

# Neuroprogressive and Dementia Network

## Annual Report 2023/2024

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# Neuroprogressive and Dementia Network

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

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

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

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

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

## OUR MISSION

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

A light blue silhouette map of Scotland is positioned on the right side of the 'OUR MISSION' box, partially overlapping the text.

# Headline Achievements

Our NDN manager, Emma Law semi-retired at the end of September 2023 and has been replaced by Jacqueline Kerr as the full time NDN manager. Emma is taking on the role of Strategic manager for NDN (a new role for the network) and maintains her involvement in ENRICH Scotland as manager and Co-Chair.

In the 2023-24 financial year, the NDN has maintained a complex and changing portfolio, with 52 unique studies being supported across eight health boards, in multiple locations.

We have supported academic research studies such as EXENATIDE PD3, COBALT (COmBining memantine And cholinesterase inhibitors in Lewy body dementia Treatment) ROPAD, PD Probiotic and CHIEF PD(Cholinesterase Inhibitor to prevent falls in Parkinson Disease) as well as larger commercial endeavours with pharmaceutical companies such as Roche, Biogen, Abbvie, Novo Nordisk and Merck. In Tayside, we have been undertaking the LUMA, PADOVA and ACTIVATE studies for Parkinson disease, being the first site in the UK to screen for LUMA and ACTIVATE. All of these studies have meant that we have been able to support participants from all over Scotland to take part in high quality research into some of the most impactful medical issues we face today.

We have expanded our portfolio to include NDN staff in Lothian working on the Deep and Frequent Phenotyping study in collaboration with Dr Catherine Pennington, which is researching early symptoms of Alzheimer Disease.

Our NDN teams in Grampian, Tayside and Lothian are working on the ENROLL-HD study for people with Huntington disease. We continue our collaboration with the Anne Rowling Clinic at the University of Edinburgh, working with people with Motor Neuron Disease in the MND-SMART trial.

NDN infrastructure has been used to support ENRICH (Enabling Research in Care Homes) Scotland by having Dr Emma Law, Network Strategic Manager as a co-chair of ENRICH Scotland enabling the financial overview and management of ENRICH Scotland staff and budget to be used in the most productive way.

We had an ENRICH Scotland conference in March 2024 where the theme was Bridging the Gap (between research and care homes) – more detail can be found in ENRICH Scotland section.



We successfully launched the NIHR dementia online rater toolkit in September 2023 - see further details in Delivering clinical research.

Finally, Dr Tom Russ was privileged to attend a reception for the Dame Barbara Windsor Dementia Mission at No 10 Downing Street in March 2024.



# Partners in Research

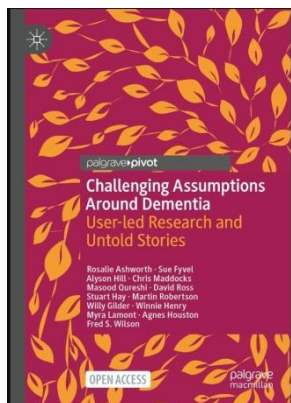
## Commitments of Partners in Research

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.



## Achievements of 2023-2024

Partners in Research has gone from strength to strength in 2023, and we are looking forward to the year ahead. One of the core pieces of works we proposed for 2023 was the co-writing of a book about dementia, focusing on the lived experience of our Partners in Research.



We launched the book in September 2023, and we are delighted to see it has been accessed over 8000 times in just a few months, and received coverage on news outlets as well as blog posts and articles.

As well as working on our book, Partners in Research has been trialling different ways of making sure we offer a diverse range of opportunities that align with the preferences of people with lived experience. We began hosting 4 different groups, spread out across the month to make sure that even if someone wished to come to all meetings there wouldn't be too much of a time burden. The PPI Input request group captures more traditional 'patient and public

CLINICAL RESEARCH REVIEW	PPI INPUT REQUESTS
DESIGN & DEVELOP CO-RESEARCH	MONTHLY DROP-INS

involvement' where researchers are invited to share their work and receive feedback. In contrast, we have a co-research group that looks at the ideas our Partners in Research wish to see explored, and where appropriate, look at how we could conduct the research as a group. Areas of particular interest include, malleability of cognitive reserve, risk factors in neuroprogressive conditions, and thresholds of care experienced by people in the community and in care homes.

