



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

Friday 14 June 2024

Opening Address

Henry Simmons is the Chief Executive of Alzheimer Scotland. In his opening address, he called for renewed commitment to advocate for Scotland's strengths in dementia and brain health research. Scotland should have a bigger role on research proposals and funding allocations to reflect the strength of research ongoing across the country. Scotland should be recognised as an equal partner, not a minor player and must work to ensure fairer treatment and access to resources.

Research is critical in offering hope to people affected by dementia and those at risk of developing it. The research community collectively must advocate for timely access to trials and treatments is urged to prevent a loss of hope among those affected, or at risk of developing dementia in Scotland.

Henry recognised the contributions of research volunteers and members of the public who take part in research. He called for better engagement with Scottish communities to increase participation in research and that everyone who wishes to take part can do so.

Brain Health Scotland

Updates from Brain Health Scotland

Alison McKean, Executive Lead for Brain Health and Research at Alzheimer Scotland provided an update on the work of Brain Health Scotland.

Brain Health Scotland's aim is to inspire and empower people to protect their brain health and reduce dementia risk through the application of evidence-based strategies on modifiable risk factors across various settings and life stages. Brain Health Scotland activities focus on awareness-raising, public health messaging and tailoring initiatives to different demographics. Alison also discussed the importance of partnerships and collaboration, ensuring all into Brain Health Scotland's activity is underpinned by substantive research and involving lived experience.

Alison highlighted some specific Brain Health Scotland initiatives, including [the My Amazing Brain](#) schools programme and a partnership project with [Davos Alzheimer Collaborative](#) for early detection of Alzheimer's.

Brain health clinic developments

Dr Catherine Pennington is a cognitive neurologist and clinical advisor to Brain Health Scotland. She discussed the development of brain health clinics highlighting the first walk-in brain health service in the UK which recently opened in Aberdeen stressed the potential of brain health clinics due to the likelihood of the availability of new treatments in the near future.

The clinic offers patients access to information and interventions they need to protect their brain. Clinics also provide opportunities to join research programmes, so everyone can join the effort to better understand brain health and disease

Behaviour change and brain health

Ailin Chen is a trainee health psychologist with Brain Health Scotland. She discussed the role of health psychology and behaviour change in promoting brain health.

Evidence shows that simply providing information is not enough to change behaviour. It is more effective to provide a person-centred approach which understands an individual's motivations, barriers, and unique circumstances.

Ailin described current projects, including a training program for staff at brain health and dementia resource centres and a brain health coaching service co-developed with the University of Stirling. This service offers personalized, non-judgmental support to individuals seeking to improve their brain health. Feedback from these initiatives has been positive, with staff feeling more confident and clients appreciating the personalized approach.

ON-FIRE: a UK-wide study on inflammation in frontotemporal dementia

Dr Maura Malpetti from University of Cambridge introduced the ON-FIRE project which focuses on frontotemporal dementia (FTD).

Maura's research focuses on the role of inflammation in FTD, specifically how the brain's immune system, including microglia and astrocytes, contributes to the disease.

Using advanced imaging techniques like PET scans, researchers found a link between FTD and brain inflammation levels. The study suggests that inflammation levels in the brain correlate with the rate of cognitive decline in people with FTD and that trial participants with higher brain inflammation decline faster, indicating inflammation's crucial role in disease progression.

Looking at potential treatments, Maura highlighted there is potential to repurpose existing immunotherapies from other fields like cancer and diabetes to treat FTD. However, the challenge is to selectively target parts of the immune system without compromising overall immune function.

The future aims of the ON-FIRE project is to recruit 1,000 diverse participants to establish an open, nationwide network for FTD inflammation research. It also seeks to develop scalable blood tests for early detection.

MASTODON-AD: A platform trial in Alzheimer's dementia

Prof Paresh Malhotra, from Imperial College London presented on the MASTODON-AD platform, highlighting its development and purpose in advancing Alzheimer's disease research and treatment.

Prof Malhotra emphasised several limitations with current Alzheimer's treatment development. These included: the limited efficacy of current Alzheimer's treatments; the challenges with new drugs in that they may not be safe for broader populations; and that research trends indicate a move towards earlier intervention which creates challenges in identifying target populations.

Prof Malhotra also shared experiences in challenges he has faced in trial design spanning from funding delays to administrative hurdles and outdated outcome measures like pen-and-paper tests, underscoring the need for modernisation.

