
JOIN DEMENTIA RESEARCH NEWSLETTER

WINTER 2018



This February will mark the third anniversary of Join Dementia Research and more than 32,000 registered volunteers. Every volunteer is unique, which is important as often a “one size fits all” approach to healthcare isn’t suitable. For that reason, researchers must involve people from as many different backgrounds and communities as possible in studies. I am therefore pleased to introduce our guest editor, David Truswell, to tell you about the Dementia Alliance for Culture and Ethnicity (DACE).

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

Hello and welcome to the January 2018 edition of the Join Dementia Research newsletter.

The Dementia Alliance for Culture and Ethnicity ([DACE](#)) is a fairly new grassroots initiative which brings together a number of large and small voluntary organisations providing information, support and services to people from Black, Asian and minority ethnic communities. DACE developed a [Call to Action](#) to improve information, services and research on these communities, and we are pleased to see it endorsed in the 2020 Implementation Plan for Dementia.



DACE’s member organisations cover a wide range of minority ethnic communities in the UK, and we are committed to helping to support members in their efforts to improve dementia information and services for these communities. A key objective for us is to stimulate the greater involvement of Black, Asian and minority ethnic communities in all aspects of dementia research. This would include co-production in design, increasing participation of Black, Asian and minority ethnic volunteers in research studies, involving community lay researchers as data gatherers, extending the range of testimony from experience used in research and helping to understand some of the features that lead to variations in the risk of dementia between ethnic communities. DACE is also keen to support the extension of research into the role of psychosocial interventions in dementia support, an area where we feel cultural expectations and belief are important factors.

David Truswell
Healthcare Consultant and Chair of the Dementia Alliance for Culture and Ethnicity

DEMENTIA RESEARCH: LATEST ARTICLES FROM THE NIHR

Research assistant reveals the challenges and rewards of recruiting for dementia studies



Frontotemporal dementia, also known as FTD, is one of the less common types of dementia. As part of our campaign for World Alzheimer's Month we caught up with Professor James Rowe, based in the Cambridge Centre for Frontotemporal Dementia and Related Disorders, at the University of Cambridge, to find out more about FTD and current research into the condition.

Me and my life: Identity, human rights and dementia

Dr. Sarah Butchard, Clinical Psychologist, and Peter Kinderman, Professor of Clinical Psychology, share their thoughts on the importance of improving the care for people currently living with Alzheimer's Disease and other forms of dementia, highlighting how this, essentially, includes protecting and promoting fundamental human rights.



Dementia research - it's not all drug trials



Professor Tom Dening, explains in his blog that dementia research is not just about drug trials. For example, at the Centre for Dementia at the University of Nottingham's Institute of Mental Health, his team is looking at hearing loss in care home residents - an important topic within dementia care where no drug is likely to be available.

NEW YEAR, NEW YOU: WHAT'S CHANGED?



When you registered to Join Dementia Research, you provided information about yourself so we can match you to research studies that you might be interested in. You are more likely to be matched to relevant studies if you keep this information up to date.

You might need to update your information if any of the following has changed:

- Your home address and other contact details
- Changes in your health or any medications you may be taking
- Your contact preferences and subscriptions (for example, whether you'd like to continue receiving our newsletters or to request email notifications about studies you may be able to take part in)

It's easy to update your details and to subscribe or unsubscribe from our communications. Simply log in to [Join Dementia Research](#), or click [here](#). If you are unable to do this, you can [contact us](#) or phone one of our [helpdesks](#), who will be happy to help.

TAKING PART IN RESEARCH: GEORGINA'S STORY



Georgina Shomroni, 54, has sadly seen the effects of dementia first-hand as multiple close family members have been diagnosed with the condition over the years. Now she is a passionate advocate for participating in research. She signed up to Join Dementia Research and has already agreed to take part in two studies, including the PREVENT study.

She told us, "We've come a long way in medicine, and research is the reason. The brain is incredibly complex but the more we know, the better our chances to slow, stop and even correct the disease; to give people back their minds and to give people their families back."

To read her story, visit Join Dementia Research [website](#).

JOIN DEMENTIA RESEARCH IN NUMBERS

These statistics are accurate as of 4 January 2018



32,286
total volunteers



8,866
participants that have enrolled
in studies to date



187
Studies have recruited



184
NHS, University & commercial sites
have used the system

AN A-Z OF DEMENTIA RESEARCH

In the run up to Christmas, you may have seen our A-Z of dementia research on social media.

Every day in December we opened a door on our advent calendar, exploring some of the most important terms and topics in dementia research. From types of dementia, and the role of the public in helping research happen, to the hope that research can bring, we hope you enjoyed our A-Z.

If you missed any, or want a recap you can find a full list at [this link](#).

Not following us on social media? Why not find us on [Facebook](#) and [Twitter](#) today?



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, and we would like to find 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

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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