Some of our Partners in Research have noted that it can be challenging to review research and/or develop research without a clear understanding of the research process and the potential barriers in place. We have sought to improve this as part of the clinical research review group, in which clinical studies officers from the NDN share some of their work and the steps they take to facilitate research. In clinical trials research, the point in which it reaches the NDN can mean that there is little scope for change in design or protocol, limiting the amount of input Partners in Research can have in his area. Therefore, after discussion with our Partners in Research, for 2024, the Clinical Research Group is being reshaped into a group that focuses on education and awareness about research processes and critical review of information presented to the public about neuroprogressive conditions. Finally, we hold monthly drop-ins which provide space for our Partners in Research to talk more freely on topics of importance to them without a set structure. The drop-ins provide space to reflect on what is working and what we should be doing differently.

Our Partners in Research are not only involved in activities within the NDN, but also in supporting research taking place outside of the NDN. Over the past year, some of our Partners in Research have been involved as co-researchers for research relating to healthy behaviour change in unpaid carers; music in care homes; using AI technology; involving people with dementia who cannot communicate verbally, among others.

One of the areas of improvement for Partners in Research outlined in the 2023 Annual Report was building stronger ties with non-dementia neuroprogressive conditions. We have recently had ethical approval for inviting our Permission to Contact Register to join Partners in Research, which should increase our diversity in members. We have also applied for funding to complete a Parkinson-led project in 2024 relating to support needs and clinical trial research.

Over the past year Partners in Research have been increasing their visibility through conference presentations in Scotland and internationally at the Alzheimer Europe Conference in Helsinki. We have also re-introduced research webinars which alternate each month between Partners in Research focus and RICH Voices focus (PPI group for ENRICH Scotland).

Finally, Dr Rosie Ashworth was nominated and voted winner of the NRS Scotland PPI impact Award for commitment to supporting, delivering and sustaining Patient and Public Involvement, and positively impacting activity across Scotland. Great recognition of the work that Rosie and Partners in Research have been doing.

# Recruitment

## Recruitment 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.

## Achievements of 2023-2024

Permission to contact provides opportunities for people living with neurodegenerative diseases across Scotland who have signed up to be contacted by our NDN teams to consider participation in our research.

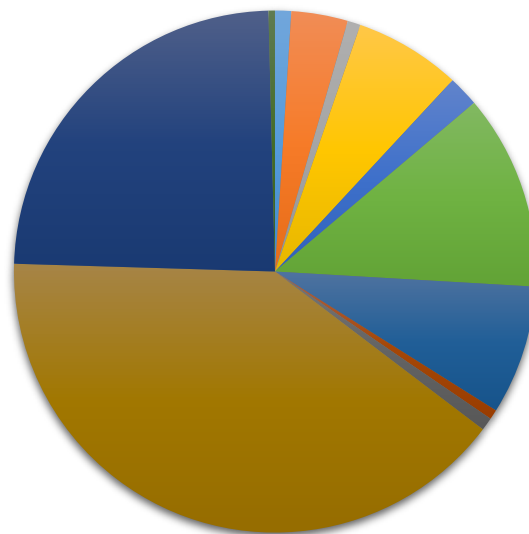
Access to the NDN's primary recruitment tool 'Permission to Contact' (PTC), has been widened with it being accepted as a study in its own right on the national Join Dementia Research (JDR) site. We have also developed online access for 'Permission to Contact' which has now gone live. Further development of the PTC ensured that the inclusion of other neuroprogressive diseases were also added to the sign up for an opportunity to register their interest in research.





Recruitment to studies can be challenging across many fields of the research community. The NDN's unique recruitment tool, Permission to Contact has provided a successful pathway for participation in research. Since its launch in 2020 PTC has enabled many people across Scotland the opportunity to be recruited into our research studies. The NDN will continue to raise the profile to inform and provide these opportunities for research participation. We have had **550** people sign up to our PTC (as of March 29<sup>th</sup> 2024).

