Celebrating Scottish Research Conference 2024
SDRC, NHS Research Scotland Neuroprogressive and Dementia Network, Brain Health ARC

Thursday 13 June 2024

The Conference was opened by the Chair of the morning session, Dr Emma Law from the NRS Neuroprogressive and Dementia Network.

The first presentations were updates from the Neuroprogressive and Dementia Network, ENRICH Scotland, the SDRC and Brain Health ARC.

NRS Neuroprogressive and Dementia Network

Dr Tom Russ, Director of the Alzheimer Scotland Dementia Research Centre and SDRC Executive Committee member, outlined the recent activities and future plans of the NRS Neuroprogressive and Dementia Network (NDN).

The network focuses on clinical research across various neurodegenerative conditions, including different types of dementia, Parkinson's disease, motor neuron disease, multiple sclerosis, Huntington's disease, and Creutzfeldt-Jakob disease (CJD). It is active in every mainland health board in Scotland and is expanding its reach to the Scottish islands. He emphasized the importance of balancing commercial and academic studies, as commercial trials bring in revenue that helps fund further research and staff employment.

Tom also discussed the Alzheimer Scotland Dementia Brain Tissue Bank, a collaborative initiative with the University of Edinburgh, allowing individuals diagnosed with dementia in mainland Scotland to donate brain tissue for research.

The NDN has strong partnerships with charities, especially Alzheimer Scotland, and their joint efforts to educate staff through the "Confident Conversations" programme. This training helps Alzheimer Scotland's post-diagnostic link workers and dementia advisors provide better support to those interested in research.

He mentioned the network's research interest register, "Permission to Contact", which securely stores data within the NHS firewall and has recently reached 600 participants. This register is crucial for recruiting volunteers for various studies, and the network collaborates closely with Join Dementia Research to maximize participation.

The network is also actively involved in several high-profile UK-wide studies and platform trials, including the LUMA trial and MND-SMART and will be involved in upcoming blood-based biomarker studies.

ENRICH

Professor Susan Shenkin provided an overview of Enabling Research in Care Homes (ENRICH) Scotland.

Involving care homes in research can enhance quality of life for residents, their families, and caregivers. ENRICH aims to demystify research processes and make participation accessible and meaningful for all involved. It actively involves care home managers, residents, families, and researchers in co-designing and implementing research. It strives to prioritize research topics based on input from care home communities, ensuring relevance and impact.

ENRICH Scotland has engaged over 330 care homes across Scotland as "research ready," indicating their willingness to participate in studies. Special initiatives include Care Home Innovation Partnerships in Edinburgh and Glasgow, which foster innovation and feedback within care settings.

Future activity aims to improve recruitment and retention of care home staff, exploring clinical trials in care home settings, and enhancing ethical and governance frameworks for social care research. The goal is to facilitate easier navigation and compliance akin to NHS standards.

ENRICH- Partners in Research

Dr Rosie Ashworth's presentation discussed the extensive patient and public involvement (PPI) work conducted by the NDN and ENRICH Scotland.

Rosie highlighted the Partners in Research network which offers various engagement opportunities for people with lived experience to be involved in research. Specific activity includes monthly drop-in sessions which provides a supportive environment where personal challenges and everyday difficulties can be openly discussed.

Partners in Research also conducts traditional PPI drop-in groups where researchers present their studies for feedback and discussion from partners with lived experience. This ensures that research aligns with the needs and perspectives of those directly affected.

Rosie played a video featuring testimonials from stories of those who have participated in the programme. These underscored the value of lived experiences in shaping research. Participants expressed empowerment and fulfilment from contributing to meaningful research that addresses real-world challenges.

Challenges raised in this presentation included the need for more diverse representation across neuroprogressive disease areas beyond dementia. There's

also a focus on improving support for researchers engaged in co-research to ensure their well-being amid emotionally challenging work.

Rosie stressed the importance of improving awareness and recognition of co-research within the academic community. She emphasized the need to bridge the gap between lived experience and academic research, ensuring that both perspectives are equally valued and integrated.

SDRC and Brain Health ARC updates

As Chair of both the SDRC and the Brain Health ARC, Prof Terry Quinn provided an update on the work of both organisations from the past year. Both SDRC and Brain Health ARC underscore Scotland's leadership in dementia and brain health research. SDRC excels in consolidating research efforts and fostering collaboration, while Brain Health ARC extends this mission by broadening the focus and integrating additional aspects crucial for advancing brain health initiatives across the lifespan. Together, these consortia represent Scotland's commitment to innovation, collaboration, and impact in neuroscientific research.

