list of **150 Network-associated book chapters, articles, and other publications**<sup>26</sup> available on Google Scholar. These span the fields of epidemiology, neuroimaging, neuropsychology, PPI, and social science.

Links with academia became even closer when John Starr founded the Alzheimer Scotland Dementia Research Centre in 2011 with generous support from Alzheimer Scotland – £1.5 Million over ten years – and the **University of Edinburgh**<sup>27</sup>. Examples of these links can be seen in the use of the Scottish Dementia Research Interest Register data by several ASDRC PhD students. The Network and the ASDRC continue to work closely – particularly since Tom Russ took over as ASDRC Director — and collaborate closely on the Scottish Dementia Brain Tissue Bank.

Professor Ian Deary was the first Co-Director of the ASDRC and, amongst other things, began the Lothian Birth Cohort studies with John Starr in 1999. He handed over to Dr Simon Cox in 2020 and the Lothian Birth Cohorts continue to be vibrant research studies with the younger cohort being currently followed up for the sixth time, now all in their mid-80s. As the cohorts have aged, there has been an increasing emphasis on neuroprogressive conditions and dementia in addition to their initial focus on 'normal' cognitive ageing.

---

*"A critical contribution to the [Lothian Birth Cohorts] study will be dementia ascertainment, at age 85, of study participants – all of whom were initially healthy at recruitment (age 70). This is thanks to the input of Dr Russ and his team.*

*"It will enable novel research into many potential factors that differentiate these deeply phenotyped individuals who develop dementia from those who do not. Further collaborative work within [Scotland] is realising the exciting potential of research avenues in participants' stem cell lines (Siddharthan Chandran) and post-mortem brain tissue (Colin Smith, Tara Spires-Jones)."*

Dr Simon Cox  
Director of the Lothian Birth Cohorts  
University of Edinburgh



---

<sup>24</sup> <https://era.ed.ac.uk/handle/1842/8823>

<sup>25</sup> <https://www.ncbi.nlm.nih.gov/sites/myncbi/tom.russ.1/collections/60984345/public/>

<sup>26</sup> [https://scholar.google.com/scholar?q=%22Scottish+Dementia+Clinical+Research+Network%22+OR+%22Neuroprogressive+and+Dementia+Network%22&hl=en&as\\_sdt=0,5](https://scholar.google.com/scholar?q=%22Scottish+Dementia+Clinical+Research+Network%22+OR+%22Neuroprogressive+and+Dementia+Network%22&hl=en&as_sdt=0,5)

<sup>27</sup> <https://www.alzscotdrc.ed.ac.uk>

The **Scottish Dementia Research Consortium (SDRC)**<sup>28</sup> – hosted and supported by Alzheimer Scotland – supports dementia research across Scotland. The Network has been actively involved in the SDRC for many years, with Peter Connelly and, more recently, Tom Russ sitting on its Executive Committee.

*The SDRC has a remit to encourage and support Scottish research and researchers with a dementia focus. Recently, we have seen major scientific and political developments in dementia, and it feels like we are closer than ever to a major breakthrough.*

*“Scotland has already played a key role in all of this and the NRS Neuroprogressive and Dementia Network is ideally placed to continue to support exciting dementia projects. The Network has achieved so much in the last twelve years, and we in SDRC are looking forward to continuing to work with Dr Russ and the team and see what the next twelve years brings.”*

**Dr Terry Quinn**  
Executive Committee Member  
Scottish Dementia Research Consortium (SDRC)



Along with the SDRC itself, the Network has been active in championing and supporting early career researchers (ECRs). Most recently, the ECRs working with the Network have included:

- **Dr Rosie Ashworth**<sup>29</sup> (NRS NDN/University of Stirling) graduated with her PhD in 2015 with a thesis entitled “**Experiences of early and late-onset Alzheimer's disease: perceptions of stigma and future outlook**”<sup>30</sup>. She now works as a CSO with the Network and is leading on our Partners in Research work and grant applications
- **Dr Lewis Killin**<sup>31</sup> worked as a CSO with the Network for several years after completing his PhD at the Alzheimer Scotland Dementia Research Centre in 2015. His thesis was entitled “Investigating the short-term memory visual binding impairment in Alzheimer's disease”<sup>32</sup>. He now works with the IMI-funded **Neuronet project**<sup>33</sup> (“Efficiently Networking European Neurodegeneration Research”) in Barcelona