### % of total Permission to Contact



■ Ayrshire & Arran    ■ Borders    ■ Dumfries & Galloway    ■ Fife  
■ Forth Valley    ■ Grampian    ■ Greater Glasgow    ■ Highland  
■ Lanarkshire    ■ Lothian    ■ Tayside    ■ Shetland

The NDN also retains close links with Join Dementia Research and SHARE to ensure we provide integrated opportunities and choice to access research for people across Scotland.

We have continued the successful programme of educating key staff in how to have a 'confident conversation' about research with the people they support. It is agreed that these staff are key to assisting in our aim to offer everyone the opportunity to participate in relevant research into a variety of conditions including dementia, mild cognitive impairment, and neuroprogressive conditions. See below for more about 'confident conversations.'

As part of the Strategy to ensure we reach the Islands as well as mainland Scotland, Tom and Emma visited Shetland in June 2023 to meet people with lived experience of dementia, and clinicians who work in the field of dementia or neuroprogressive illnesses, and social care staff. They discussed how people in Shetland could best be involved in research with all these groups. They were delighted with the enthusiasm and 'can-do' attitude of everyone they met.

# ENRICH Scotland

## Commitments of the Network

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.

## Achievements of 2023-24

- Developed the network.
- Expanded the Research Ready Care Home Network from 147 in December 2022 to 295 in March 2024. These are distributed throughout Scotland (urban and rural), include homes in areas of high and low deprivation, and represent local authority, private and third sector homes. This means that more than one quarter of all care homes in Scotland are now registered as Research Ready. By comparison, NIHR ENRICH (which has been established in England since 2012) has registered 1000 from a pool of over 14,000 care homes as Research Ready.
- Maintained a team of one senior Clinical Studies Officer (CSO), and six CSOs offering all care homes a named person responsible for supporting research.
- Supported research studies.
- Worked with a further 20 research teams since December 2022, offering individual support depending on the needs of each team. Support has been mostly with recruitment (n=11), and expert advice (n=4), study delivery (n=2), data analysis (n=2) and PPI (n=2).
- Completed the first ENRICH Scotland research study in collaboration with Edinburgh Napier University, funded by NHS Lothian for £150,000. This explored staff retention in the care home sector from the perspective of care home managers ('CHURN' study).
- Sent a monthly newsletter to all Research Ready Care Homes outlining current research opportunities available to them along with information about research-associated events, training and publications/reports of interest.
- Changed the quarterly Care Home Research Forum to a hybrid event rather than online. 36 researchers have signed up to this research forum.



- Piloted a new Care Home Managers Forum where we bring together care home managers from across Scotland and Researchers from across the United Kingdom (UK) who are interested in supporting research in care homes. Forty managers have signed up.
- Bid for one feasibility trial in collaboration with the Neuroprogressive and Dementia Network (NDN).
- Supported the Lothian Care Home Innovation Partnership (CHIP) to hold regular meetings to implement tests of change, including an in person meeting in Braeburn Care Home. Formed closer links with NHS Lothian QI team. Co-creating research projects.

#### Developed RICH Voices (PPI) and Resources

- The Patient and Public Involvement (PPI) group called RICH (Research in Care Homes) Voices created an introductory film explaining care home research in Scotland.
- RICH Voices created a content library of photographs that can be used to illustrate research participation and PPI activities in care homes.
- RICH Voices held a logo competition to increase the visibility of RICH Voices and encourage group identity/cohesiveness. The winning logo was designed by a Research Ready care home manager.
- RICH Voices have recorded and produced four podcast episodes where members of the Research Ready care home staff network were interviewed.