Alzheimer Scotland Student Research Programme

Established in 2022 by Alzheimer Scotland, with support from the Scottish Dementia Research Consortium, the Programme aims to nurture the next generation of dementia and brain health researchers in Scotland. It funds Masters level studentships and focuses on professional and personal development of awardees, including research skills, dementia education, and networking. Central to the programme is the involvement of people with lived experience of dementia through partnerships with the Scottish Dementia Working Group and the National Dementia Carers Action Network. They play a crucial role in selecting projects and supporting students throughout their research journey.

Alzheimer Scotland Student Research Programme 2023 Award Recipient:

Kelly Kelly

The first recipient of this award was Kelly Kelly hosted at the Alzheimer Scotland Centre for Policy and Practice at UWS. Her research focuses on young onset dementia and trauma-informed care. Those with young onset dementia often face prolonged diagnostic pathways that exacerbate psychosocial stressors.

At the current stage of her project, Kelly is conducting her literature review to identify gaps in knowledge regarding trauma-informed care in the diagnostic process for young onset dementia and awaiting approval for her ethical applications.

She plans to develop her recruitment strategy and commence interviews once approvals are in place. Kelly plans to use a qualitative research design with semi-structured interviews involving individuals diagnosed with young onset dementia, healthcare professionals, and family caregivers.

Her findings will be disseminated her findings through various mediums including written reports, vlogs, presentations at conferences, and poster presentations. This research has the potential to influence how healthcare practitioners implement trauma-informed approaches in the diagnostic journey of young onset dementia.

2024 Winners:

Neurostructural underpinnings of the relationship between Traumatic Brain Injury and Dementia, University of Edinburgh, Supervisor- Prof Simon Cox, Student- Katie Robertson

A systems approach to implementing digital tools for earlier Alzheimer's detection in Scottish primary care services, University of Strathclyde, Supervisor- Prof Anja Maier, Dr Coco Newton

Early Career Researcher Presentations

This ECR session featured five speakers.

AMPER: Agent-based Memory Prothesis to Encourage Reminiscence, Mei Yii Lim, Heriot-Watt University and Katerina Pappa, University of Strathclyde

AMPER is an interdisciplinary project aiming to enhance the quality of life for individuals with Alzheimer's through reminiscence therapy. This therapy involves a digital character that facilitates memory recall by using generationally relevant material, personal uploads, and themed content, engaging users in conversations to evoke memories and stimulate mental activity.

The project, co-designed with stakeholders, emphasizes a personalized and socially engaging experience, leveraging technology for remote participation and frequent monitoring. The app's interactive interface ensures a safe and coherent reminiscence process, providing a novel approach to maintaining autobiographical memory and identity in people living with Alzheimer's.

DeepThickness: A Novel Deep Learning Method for Estimating Cortical Thickness Trajectories in Alzheimer's and Healthy Populations, Connor Dalby, University of Glasgow

DeepThickness is a deep learning method for estimating cortical thickness trajectories in people with Alzheimer's. Cortical thickness, a potential biomarker for Alzheimer's, can change up to 20 years before clinical symptoms appear. This research aims to create a normative model of cortical thickness for different clinical groups, using large datasets like the UK Biobank. DeepThickness offers significant improvements over traditional methods, generating cortical thickness estimates in 35 seconds compared to seven hours. This model not only accelerates data processing but also improves accuracy, enabling early detection of Alzheimer's and other neurodegenerative diseases. By examining cortical thickness changes over time, the

model can predict disease progression, offering a valuable tool for early intervention and treatment planning.

Dementia and Multimorbidity - A Research Priority, Dr Lucy Stirland, University of Edinburgh

Dr Lucy Stirland, an old age psychiatrist from the University of Edinburgh, highlighted the critical issue of dementia coexisting with other long-term conditions, known as multimorbidity. Her upcoming project, funded by the Global Brain Health Institute, aims to identify research priorities for those affected by both dementia and multiple conditions. Despite the prevalence of multimorbidity among people with dementia, existing research often overlooks these complexities. Stirland's study will involve online focus groups with people with dementia and caregivers to identify meaningful outcomes for dementia trials. The goal is to influence future research and policies, ensuring they address the real-world challenges faced by those living with both dementia and other health conditions.

