

 <p>Scottish Brain Health Register</p>	<p>The Scottish Brain Health Register Newsletter</p>
	<p>April 2021</p>

Welcome to the second issue of the Scottish Brain Health Register (SBHR) Newsletter. This newsletter keeps you informed about SBHR. The current issue is packed with information on the latest research from the Centre for Dementia Prevention (www.edp.ed.ac.uk), as well as an introduction to the new Brain Health Scotland initiative, and lots more. You'll also find out about a FREE online dementia and brain health course. We hope you enjoy the latest edition of the newsletter.

SBHR makes access to dementia research possible and aims to match you to research you are interested in. The register is open to all adults regardless of their current health. You can find contact details at the end of this newsletter if you know someone who would like to find out more or register!

Note that we have now moved premises to the Western General Hospital. Our address is printed at the end of this Newsletter.



Social Media

Follow our related social media accounts on Twitter for the latest news and research;

- SBHR**
[@ScotBHR](https://twitter.com/ScotBHR)
- Centre for Dementia Prevention**
[@CenDemPrevent](https://twitter.com/CenDemPrevent)
- Brain Health Scotland**
[@brainhealthscot](https://twitter.com/brainhealthscot)



From CONCERT-D to SBHR

In 2020 the research register changed its name from the 'CONsent to Consent for Research and Trials – Dementia' (i.e. CONCERT-D) to SBHR. But why?

CONCERT-D was a research register for dementia research that originated from a paper system used in London. SBHR evolved from this system to facilitate Scottish research and move toward a secure digital system that makes matching people to research studies quicker and more efficient. SBHR also improves data storage and administration, allowing better access to data for researchers.

Because we moved to a digital system we required everyone formerly on CONCERT-D to consent to SBHR. This is to comply with regulations designed to keep you informed and your data safe.

Brain Health – It's important!

Researchers are now understanding that many of the risk factors that contribute to diseases which affect the brain are within our control to change.

These "modifiable risk factors" can include dietary choices, smoking and alcohol, exercise, sleep and lifestyle.



It is now thought that brain diseases are likely to start years, if not decades, before any symptoms emerge. And whilst some risk factors do not change, such as our family history and genetics, we can make changes no matter what our age to our diets and lifestyles to improve our brain health and lower the risk of brain disease.



Brain Health Scotland is a newly formed organisation developed in partnership with Alzheimer Scotland, and funded by the Scottish Government. Its purpose is to promote awareness of brain health and to provide new brain health clinics across Scotland where patients can get information and resources on improving brain health. They will also provide access to research opportunities.

Find out more here:
<https://www.brainhealth.scot/>



Free Online Course

Brain Health Scotland, in partnership with The University of Edinburgh, have developed a free online course for understanding brain health and preventing dementia.

The course runs across four weeks with content presented as an engaging mix of video clips, articles, and short interactive quizzes. The course takes an interactive and sociable approach to learning, with regular discussions encouraged to engage learners with their fellow classmates and to reflect and share opinions on the subjects covered.

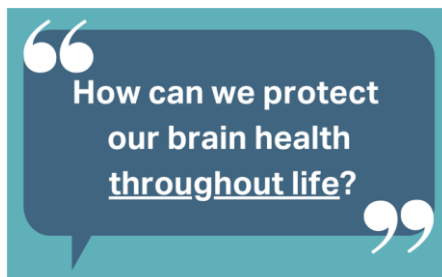
Each week explores a different theme related to brain health and approaches for dementia prevention.

Week 1: The biology of brain diseases

Week 2: Risk factors for brain disease

Week 3: Clinical research programmes

Week 4: Healthcare services and brain health around the world



The course will appeal to everyone with an interest in brain health, with no prior knowledge required. Registration is open now via - <https://edin.ac/2ZNs9zy>

SBHR Research Update

There has been a lot of activity over the last few years on SBHR with many registrants successfully enrolling on a number of research studies.

The PREVENT study, which has been investigating midlife risk factors for dementia, hit a big milestone in February 2021 when it enrolled its 700th participant.

Despite the fact the study is still ongoing, there have been a number of publications already, which are helping researchers understand the early brain changes found in those at risk of dementia.

The European Prevention of Alzheimer's Study (EPAD) ended in 2020. This was a large European wide collaboration aimed at understanding dementia and forming clinical trials of new medicines to fight against Alzheimer's disease. It is therefore very exciting that a new project called EPAD Scotland will soon be opening and will continue this important research.

In December 2018 the "Dementia Buddy scheme", which recruited from SBHR, was featured on the BBC News (<https://www.bbc.co.uk/news/av/uk-scotland-46705885>). The Buddy Scheme brought people with dementia and researchers closer by providing tours around the various University of Edinburgh labs. This gave a behind the scenes insight into how research is conducted and gave an opportunity for researchers to hear about the lives of people with dementia and their carers.

You can find out more about studies currently recruiting on page 4 of the newsletter.

Centre for Dementia Prevention



'Normal' Forgetting!

Most of us at times walk into a room at home and immediately forget why we went there in the first place! Whilst this can be normal it can also be worrying if it happens often. What isn't clear is how frequent these kinds of everyday memory lapses occur in healthy people, and when they are a sign of more serious memory problems.