#### Conferences/webinars/papers

- Organised the second ENRICH Scotland conference, which was held in March 2024 in Edinburgh Zoo. The feedback was overwhelmingly positive and here are the links to most of the presentations:  
<https://www.youtube.com/playlist?list=PLeUI1GHB4EvQr39svpWTjKQOqB0NNeFOd>
- Held an 'introduction to ENRICH Scotland' webinar (also available on the website)
- With DHI Healthy Innovation, held a meeting at the National Robotarium on technology and innovation in care homes oct-2023-haic\_compressed.pdf (dhi-scotland.com) · Recorded a podcast episode for IRISS FM introducing ENRICH Scotland Iriss.fm, Scotland's social services podcast: ENRICH Scotland: supporting research in care homes.
- Published a descriptive paper in an academic journal explaining ENRICH Scotland and our model to enable research in care homes <https://doi.org/10.12968/nrec.2022.0030>
- Updated our website ENRICH Scotland | NHS Research Scotland | NHS Research Scotland to include guidance for researchers and care home staff, and a video discussing PPI involvement

- Regular updates to our blog aimed at care home staff, and engagement on Facebook and Twitter (X)
- Attended four Conferences where we introduced our ENRICH model through oral presentations, stalls and posters

# Engagement

## Commitments of the Network

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.

## Achievements of 2023-2024

As of February 2024, 181 Alzheimer Scotland dementia advisors / link workers / post-diagnosis support workers have undertaken the Confident Conversations training, building connections between NDN and Alzheimer Scotland to enhance capabilities and confidence in discussing, promoting and enabling participation in research. (see previous section for more details).

We are planning a joint conference with SDRC in June 2024. Watch this space for further details!

Alzheimer Europe Conference – Emma Law and Rosie Ashworth attended this excellent conference hosted by Alzheimer Europe in Helsinki in October 2023.



Our take-away findings from the conference were as follows:

- There were many networking opportunities and we have since made contact with The STAND (Striving Towards A New Day), a third sector organisation acting as a peer support group for people living with younger onset dementia, with approximately 26 meeting areas in Scotland, and Kirrie Connections - a dementia support hub in North Tayside, and The Heart of Newhaven community hub, Mens shed, and the Cyrenians.
- LGBTQ+ representation in care homes: We want to work with research-ready care homes to capture the demographics of their residents including gender identity and sexuality. There is a potential collaboration with Phil Harper, John Hammond and Daithi Cree, who all are experts in this field including lived-experience.
- Advance Research Planning- we want to include ARP with research ready care homes to increase access/participation in research. Potential collaborations with Victoria Shepherd.
- Challenges in co-research: Creating a peer-to-peer support network within Partners in Research to support people who are working in co-research with people with dementia, neuroprogressive conditions and ageing population research.
- In many ways we are ahead of the curve with a lot of 'patient and public involvement' related work. One of the challenges we all face in this area is having appropriate funding to support involvement of people with lived experience.
- There were lots of examples of where the recommendations that researchers gave were essentially what we already do within the NDN and ENRICH Scotland, particularly around relationship building and retention.
- We promoted the Partners in Research book.

Tom Russ has become the vice chair of the Brain Health and Dementia ARC (Alliance for Research Challenges). This is one of four ARCs supported by the Scottish Funding Council.

In June 2023 we continued our annual training session with higher trainees in old age psychiatry from across Scotland about research, its implications, and how to connect locally with ongoing research activities.

We were asked to attend the Scottish Faculty of Old Age Psychiatrists to deliver a session on the Network and this was a prime opportunity to engage with clinicians. This took place in May 2023 and discussion was centred around the toolbox we have created to help clinicians signpost people who might have an interest in participating in research but are unsure in which direction to send them.

We held our first writing retreat in conjunction with ENRICH Scotland and Edinburgh University in January 2024. This was a great opportunity for excellent collaboration and planning as well as undertaking lots of writing for papers to be published.

An event was organised by Dr Gordon Duncan, NHS Lothian, in September 2023 for people with lived experience of Parkinson disease. The title of the event was Learning to Listen – a patient centred approach to Parkinsons care and research. The Permission to Contact scheme was promoted at the event and we received many applications to join after the event. A further event is being organised by Dr Esther Sammler, NHS Tayside in April 2024 in conjunction with the Regional Interest Groups.

The staff have had the opportunity to attend training sessions such as the Lewy body masterclass in Sheffield and attending various conferences eg Parkinson/MND. We also hold 6 weekly senior CSO meetings and an annual Network meeting.