To address these challenges, Prof. Malhotra introduced MASTODON-AD, a proposed platform trial modelled after successful cancer trials which would concurrently evaluate multiple treatments and efficiently phase out ineffective ones.

He stressed the importance of collaboration across institutions and with patient advocates to ensure trial inclusivity, robustness in outcome measures, and person-centred research design. The next steps for MASTODON-AD include proposals for potential treatments, refining trial design with diverse input and validating novel outcome measures suitable for varied participant demographics and languages.

SIGN Guidelines implications for research

Dr Adam Daly, from the University of Glasgow presented on the SIGN (Scottish Intercollegiate Guidelines Network) Guidelines which are designed to provide evidence-based recommendations for healthcare professionals to ensure patients receive the most effective treatments and improve healthcare outcomes. They aim to standardise care based on the best available evidence, reducing variation in clinical practice.

These guidelines go through a rigorous development process, involving a systematic review of the current evidence. These involve multi-disciplinary groups, including clinicians, researchers, and patient representatives, contribute to the guideline creation. The guidelines' validity and reliability are tested through peer review.

They are comprehensive, covering diagnosis, treatment, and management of medical conditions. They are also kept up to date to constantly reflect new research and clinical practices.

While the guidelines cover various medical conditions, Dr Daly provides an example of dementia as a case study. He explains how the guidelines provide detailed

recommendations on diagnosis, pharmacological and non-pharmacological treatments, and patient management.

There have been some challenges in guideline implementation, such as ensuring widespread adoption and integrating guidelines into clinical workflows. However, Dr Daly emphasised the critical role of SIGN Guidelines in enhancing the quality and consistency of healthcare, ultimately leading to better patient outcomes by improving patient care. He encourages healthcare professionals to utilise these guidelines in their practice and participate in future updates.

Prioritising Research Questions (PICO) Method

Prof Terry Quinn introduced this session, which was interactive and encouraged discussion among delegates. The purpose was to use the experience and expertise of those in the room to think of research questions. Responses were collected and potentially used to inform future commissioned research calls.

Before beginning the exercise, Terry asked delegates to use the PICO Method to come up with research questions. This is as follows:

- **Population (P):** The specific group of individuals being studied.
- **Intervention (I):** The treatment or action being tested.
- **Comparison (C):** The control or alternative to the intervention.
- **Outcome (O):** The measures of success or effect of the intervention.

Terry then asked participants to develop their own PICO questions, focusing on brain health and older adults, but not limited to these areas. This introduction set the stage for an engaging and productive session where attendees could actively contribute to shaping future research priorities in dementia and related fields.

ECR Presentations

To explore the effectiveness of arts-based methods to develop social leaders in dementia, Suzie Beresford, Alzheimer Scotland

Suzie's research, conducted as part of her Masters in Research at Queen Margaret University in 2023, investigates how arts-based methods facilitate equality of voice, democratize group settings, and encourage engagement, specifically within the BOLD (Bringing Out Leaders in Dementia) program. These activities helped reduce stigma, provided respite for caregivers, and fostered a supportive community. Susie concluded that arts-based methods promote equality of voice and can effectively support dementia care, with potential implications for broader policy and practice.

Resting-state EEG signatures of Alzheimer's disease are driven by periodic but not aperiodic changes, Martina Kopcanova, University of Dundee

Martina's undergraduate research, funded by the Carnegie Trust, explores EEG (electroencephalogram) signatures in Alzheimer's disease. Collaborating with experts from institutions like Harvard Medical School, Cardiff, Bath, and Columbia University, Martina aimed to identify early markers of cognitive decline in Alzheimer's

through EEG, a cost-effective and noninvasive method. Martina's study provides mechanistic clarity and distinguishes Alzheimer's EEG markers from those of other conditions like Parkinson's and schizophrenia, which show changes in aperiodic activity. The research underscores the potential of EEG spectral power ratio as a prognostic marker for disease progression and response to interventions in Alzheimer's.

Co-design of research - why is it important and how to we get it right? (Views from the autistic community), Lynsey Stewart, University of Strathclyde

Lynsey's research focuses on improving dementia detection and assessment in the autistic population. Recognising the unique cognitive differences and communication styles of autistic individuals, she emphasises the importance of co-design in research. Supported by her supervisors and a steering group including Spectrum Voices, an autistic-led group, Lynsey advocates for involving the autistic community in every research stage. Her video presentation features autistic individuals discussing the significance of co-design, which ensures their perspectives and experiences are integral to research development. This work aims to create more inclusive and effective dementia detection methods by integrating autistic voices into the research process, addressing the gap in current approaches that often overlook this population.