*“The ASDRC was and remains an excellent gateway into the field of dementia research in Scotland. Through its relationship to the Network, cooperative philosophy, and role in projects like the Brain Tissue Bank, it presents researchers with a significant source of inspiration, letting them see the landscape in front of them, filled with examples of how clearly and effectively academics, health and social care workers and families living with diagnoses can work and learn together. The Network and ASDRC support and mentor early researchers to know where and how they can play their part, and that type of guidance, for me, was invaluable.”*

**Dr Lewis Killin**  
Early Career Researcher

<sup>28</sup> <https://www.sdrc.scot>

<sup>29</sup> [Twitter @DrRAshworth](https://twitter.com/DrRAshworth)

<sup>30</sup> <http://hdl.handle.net/1893/24380>

<sup>31</sup> [Twitter @lewiskillin](https://twitter.com/lewiskillin)

<sup>32</sup> <https://ethos.bl.uk/OrderDetails.do?uin=uk.bl.ethos.735530>

<sup>33</sup> <https://www.imi-neuronet.org/>

*“Moving to Scotland to do my Alzheimer’s Society-funded PhD has been a great experience. Most importantly it has shown me that there is a different way to doing research, one that prioritises lived experience and collaboration. With guidance from my supervisors, I have recruited a team of co-researchers living with young onset dementia to explore inclusivity in volunteering and to co-produce a Thematic Analysis. The group also benefits greatly from having Dr Rosie Ashworth from the Network on board as a co-facilitator.”*

Rosie Vincent  
Alzheimer’s Society-funded Early Career Researcher



Indeed, many Network staff have been supported in their academic development through the Network. A number of CSOs have been supported to complete Master’s degrees in relevant subjects while working including Jacqui Kerr, Bernie McInally, Tiffany Stewart, and Leigh-Ann Whyte. Emma Law, in turn, was supported to complete her PhD studies part-time while continuing in her role as Network Manager. She graduated from the University of Stirling in 2016 with a thesis entitled “Research in care homes issues of participation and citizenship”<sup>34</sup>.

As well as working on commercial clinical trials (run by pharmaceutical companies), we have been involved in a large number of clinical and research trials led by academics at universities. **(Commitment 17: Acting as an expert resource in research processes)**

These have included:

- **Parkinson’s Disease:** TOPHAT, Chief PD, PD Comm, PD Frontline
- **Alzheimer’s and other dementias including Mild Cognitive Impairment:** EPAD, the RADAR trial, AMYPAD, AD Genetics, DLB Genetics, AFFECT, IDEAL, Free-Cog, EvLi
- **Motor Neurone Disease:** MND-SMART
- **Multiple Sclerosis:** Future MS (starting in 2022)
- **Huntington’s Disease:** Enroll-HD
- **Very Late-Onset Schizophrenia-Like Psychosis:** ATLAS

<sup>34</sup> <http://hdl.handle.net/1893/25305>

*“On reflecting on the RADAR study whilst finalising our report to funder and the publication of the main results, I continue to be struck by how important and effective the Scottish Network was to us in being able to achieve successful completion of the study. Although the Network comprised about 1/3 of the sites involved, it helped to recruit almost half of the study cohort.*

*“I also have to say I was always hugely impressed and grateful at how flexible and agile the network was in being able to work across sites if the need arose but also the huge value there was in local knowledge in the co-ordinating team in being able to identify how and when sites might contribute and the excellent the network co-ordinating team were at communicating with the RADAR study team. If I personally am involved in or leading any future studies, the Scottish Network would be my first port of call as a collaborator and I thank everyone for their efforts in the RADAR study.”*

**Professor Pat Kehoe**  
RADAR Chief Investigator and Faculty of Health Sciences  
Research Director, University of Bristol



We look forward to continuing our academic collaborations in the future and would like to invite interested collaborators to get in touch. We are particularly excited to contribute to the work of the recently founded Advanced Care Research Centre at the University of Edinburgh.

*“The Advanced Care Research Centre is focused on understanding and improving care for people in later life to support independence and quality of life. Neuro-progressive conditions have enormous impact in later life, and will be a significant focus of our work, aligned to the work of the Network.”*

**Heather Wilkinson / Bruce Guthrie**  
Advanced Care Research Centre  
University of Edinburgh



## Section 6 – Scottish Dementia Brain Tissue Bank

### Commitments

18. Increasing the numbers of donors by offering the possibility of signing up to the Scottish Dementia Brain Tissue Bank (SDBTB) as widely as possible
19. Maintain the high quality of clinical data collected and harmonise with other datasets
20. Continuing to explore the possibility of including as much of the Scottish population as possible

One of the first projects the Network was involved in was the setting up of the Scottish Dementia Research Interest Register (SDRIR). This was essentially a ‘consent to consent’ register where people with a diagnosis of dementia and their carers could register their interest in finding out about research opportunities when they arose, with no obligation to take part.