We currently send out a quarterly newsletter to a distribution list which includes information about current studies, what's happening in the Network and in the Local Health boards. This year we have also started to do more detailed information sheets in our local Health Boards for the clinicians and partners about our studies and activities relevant to their area.

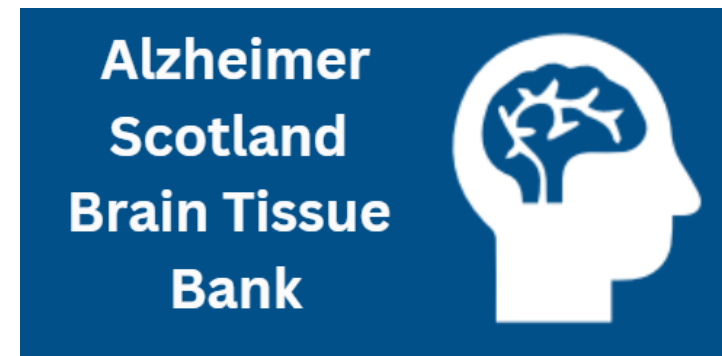
Finally, we are using social media a lot more and posting about activities. On World Lewy Body Day on January 28<sup>th</sup> 2024 we developed a press release which was shared on all social media platforms: <https://t.co/OISveB2b1Q>



# Alzheimer Scotland Brain Tissue Bank

## Commitments of the Network

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.



## Achievements of 2023-2024

The Alzheimer Scotland Dementia Brain Tissue Bank (ASDBTB), continues to offer information to a wider audience about the role and purpose of the sign-up and consequent donation offers for people with dementia, through their collaboration with Alzheimer Scotland.

Dr Tom Russ, ASDBTB director says “In order to shed more light on how brain changes relate to the symptoms of dementia, we need two things; samples of brain tissue and information about how this person was when they were alive”.

The ASDBTB is featured as a study on JDR, which offers the opportunity for anyone with a diagnosis of any type of dementia to be offered access to donating their brain tissue after death. The numbers of donations remain small but steady, as we are unable to accept large numbers of donations due to the paucity of neuropathologist specialist who can remove the necessary samples of brain tissue and the cost of doing this, including transport of the body.

The NDN team have been distributing leaflets about both joining JDR and the ASDBTB during the Confident Conversations training days, to enable staff to have another suggestion in their tool box, of how people who may be interested in participating in research, sign up for brain tissue donation.

# Delivering Clinical Research

## Commitments of the Network

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.



## Achievements Of 2023-2024

Jacqui Kerr took over the role of Practice Lead Facilitator for Scotland in July 2023 with the aim to promote and roll out the National Institute for Health and Social Care Research Dementia Rater Online Toolkit to our NDN Teams across Scotland. The premise of the NIHR online dementia rater toolkit is to provide a structured and standardized training platform for the most frequently used assessment tools in NIHR clinical research studies of Dementia.

