



JOIN DEMENTIA RESEARCH NEWSLETTER

WINTER 2017



Hello and welcome to the Join Dementia Research winter newsletter.

Over the coming editions, you'll be hearing from different people offering their views on dementia research and I am delighted that Dr Susan Hamer is the first to offer her insights.

Professor Martin Rossor, National Director for Dementia Research at the National Institute for Health Research

I am pleased to have been asked to be the first guest editor this issue and my thanks to Professor Martin Rossor for this opportunity.

In my role, I look after the nurses and scientists who support the research being carried out in the NHS for dementia studies. I, along with colleagues, endeavor to make sure they have the skills and resources they need to do a great job.

It might be tempting to think that passionate and visionary individuals working alone are key to driving research forward. But to find solutions to the complex health challenges we face today, we have to work in teams.

The best teams are full of different sorts of people all using their different expertise to contribute. That means it's about multiple investigators, the wider research staff, charities and critically, the volunteers such as yourself, all working together.

You play a crucial role in this - it is through the questions you ask, the ideas you have, your willingness to take part and the ambition we share, that we will take the steps forward we need in order to beat dementia once and for all.

It's great to have you on the team.

Dr Susan Hamer
Director of Nursing, Learning and Organisational Development,
NIHR Clinical Research Network



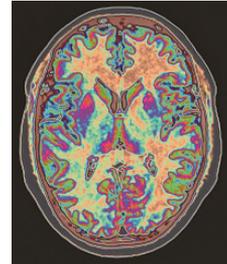


LATEST JOIN DEMENTIA RESEARCH STUDIES

There are always a variety of new studies being added to Join Dementia Research. Below are just a few of the most recent ones. To see if you are eligible to take part in these, or any other studies that are currently on the system, simply get in touch with one of the helplines overleaf or log in to your account online.

Understanding cognition and action in Pick's disease (frontotemporal dementia, FTD)

Dementia prevents some areas of the brain 'speaking with' other parts of the brain. This is not only due to physical damage to the brain, but also due to the loss of critical chemicals (called neurotransmitters) that enable brain cells to work together for thinking or action. This study is using a new type of brain scanner, called MEG, that measures the tiny electromagnetic signals from brain cells as they work.



This study is recruiting healthy participants and people with a diagnosis of Pick's Disease in the Cambridge area.

The DECIDE Study



Maintaining carer quality of life and finding a way of assessing it are important for the carers, those cared for, and for society. The DECIDE study is looking to develop a new assessment to help improve the lives of carers.

This study is looking for people who care for someone who has dementia and who lives in the community (e.g. not living in a residential or nursing home).

The DREAMS START Study

Sleep problems are common in people living with dementia, with around 40% of people living with dementia experiencing sleep disturbance. However, there are currently no treatments that consistently improve sleep problems for people living with dementia. The DREAMS START study is testing out a new programme for people with dementia and their family caregivers, to see if it is acceptable for those taking part.



This study is taking place in London and participants will need to be based within a 5 mile radius.



CHAMPION PROFILE - JACQUI CANNON

A vital part of Join Dementia Research is our network of Champions who promote and publicise the service in their local area. The Champions are people from around the UK, with and without memory problems, who care about dementia research, and want to play a role in accelerating progress.

One of these Champions is Jacqui Cannon who has been raising awareness in Greater Manchester since March 2016. She has organised a range of activities including an initiative at her local supermarket and an event for healthcare professionals in her region.



Jacqui Cannon,
Join Dementia Research Champion

To read the full story you can request a hard copy from any of the charity helplines overleaf or alternatively, you can visit: www.tinyurl.com/jacqui-champion

HOPES FOR THE FUTURE OF DEMENTIA RESEARCH

In the run up to Christmas, we asked people to share their hopes for the future of dementia research and we had a lot of replies. We heard from lots of different people – from healthcare professionals, to charity staff, and members of the public.

We shared a number of these on our social media channels, and a hard copy of all of the quotes that were featured can be requested from the charity helplines, as well as being viewed on our website.

Visit: www.tinyurl.com/research-hopes

We'd love to hear your thoughts too! You can share your hopes for the future of dementia research by writing to us at the address overleaf.

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Join
dementia
research

"Around three-quarters of a million people currently have dementia so research into activities, care and services is just as important as trying to find a cure."

Professor Tom Dening,
Professor of Dementia Research,
Institute of Mental Health

www.joindementiaresearch.nihr.ac.uk

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Join
dementia
research

"I signed up because I am interested in what's going on with me and getting to know more about my condition. I hope that taking part in research will help me and other people who have similar conditions."

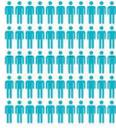
Derek Delahaye,
Join Dementia Research
Volunteer

www.joindementiaresearch.nihr.ac.uk



JOIN DEMENTIA RESEARCH IN NUMBERS

These statistics are accurate as of 31 January 2017



26,186
total volunteers



44,701
screenings



6,943
participants enrolled
in studies



27%
of volunteers currently
participating in studies



124
Studies have recruited



91
Studies currently open
to recruitment



721
trained researchers
using the service



152
NHS, University & commercial
have recruited using the sy:

TELL US WHAT YOU THINK

We are always looking for ways that we can improve our service. We would love to hear your feedback on this newsletter as well as finding out about your experiences of registering as a volunteer and being part of the Join Dementia Research initiative.

Please provide us with your feedback by writing to us at the address below or email us at: comms.jdr@nih.ac.uk



Thanks also to everyone who responded to the recent Join Dementia Research user survey that was featured in our last newsletter. We will share the results with you when they are ready.

GET IN TOUCH

To update your information on Join Dementia Research, please call one of the helplines:

Alzheimer Scotland: 0808 808 3000

Alzheimer's Research UK: 0300 111 5 111

Alzheimer's Society: 0300 222 1122

Calls to Alzheimer Scotland are free, calls to other Helplines cost no more than a national call from any type of phone or provider and calls are included in any free call packages on landlines and mobiles.

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Our mailing address is:

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Research, c/o NIHR
Clinical Research
Network Coordinating
Centre, Minerva House,
5 Montague Close,
London, SE1 9BB**

To unsubscribe from receiving this newsletter, please ring one of our helplines above or email us at comms.jdr@nih.ac.uk

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