Approximately 2000 people signed up to the register and were presented with research opportunities relevant to them. However, the data recorded on the register are also useful for research and were used in several articles, including:

- Law et al. (2013) Does the Addenbrooke's Cognitive Examination-revised add to the Mini-Mental State Examination in established Alzheimer disease? Results from a national dementia research register. *International Journal of Geriatric Psychiatry* **28**(4): 351-5.<sup>35</sup>
- Law, Starr & Connelly (2013) Dementia research – what do different public groups want? A survey by the Scottish Dementia Clinical Research Network. *Dementia* **12**(1): 23-28.<sup>36</sup>
- McGrory et al. (2014) Lawton IADL scale in dementia: can item response theory make it more informative? *Age and Ageing* **43**(4): 491-5.<sup>37</sup>
- Russ et al. (2015) Prediction of general hospital admission in people with dementia: Cohort study. *British Journal of Psychiatry* **206**(2): 153-9.<sup>38</sup>

“We have been investigating the trends in the data published by the Scottish Government on Alzheimer's and other dementia deaths. The SDRIR is an invaluable resource for understanding why someone with dementia does or doesn't have dementia recorded on their death certificate when they die. Without a Scottish clinical data set, it would not be possible to understand the trends present in the data published by the Scottish Government, so we are very grateful to everyone who has contributed to the SDRIR and enabled us to use it for this study.”

Luisa Parkinson  
PhD student  
Alzheimer Scotland Dementia Research Centre



<sup>35</sup> <https://doi.org/10.1002/gps.3828>

<sup>36</sup> <https://doi.org/10.1177/0142723711420309>

<sup>37</sup> <https://doi.org/10.1093/ageing/aft173>

<sup>38</sup> <https://doi.org/10.1192/bjp.bp.113.137166>

This was an entirely new type of national register in Scotland at the time and much of its function has since been taken over by the UK-wide Join Dementia Research<sup>39</sup>. The Network has joined with the National Institute for Health Research and Alzheimer Scotland in supporting this endeavour to increase the number of people living with dementia taking part in research.

While one function of the SDRIR has been superseded by JDR, it continues as the database for storing the clinical data associated with the brain tissue samples generously donated to the Scottish Dementia Brain Tissue Bank. The SDBTB has been generously funded by Alzheimer Scotland since its foundation in 2011 and we are grateful to their ongoing commitment to this project. To date, a total of 124 donors have signed up and 55 of these have donated brain tissue after their death.

In addition to the generosity of donors and their families, the SDBTB is possible through close collaboration with the **ASDRC**<sup>40</sup> – in particular Denise Munro, administrative secretary – the **Edinburgh Brain and Tissue Bank**<sup>41</sup>, and the **Health Informatics Centre**<sup>42</sup> at the University of Dundee. We are also very grateful to the volunteers from the Alzheimer Scotland Dementia Helpline for their help coordinating these donations. A new development this year is that we will be issuing Brain Tissue Donor Cards – analogous to organ donor cards – to all registered prospective donors with instructions to call the Helpline when the person dies.

---

*“It is only through the generosity of donors and their families who support brain donation that translational research studying Alzheimer’s disease can take place — that is, looking at the results generated from non-human research (studying cells in a dish or animal models) and applying them to the human brain tissue in which the cellular changes typical of Alzheimer’s disease are present. Only then can we assess the relevance of a research observation.*”

*“We support local, national and international research programmes studying the cellular changes in Alzheimer’s disease, and ultimately looking at ways to stop or slow the progression of cellular damage.”*

Professor Colin Smith  
Professor of Neuropathology  
University of Edinburgh



A decade after it started, we have plans to build on the Scottish Dementia Brain Tissue Bank to offer the opportunity to donate brain tissue to more people with dementia and also make these precious donations of brain tissue even more valuable from a research perspective (**Commitment 18: Increasing the numbers of donors by offering the possibility of signing up to the SDBTB as widely as possible**). One way to make these samples as valuable as possible is making sure that the data we collect is in line with similar English

---

<sup>39</sup> <https://www.joindementiaresearch.nihr.ac.uk>

<sup>40</sup> <https://www.alzscotdrc.ed.ac.uk>

<sup>41</sup> <https://www.ed.ac.uk/clinical-brain-sciences/research/edinburgh-brain-and-tissue-bank/about-the-brain-and-tissue-bank>

<sup>42</sup> <https://www.dundee.ac.uk/hic>

and European dementia brain tissue banks, such as **Brains for Dementia Research**<sup>43</sup>. This will allow the samples to be used in larger collaborative projects.