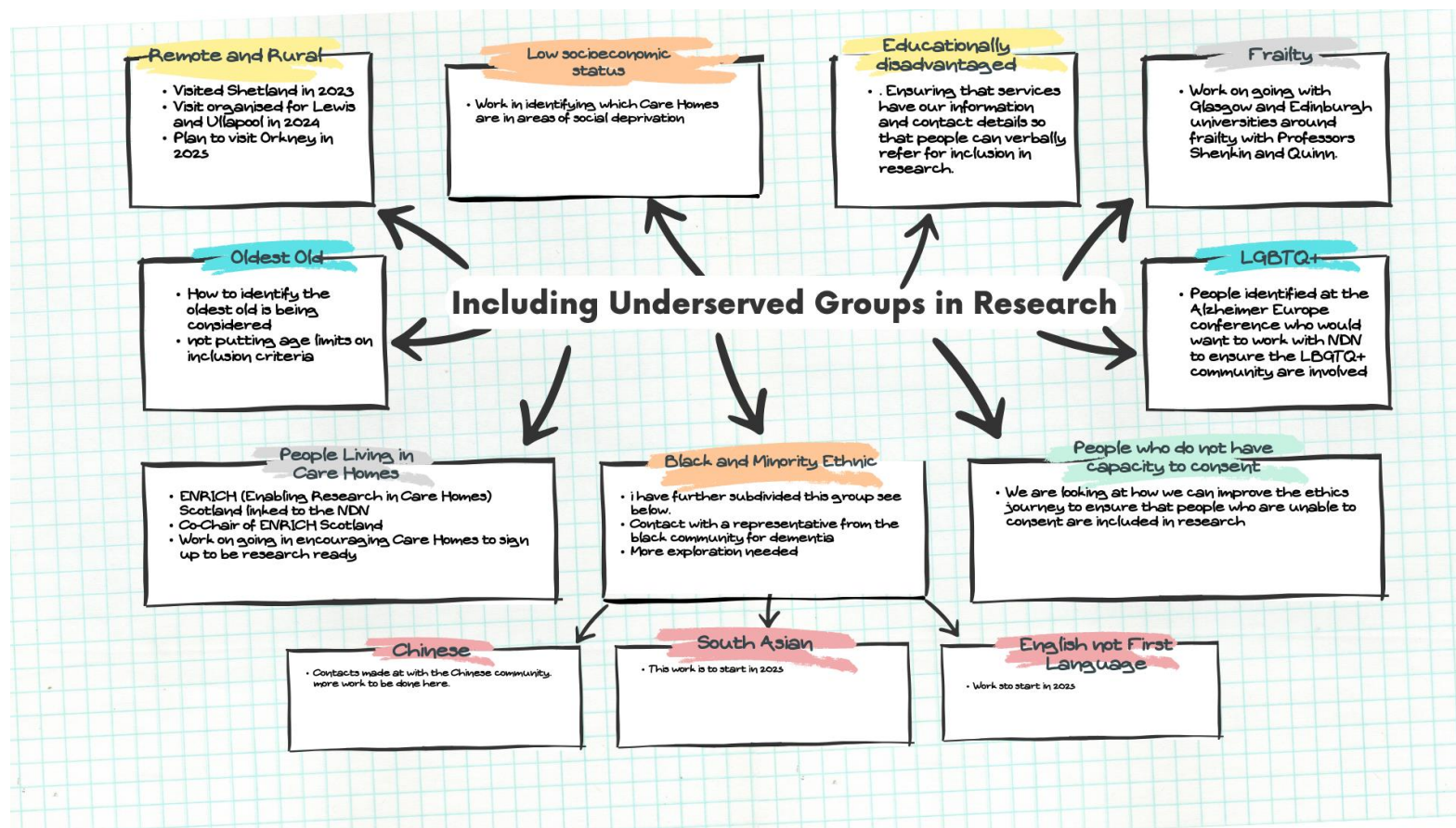
In September 2023 we successfully launched the online toolkit, with many of our Clinical Studies Officers having joined the online platform to complete their training. We are also pleased to announce that we have 2 new Practice Lead Facilitators joining Jacqui to work on the programme from our NDN team – Kate Ferguson and Dr Rosalie Ashworth.

Future work streams will include an NIHR Online Rater Toolkit for other neurodegenerative disease areas such as Parkinson Disease - so watch this space for future developments of the online training platform.

We have grown in reputation over the years and continue to be approached by major pharmaceutical companies to include the NDN in studies at an early stage. We have been able to extend our portfolio of Parkinson disease research in Lothian, Greater Glasgow & Clyde and Tayside. We have been involved in Huntington research delivery in Grampian, Tayside and Lothian.

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

In Emma Law's new post as strategy lead for NDN, she has pulled together some of the underserved groups in research and is looking at ways to involve more people from these groups in research. See diagram below:



# The Future

## Commitments for 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.

The Future



Over the past 12 months, the NDN have successfully achieved and built upon our strategy and commitments pledged.

Building on our collaborations and relationships formed in 2023/2024 will be a key focus for the continued success of the NDN in the coming year for across Scotland and the wider UK.

Promoting our excellent research opportunities as a researcher or a research participant across Scotland will continue to be at the forefront of our strategy and development plan.