A recent study by Dr Laura McWhirter and medical students from the University of Edinburgh published in the Journal *CNS Spectrums* provides light on this.

They asked 124 healthy, young and highly educated individuals to tell them about their forgetful moments with an aim to classify 'normal' forgetfulness. They found that memory lapses are very commonly reported and can be very frequent. So much so that many healthy individuals would have met criteria for a diagnosis called 'functional cognitive disorder'. This is when memory problems interfere with daily life but there is no brain disease that causes it.

This means that clinicians who are assessing people with memory problems have a better idea of how often normal forgetting occurs. This may help reduce misdiagnoses and better inform patients on their memory concerns.

Research in the face of the Coronavirus Pandemic

The Coronavirus 2019 (COVID) pandemic halted all research across the UK, including the Centre for Dementia Prevention. This was required to protect participants and staff, and to stop the spread of the virus. Toward the end of 2020 research at the Centre restarted.

To adapt to government and research authority regulations we had to make a number of changes to how research studies were delivered, including installing one-way systems, PPE, hand sanitizers, and even remote testing. The protection of participants and staff was our upmost goal. Dementia has not gone away and it is important to keep research going as best we can to continue the fight against dementia and poor brain health.

Stina Saunders, a PhD candidate at the centre, details some of the changes she had to make to continue her research into how individuals adjust to a diagnosis of Mild Cognitive Impairment (MCI).



MCI Adjustment Study

The MCI Adjustment study was undertaken as a PhD project by Stina, and explores how diagnostic test results are communicated to patients in Memory Clinics. The study aims to understand how information given to patients about their brain health could impact the cognitive and psychological reaction to their diagnosis.

In order to understand the longer-term impact of diagnostic test disclosures on their memory and thinking abilities, Stina assessed people with cognitive tests and questionnaires before they received a diagnosis at a Memory Clinic, and over a long period of time after their diagnosis. Originally participants were seen in-person at home or at a research facility. In reaction to the travel restrictions imposed following the COVID pandemic, Stina had to adapt her study by carrying out visits remotely.

What is Mild Cognitive Impairment (MCI)?

MCI is when a person has objective memory or thinking difficulties diagnosed by a doctor but without any signs of brain disease. The person can still function independently in everyday life.

Some people with MCI will go on to develop dementia, whilst others make no change at all. Some people can even go back to normal cognitive functioning altogether.

This is why some researchers argue it is not a diagnosis and may not always help the individual! With further research we hope to better understand MCI.

Stina used online video platforms such as NHS Near Me and for those people who did not have access to the internet or a smartphone, visits were conducted over the telephone.

Using a telephone or the internet to complete study visits is not the same as seeing people in-person. As researchers we have to adapt how we administer memory and thinking tests across the telephone or internet, whilst not compromising on how they work. We also have to make sure that we comply with regulations to keep data we collect safe and secure. We have been grateful to continue to carry out this important study we are hugely grateful to study participants who have been so flexible and adaptive in such a challenging environment.

The research may help shape how clinicians talk to patients who attend Memory Clinics about their memory issues and what impact this might have on their psychological health.

Follow us on social media or on our website (<http://centrefordementiaprevention.com/>) to stay informed when the results of the MCI are published.



The SPeAK Study is Recruiting

The 'Speech on the Phone Assessment Study', or SPeAK for short, is an exciting new study led by the University of Edinburgh where participants can contribute to research on early identification of Alzheimer's disease without leaving their home.

The SPeAK study aims to detect patterns of speech, identified during memory and thinking tasks completed over the telephone, that might predict people who are at risk for developing Alzheimer's disease. Those at risk will have elevated levels of amyloid or tau, which are biological markers commonly associated with Alzheimer's disease.

The SPeAK team also want to understand if memory and thinking tasks can be completed as effectively with an automated computer tester compared to a human tester on the phone. In the first testing session, participants are tested by the study team and in the second testing session, an automated voice. Participants are followed up with a questionnaire which evaluates their experience of being tested over the phone in order to understand how participants feel about completing memory and thinking tasks compared to face-to-face testing.

Using remote data collection like this increases access to research studies which is an important goal for the field. Particularly as it can help reach isolated people and groups. Ensuring that thinking and memory tasks administered over the phone are suitable, as well as understanding participant experiences of this is imperative to achieving this goal. These types of studies are valuable and particularly relevant during COVID-19 times, and we are very excited at the opportunity to re-engage with our participants after a long break!



Scottish Dementia
Research Consortium

The Scottish Dementia Research Consortium is a membership organisation and network which aims to support all dementia and brain health research in Scotland. Our network involves researchers from all over the country, in all disciplines ranging from dementia prevention, diagnosis and developing treatments in the future as well as researchers that help the lives of those living with dementia today.

The SDRC are an active organisation and we regularly host events, create resources, and organise opportunities for researchers to collaborate. The purpose of our activities is both to champion the work of our world-class dementia researchers that is already taking place throughout Scotland, and to help develop this research further still by supporting personal and professional development.

Above all else, the SDRC ensure that the voice and views of people with dementia and their families are central to all research and are fully represented in Scotland, the UK and internationally.

To find out more about the SDRC go to the website;

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

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