Designing Dementia-Friendly Homes with Virtual Reality, Martin Quirke, University of Stirling

Dr Martin Quirke from the University of Stirling shared insights from a project aimed at designing homes for healthy cognitive aging using virtual reality (VR). Led by Professor Alison Bowes, the project involved Co-designing prototype homes through VR workshops. Participants, including older adults and housing professionals, provided feedback on home designs to enhance accessibility and safety for people living with dementia. Key findings emphasised the importance of visual access, lighting, ergonomics, and strategic storage solutions. The iterative VR process allowed for practical, user-centred home designs, ensuring that future homes support the independence and well-being of individuals with cognitive impairments.

Identifying drugs for repurposing in dementia using the UK Biobank cohort, Dr Jodi Watt University of Glasgow

Dr Jodi Watt from the University of Glasgow explores the potential of repurposing existing drugs to treat dementia, leveraging the extensive data available from the UK Biobank. Given the limited effectiveness and high costs of current dementia drugs, repurposing known medications could be a game-changer.

Watt's team conducted a phenome-wide association study (PheWAS) using the entire Biobank cohort, analysing cardiovascular risk factors and medications. They found significant associations between dementia and drugs like insulin, aspirin, and metformin, though these findings are influenced by indication biases.

To address these biases, the researchers focused on a cardiovascular sub-cohort and made further adjustments, reinforcing their initial findings. Despite challenges like reverse causation, their work demonstrates the potential of large-scale studies to identify new treatments for dementia.

Future research will include more sensitive markers and collaboration with larger databases to validate these findings, with the goal of presenting viable repurposed drugs to expert panels for further investigation.

MND SMART- Delivering Innovation for Definitive Trials in Motor Neurone Disease

Prof Suvankar Pal presented on the MND SMART trial, focusing on advancements in motor neurone disease (MND) research and the trial's innovative approach. MND is a devastating neurological disorder characterized by progressive muscle weakness, speech and swallowing difficulties, and respiratory problems. Despite its severity, treatment options are limited, with only one licensed drug available since 1995.

The MND SMART trial addresses the urgent need for effective therapies by employing a multi-arm, multi-stage (MAMS) clinical trial design. This approach allows simultaneous testing of multiple interventions against a placebo, with ongoing evaluation through interim analyses. Unlike traditional sequential trials, MAMS reduces time and costs, accelerating the discovery of effective treatments.

Suvankar outlined some achievements and milestones of the project including recruitment goals.

Beyond clinical outcomes, the trial has significantly impacted the MND research landscape, fostering collaborations with industry, academia, and patient advocacy groups. This includes pioneering efforts in biomarker discovery, digital pathology, and voice analysis to enhance early diagnosis and treatment monitoring.

The presentation underscored the pivotal role of patient involvement in study design and implementation.

Updates on Research of other Neuroprogressive Diseases (including non-Alzheimer dementias)

This afternoon session covered research progress from a range of diseases, including MND, Parkinson's, Multiple Sclerosis, Huntington's disease and vascular disease. Speakers included representatives from research funding organisations, researchers and people with lived experience. The underlying theme across these presentations was the critical role of research funding and collaboration in advancing treatment and care strategies in Scotland and beyond.

MND

Jane Haley is Director of Research at MND Scotland which the primary support and research funding organization in Scotland. She discussed various aspects of motor neurone disease (MND) and the charity's research initiatives. She emphasized the critical need for early and accurate MND diagnosis, citing the prolonged diagnostic delays currently experienced.

Haley underscored collaborative efforts across the UK, facilitated by initiatives like the UK MND Research Institute, aiming to enhance research coordination and funding efficiency. She acknowledged overlaps with dementia research and emphasized the importance of infrastructure like the Brain Tissue Bank for advancing MND research.

Susan Murray, a participant in the MND SMART trial, shared her personal journey with MND, highlighting the emotional and physical challenges of trial participation. Despite disappointments from trial outcomes, Murray remains optimistic about contributing to future breakthroughs, urging others with MND to engage in research.

Parkinson's

Dr Gordon Duncan from the University of Edinburgh introduced Parkinson's disease from a researcher perspective, emphasising the importance of clinical research to improve treatments and quality of life. He outlined ongoing studies supported by the NDN, focusing on disease-modifying therapies and symptomatic treatments. Gordon advocated for the involvement of people living with Parkinson's in research through initiatives like the permission to contact scheme.