Speaking with the scientists who use these brain tissue samples, we have also learned that, in addition to the detailed information we collect when someone joins the register, it would be helpful to have repeated testing of their cognition. Therefore, going forward we will be asking people who sign up if they would be happy to be recontacted by telephone each year to repeat a telephone test of memory and executive function. We will be using the **Free Cog test**<sup>44</sup> created by the University of Manchester and Greater Manchester Mental Health NHS Foundation Trust in collaboration with a group of people living with dementia (**Commitment 19: Maintaining the high quality of clinical data collected and harmonise with other datasets**).

---

*“I would like to express my thanks on behalf of myself and my co-authors that the Free Cog has been adopted in such a prestigious study in Scotland. We very much see the Free Cog as a work in progress in terms of its unique combination of executive and cognitive function and the information that will be gathered as part of the Scottish study will be a fantastic addition to our evidence base.”*

Professor Alistair Burns  
Professor of Old Age Psychiatry  
University of Manchester



More information about the Free Cog can be found in the following articles:

- Larner (2019) Free-Cog: Pragmatic Test Accuracy Study and Comparison with Mini-Addenbrooke's Cognitive Examination. *Dementia & Geriatric Cognitive Disorders* **47**(4-6): 254-63.<sup>45</sup>
- Burns et al. (2021) A novel hybrid scale for the assessment of cognitive and executive function: The Free-Cog. *International Journal of Geriatric Psychiatry* **36**(4): 566-72.<sup>46</sup>
- Burns & Larner (2021) Do we need yet another cognitive test? Free-Cog, a novel, hybrid, cognitive screening instrument. *Journal of Neurology, Neurosurgery and Psychiatry* [ePub ahead of print].<sup>47</sup>

---

*“Our research would not be possible without the Scottish Dementia Brain Tissue Bank. It is a hugely valuable scientific resource that will help develop life-changing treatments in future.”*

Professor Tara Spires-Jones  
Deputy Director, Centre for Discovery Brain Sciences  
The University of Edinburgh



<sup>43</sup> <https://bdr.alzheimersresearchuk.org>

<sup>44</sup> <https://www.gmmh.nhs.uk/download.cfm?doc=docm93jjm4n7882.pdf&ver=10489>

<sup>45</sup> <https://doi.org/10.1159/000500069>

<sup>46</sup> <https://doi.org/10.1002/gps.5454>

<sup>47</sup> <http://dx.doi.org/10.1136/jnnp-2020-325830>

Examples of the high-quality scientific papers using tissue samples from the Scottish Dementia Brain Tissue Bank:

- Kurucu et al. (In press) Inhibitory synapse loss and accumulation of amyloid beta in inhibitory presynaptic terminals in Alzheimer's disease. *European Journal of Neurology*.<sup>48</sup>
- Tulloch et al. (2021) Maintained memory and long-term potentiation in a mouse model of Alzheimer's disease with both amyloid pathology and human tau. *European Journal of Neuroscience* **53**(2): 637-48.<sup>49</sup>
- Hesse et al. (2019) Comparative profiling of the synaptic proteome from Alzheimer's disease patients with focus on the APOE genotype. *Acta Neuropathologica Communications* **7**: 214.<sup>50</sup>
- Jackson et al. (2019) Clusterin accumulates in synapses in Alzheimer's disease and is increased in apolipoprotein E4 carriers. *Brain Communications* **1**(1): fcz003.<sup>51</sup>
- Pickett et al. (2019) Amyloid Beta and Tau Cooperate to Cause Reversible Behavioral and Transcriptional Deficits in a Model of Alzheimer's Disease. *Cell Reports* **29**(11): P3592-604.<sup>52</sup>
- Pickett et al. (2018) Region-specific depletion of synaptic mitochondria in the brains of patients with Alzheimer's disease. *Acta Neuropathologica* **136**: 747-57.<sup>53</sup>
- McInnes et al. (2018) Synaptogyrin-3 Mediates Presynaptic Dysfunction Induced by Tau. *Neuron* **97**(4): P823-35.<sup>54</sup>
- Henstridge et al. (2017) Synapse loss in the prefrontal cortex is associated with cognitive decline in amyotrophic lateral sclerosis. *Acta Neuropathologica* **135**: 213-26.<sup>55</sup>
- Zhou et al. (2017) Tau association with synaptic vesicles causes presynaptic dysfunction. *Nature Communications* **8**: 15295.<sup>56</sup>
- Henstridge et al. (2015) Post-mortem brain analyses of the Lothian Birth Cohort 1936: extending lifetime cognitive and brain phenotyping to the level of the synapse. *Acta Neuropathologica Communications* **3**: 53.<sup>57</sup>