Dementias Platform UK: Trials delivery and the role Scotland could play in this

Prof Vanessa Raymont from the University of Oxford discussed the work of Dementias Platform UK (DPUK) and an exciting new trial related to dementia research. Over the past 30 years, numerous clinical trials for new dementia drugs have failed, but recent advancements suggest a significant shift in treatment opportunities and diagnostic methods. This year, the UK is likely to approve its first disease-modifying drug for Alzheimer's, which could dramatically change dementia services and expectations.

DPUK, funded by the Medical Research Council and industry, has three main components: a data portal for storing and accessing research data, an Experimental Medicine Incubator for developing new research ideas, and a Trials Delivery Framework (TDF) that enhances trial efficiency using NHS data. The TDF has expanded its infrastructure, including a network of 58 trial sites across the UK, focusing on underrepresented populations.

One key project, funded by Alzheimer's Research UK and other organizations, aims to validate the utility of blood biomarkers for diagnosing and predicting dementia, focusing on diverse populations. This project will assess if these blood tests can be effectively used in clinical settings and if they provide accurate diagnostic and prognostic information. The study will recruit 3,000 participants, including those from underrepresented groups, and will conduct a randomized controlled trial to evaluate the impact of biomarker information on patients' quality of life, healthcare usage, and economic costs.

This research highlights the potential for new diagnostic tools and treatments to transform dementia care, emphasizing the need for inclusive recruitment and real-world applications.

Experts with lived experience

The final Conference session focussed on those with lived experience and their involvement in research.

Seven speakers have lived experience, and these were: Margaret McCallion, Stuart Dougall and Rynagh Flynn from the Scottish Dementia Working Group (SDWG); Elaine Deehan, Frank O'Hagan and Marion Ritchie from the National Dementia Carers Action Network (NDCAN) and Stephen Brannan from Partners in Research.

They discussed their experiences of being involved in research from different perspectives. From being involved in working groups which prioritise research, contributing to studies and promoting public involvement to integrate lived experience into research. Being involved in research can also enhance future generations' understanding and treatment of dementia, bringing a unique perspective to the table. Together, these voices advocate for a collaborative approach in dementia research, emphasising the value of lived experiences in shaping meaningful and impactful studies.

Speakers also provided advice to the researchers in the room. They stressed the necessity of accessible and clear information about support services and research findings, calling for feedback mechanisms to inform participants on their individual progress during studies. They also called for more inclusive research. One example from Marion Ritchie was to consider the unique experiences of female caregivers and individuals living with dementia, particularly highlighting the under-researched area of women's health in relation to dementia. Another by Stephen Brannan was not to unduly exclude participants based on comorbidities.

The final speaker was Lindsay Kinnaird from the University of Edinburgh who discussed the significance of co-production in dementia research. She represents the Edinburgh Centre for Research on the Experience of Dementia (E-CRED). She emphasised the value of involving people with lived experience in the research process, using the term "co-production" to denote collaboration where all contributions are equally valued.

One example of lived experience leading the research that Lindsay discussed was the BUDS (Better Understanding Dementia Diagnosis) project, which investigated dementia diagnoses during the COVID-19 pandemic. This project involved regular online meetings, material reviews, and thematic analysis, ensuring that lived experience researchers contributed meaningfully.

Despite the benefits, there are structural challenges in co-production, such as funding constraints and restrictive university policies that hinder the full inclusion of

lived experience researchers. She called for changes to empower these researchers as leaders, ensure proper compensation, and facilitate genuine collaboration.

Lindsay stressed the ethical imperative to involve those living with dementia in setting research priorities and urged ongoing learning and adaptation within the research community and beyond.

Prizes

The Conference concluded with the Celebrating Scottish Research Awards, which recognised the hard work and successes of brain health and dementia researchers based in Scotland, across all disciplines and career stages.

The winners are as follows:

1. **Academic Citizenship:** Professor Debbie Tolson, Dr Lucy Stirland
2. **Supporting Early Career Researchers:** Dr. Lisa Davison, Dr Lorraine Work
3. **Rising Star:** Dr. Rose Penfold, Dr Cate Pemble
4. **Best Early Career Researcher Presentations:** Suzie Beresford and Dr. Connor Dalby.
5. **Poster Prizes:**
 - Austin Dibble
 - Sara Scarfo
 - Lauren Binning

Congratulations to everyone who received an award and thank you to all those who nominated them!