Stephen Brown shared his personal story as someone living with Parkinson's for 11 years. He shared his experience of participating in a clinical trial, describing the challenges, uncertainties and benefits of taking part.

James Jopling represented Parkinson's UK, detailing their role in funding research projects. James emphasised community involvement in shaping research priorities based on disease progression timelines. He also highlighted efforts to increase participation in clinical trials post-COVID, addressing logistical challenges and patient needs and discussed the importance of accessibility in research, including online options and home visits.

Dr Tom Gilbertson from the University of Dundee presented on innovative research using focused ultrasound for minimally invasive neuromodulation in Parkinson's disease. He showed videos demonstrating the effects of deep brain stimulation (DBS) and focused ultrasound on tremor reduction and highlighted efforts to map brain circuits involved in motivation and their potential for future therapeutic interventions.

Multiple Sclerosis

Caitlin Asbury, Research Communications Manager at the MS Society, provided an overview of MS as a demyelinating neuroprogressive condition affecting a significant number of people in the UK and Scotland. She highlighted the MS Society's efforts in providing support services, advocating for MS, running awareness campaigns, and funding cutting-edge research.

Caitlin discussed several research projects funded by the MS Society in Scotland such as the Edinburgh Centre for MS Research and the Doctoral Training Centre at Glasgow Caledonian University.

Peter Foley, a neurology consultant and principal investigator at the University of Edinburgh, discussed clinical trials at the University of Edinburgh, specifically the Octopus trial. He outlined the Edinburgh-based research facility's role in testing new MS treatments through various studies, including randomised controlled trials.

The Octopus trial is innovative in a variety of ways. First, it aims to addresses the gap in treatments for progressive MS. Secondly, it is dynamic with multiple treatment arms that evolve over time based on ongoing research outcomes.

Sandra Fryer shared her personal journey with MS, from initial symptoms in 2011 to her diagnosis of primary progressive MS in 2021. She shared her decision to participate in the Octopus trial, motivated by potential benefits for future generations of people diagnosed with MS and the supportive environment of the Edinburgh clinic. Sandra also shared positive experiences emphasising the comprehensive care received during sessions involving tests and evaluations.

Huntington's disease

Louise McCabe, a Trustee at the Scottish Huntington's Association (SHA) and a social researcher at the University of Stirling, emphasized the comprehensive support SHA provides to families affected by Huntington's disease (HD) across Scotland. She highlighted SHA's multifaceted approach, including clinical support, specialist services for children, financial well-being support, and youth services. Louise underscored SHA's deep engagement in research, mentioning ongoing trials and studies in Scotland and the organization's commitment to involving HD families in research efforts. She also announced SHA's new grants call to support HD research engagement and impact initiatives.

Gillian McNab and Marie Short, both personally affected by HD, shared their experiences participating in HD research. Despite the challenges and discomfort involved in some procedures like lumbar punctures, they expressed their dedication to advancing HD research for the benefit of future generations. Marie also highlighted her role in the growing research initiatives in Europe, advocating for Scotland's active participation.

Dr Peter Foley at the University of Edinburgh is also an HD researcher. He discussed the clinical aspects of HD and ongoing research in Edinburgh. He outlined the symptom clusters of HD—movement problems, mental health effects, and cognitive decline—and the current lack of curative therapies. Peter highlighted the importance of observational studies like Enroll-HD in gathering data for research and potential trial recruitment. He expressed his ambition to expand Edinburgh's involvement in interventional trials in the future, aiming to enhance treatment options for HD.

Vascular disease

Dr Fergus Doubal from the University of Edinburgh presented on vascular disease, covering several key aspects related to vascular dementia, stroke-related cognitive decline, and emerging treatments.

Small Vessel Disease (SVD) is a major cause of vascular dementia. It affects small blood vessels in the brain and is diagnosed via MRI scans showing characteristic white or black spots. It currently lacks effective treatments.

He discussed ongoing drug trials that originally used for other conditions but showing promise in treating small vessel disease-related cognitive decline and stroke prevention.

Fergus explored the use of advanced MRI techniques to study blood flow in the brain, crucial for understanding vascular disease mechanisms and testing new drugs.

He touched upon using AI to analyse brain scan reports across Scotland to identify undiagnosed cases of small vessel disease, aiming to improve early detection and intervention. Despite promising research, Fergus noted the current gaps in clinical services for treating small vessel disease effectively, emphasizing the need for better healthcare delivery systems.