---

<sup>48</sup> <http://dx.doi.org/10.1111/ene.15043>

<sup>49</sup> <http://dx.doi.org/10.1111/ejn.14918>

<sup>50</sup> <http://dx.doi.org/10.1186/s40478-019-0847-7>

<sup>51</sup> <http://dx.doi.org/10.1093/braincomms/fcz003>

<sup>52</sup> <http://dx.doi.org/10.1016/j.celrep.2019.11.044>

<sup>53</sup> <http://dx.doi.org/10.1007/s00401-018-1903-2>

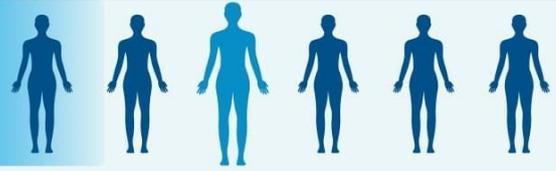
<sup>54</sup> <http://dx.doi.org/10.1016/j.neuron.2018.01.022>

<sup>55</sup> <http://dx.doi.org/10.1007/s00401-017-1797-4>

<sup>56</sup> <http://dx.doi.org/10.1038/ncomms15295>

<sup>57</sup> <http://dx.doi.org/10.1186/s40478-015-0232-0>

## Donating brain tissue – the process



I want to donate my  
brain tissue



Information pack



Staff visit



Telephone follow-up



Family notify the team  
of your death

If you are diagnosed with dementia and want to donate your brain tissue for research after you die, you need to advise either the Alzheimer Scotland Dementia Research Centre or the NRS Neuroprogressive and Dementia Network using the contact details opposite.

You would then receive an information pack to help you discuss your wishes with your family.

This is followed by an approach from one of our team to arrange to visit you. This can be at home, in a hospital clinic, or via a video link. The visit is designed to complete a thorough assessment and we ask that you are accompanied by a carer, family member or someone who knows you well.

A member of the team would contact you around a week later to take you through a telephone assessment and would continue to contact you annually, by phone, to complete this short assessment.

Your brain tissue must be taken within hours of you dying at a special facility in Edinburgh and there would be no cost to your family to do this. Researchers would return your body promptly to allow your family to make funeral arrangements.

At the moment, because of the requirement that the brain tissue is harvested very soon after death, it is only feasible for us to register people living on the mainland. In line with our general commitment to involve people living in remote and rural locations in research, we will continue to explore whether there is any way for us to involve people from the islands in the SDBTB (**Commitment 20: Continuing to explore the possibility of including as much of the Scottish population as possible**).

## Section 7 – Delivering Clinical Research

### Commitments

21. Continuing to build our reputation in delivering cutting edge clinical research in neuroprogressive conditions and dementia across Scotland
22. Increasing the number of people with these conditions taking part in research

The main function of the Network over the years has been delivering clinical neuroprogressive and dementia research across Scotland. We are now recognised as an expert organisation in delivering clinical trials, in partnership with local Clinical Research Facilities (**Commitment 21: Continuing to build our reputation in delivering cutting edge clinical research in neuroprogressive conditions and dementia across Scotland**).

We have recruited very well to studies across Scotland. We now have skills in running highly complex intervention trials, such as Biogen's trial of Aducanumab – which was recently licensed in the US as a treatment for Alzheimer's dementia – which we ran in several sites across Scotland, and which involved a monthly intravenous infusion of the study drug or placebo.

We have built on the expertise gained in Dementia trials to encompass trials in Parkinson's, Huntington's, and Motor Neurone Disease. We will begin our first network input to an MS trial in 2022 (**Commitment 22: Increasing the number of people with these conditions taking part in research**).

*"IQVIA are delighted to partner with the NRS Neuroprogressive and Dementia Research Network (NDN) to deliver high quality, innovative, commercial research across the spectrum of diseases and disorders that contribute to the Scottish NDN therapeutic landscape. By expanding on established expertise and knowledge within the Network, and through collaborative working, we're bringing more mid-and large-sized Pharmaceutical Sponsor opportunities to even more patients.*

*"Via an enriched research pipeline, we are committing to each individual patient, their families, as well as to the network of researchers across Scotland. We look forward to our continued partnership as we strive to bring these pioneering treatments into reality."*

IQVIA



*“GAP [Global Alzheimer’s Platform] are exciting to be partnering with the NDN to co-develop processes and activities that speed up the delivery of AD trials to expedite getting new medicines to AD patients. GAP will bring expertise in study start-up and site support to work with the NDN network on implementing solutions in Scotland that will deliver this mission for the benefit of sites, researchers and patients.*

*“The strategy the NDN team have developed is another positive step forward in this mission and demonstrates the value of the NDN to the dementia research community.”*

**Judith Syson**  
European Implementation Team  
Global Alzheimer’s Platform



*“The NDN have been dynamic and engaged in attracting trials with innovative and clinically transformative therapies in neuroprogressive diseases. NHS Tayside are proud to host the Network and have worked in collaboration with the fantastic NDN team since its inception to deliver on a number of successful clinical trials.*

*“The pipeline in this area is hugely exciting and I have no doubt that the NDN will continue to be at the forefront of Scottish neuroprogressive disease research.”*

**Professor Jacob George**  
Director of Research & Development  
NHS Tayside



## Section 8 – The Future

### Commitments

23. **Nurturing the next generation of Investigators so that excellent research can continue in Scotland, and we can have an impact on cause, cure, and care.**

It is easy to forget that none of this was happening in Scotland when the Network was set up. For example, in the year 2007-8 which was immediately prior to the Network's inception, the total number of patients recruited to clinical trials recognised on a national portfolio was three! Major clinical research was being undertaken by only a few clinicians, often recruiting people from local centres only. Contrast the picture now, with several active sites recruiting to a portfolio of high-quality – and often highly complex – studies, with Scotland being the top recruiting site for studies like RADAR, EPAD, and MND-SMART.

We are pleased to look back over the last decade or more and see how far things have come in terms of research activity in Scotland. More importantly, it is great to see the positive effects on the lives of people living with neuroprogressive conditions and dementia.

There is still a long way to go, both in terms of discovering disease-modifying treatments or preventative strategies for these conditions and how best to support and care for people affected. There is also an urgent need for us to move from a place where research is something that is done to people with a condition towards a place where research is done with them.

It is exciting to think where we will be a decade from now and the whole Network is delighted to be at the heart of clinical research in Scotland. Once again, we look forward to taking this journey with you!

## Abbreviations

<b>AHP</b>	Allied Health Professionals – an umbrella term for a dozen different professions working in healthcare, including occupational therapists, physiotherapists, speech and language therapists, and arts therapists <a href="https://www.gov.scot/publications/allied-health-professionals-list/">https://www.gov.scot/publications/allied-health-professionals-list/</a>
<b>BHS</b>	Brain Health Scotland <a href="https://www.brainhealth.scot">https://www.brainhealth.scot</a>
<b>CSO</b>	Chief Scientist Office, Scottish Government <a href="https://www.cso.scot.nhs.uk">https://www.cso.scot.nhs.uk</a>
<b>DEEP</b>	Dementia Engagement and Empowerment Project <a href="https://www.dementivoices.org.uk">https://www.dementivoices.org.uk</a>
<b>ECRs</b>	Early Career Researchers — a term often including PhD students and post-doctoral researchers on their way towards independence.
<b>ENRICH</b>	ENhancing Research In Care Homes <a href="https://enrich.nihr.ac.uk">https://enrich.nihr.ac.uk</a> <a href="https://www.nhsresearchscotland.org.uk/research-in-scotland/facilities/enrich">https://www.nhsresearchscotland.org.uk/research-in-scotland/facilities/enrich</a>
<b>GDPR</b>	General Data Protection Regulation
<b>HIC</b>	Health Informatics Centre, University of Dundee <a href="https://www.dundee.ac.uk/hic">https://www.dundee.ac.uk/hic</a>
<b>JDR</b>	Join Dementia Research <a href="https://www.joindementiaresearch.nihr.ac.uk">https://www.joindementiaresearch.nihr.ac.uk</a>
<b>NDCAN</b>	National Dementia Carers Action Network <a href="https://www.alzscot.org/our-work/campaigning-for-change/have-your-say/national-dementia-carers-action-network">https://www.alzscot.org/our-work/campaigning-for-change/have-your-say/national-dementia-carers-action-network</a>
<b>NDN</b>	Neuroprogressive and Dementia Research, NHS Research Scotland <a href="https://www.nhsresearchscotland.org.uk/research-areas/dementia-and-neurodegenerative-disease">https://www.nhsresearchscotland.org.uk/research-areas/dementia-and-neurodegenerative-disease</a>
<b>‘Network’</b>	This refers to the SDCRN and the NDN. The former began in 2008 and became the latter in 2015-16.
<b>NHS</b>	National Health Service
<b>NIHR</b>	National Institute of Health Research (England & Wales) <a href="https://www.nihr.ac.uk">https://www.nihr.ac.uk</a>
<b>NRS</b>	NHS Research Scotland <a href="https://www.nhsresearchscotland.org.uk">https://www.nhsresearchscotland.org.uk</a>
<b>PI</b>	Principal Investigator of a research project or trial
<b>PPI</b>	Patient and Public Involvement
<b>PROTECT-CH</b>	Prophylactic Therapy in Care Homes Trial <a href="https://www.protect-trial.net">https://www.protect-trial.net</a>
<b>SDBTB</b>	Scottish Dementia Brain Tissue Bank
<b>SDCRN</b>	Scottish Dementia Clinical Research Network, CSO. The original organisation formed in 2008 to conduct clinical dementia research in Scotland. Became the NDN in 2015-16.
<b>SDRC</b>	Scottish Dementia Research Consortium <a href="https://www.sdrc.scot">https://www.sdrc.scot</a>
<b>SDRIR</b>	Scottish Dementia Research Interest Register
<b>SDWG</b>	Scottish Dementia Working Group <a href="https://www.alzscot.org/our-work/campaigning-for-change/have-your-say/scottish-dementia-working-group/about-the-sdwg">https://www.alzscot.org/our-work/campaigning-for-change/have-your-say/scottish-dementia-working-group/about-the-sdwg</a>
<b>SHARE</b>	Scottish Health Register and Biobank <a href="https://www.registerforshare.org">https://www.registerforshare.org</a>
<b>SINAPSE</b>	Scottish Imaging Network: A Platform for Scientific Excellence <a href="http://www.sinapse.ac.uk/">http://www.sinapse.ac.uk/</a>
<b>SULSA</b>	Scottish Universities Life Sciences Alliance <a href="https://sulsa.ac.uk">https://sulsa.ac.uk</a>



# Find out more

Find out detailed information on our work on our website:

 [www.nrs.org.uk/ndn](http://www.nrs.org.uk/ndn)

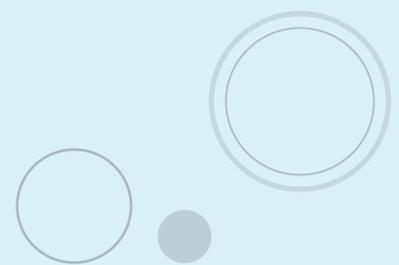


If you would like further information, or have a question in relation to the NRS NDN strategy, please email: [TAY.ndntayside@nhs.scot](mailto:TAY.ndntayside@nhs.scot)

Follow our social channels for the latest news and updates.

 **Neuroprogressive and Dementia Network**

 **@NRS\_NDN**



NRS NDN has offices around Scotland with the main headquarters in Dundee: Corridor M, Level 5, Ninewells Hospital & Medical School, Dundee, DD1 9SY. Tel: 01382 423086

Regional offices are also based at:

- Royal Cornhill Hospital, Aberdeen
- Western General Hospital, Edinburgh
- Queen Elizabeth University Hospital, Glasgow

NRS NDN is managed by:

- Dr Emma Law, NRS NDN Manager
- Dr Tom Russ, NRS NDN Clinical Research Champion



Network Portfolio studies are covered in the Borders, Ayrshire and Arran, Lanarkshire, Highland, Forth Valley, Dumfries and Galloway, Orkney and Shetland, Western Isles and Fife