Recently I’ve been reflecting on how far UK dementia research has come, and what the next steps might be. We’ve seen remarkable progress over the past few years and Join Dementia Research has played a part in that. This would not have been possible without people like you registering and volunteering for studies.

Even if you have not yet taken part in a study, simply by signing up you have helped researchers. You have enabled them to use Join Dementia Research to see how many suitable volunteers they are likely to reach with their study, meaning they can check whether a study is feasible before they set it up.

This means that researchers can plan trials in the most effective way, which gives them the best chance of making a difference. So, whether or not you have taken part in studies, you are making a valuable contribution for which I, and the research community, are most grateful.

Thank you.

Professor Martin Rossor  
NIHR National Director for Dementia Research
New type of dementia discovered

In April, a team of researchers announced that they have identified a new form of dementia.

Known as LATE, this dementia shares many similarities with Alzheimer’s disease, but tends to lead to a more gradual decline in memory.

LATE (limbic-predominant age-related TDP-43 encephalopathy) appears to be linked to the accumulation of a protein called TDP-43 in the brain, whereas Alzheimer’s is linked to the proteins amyloid beta and tau.

Up to a third of people diagnosed with Alzheimer’s may instead have LATE. Some people may also have both types of disease.

This may explain why some recent trials of treatments for Alzheimer’s disease have been unsuccessful and help open up new research avenues in the future.

Attitudes towards dementia and research in the UK

Earlier this year, Alzheimer’s Research UK surveyed 2,361 adults across the UK for their Dementia Attitudes Monitor Report – an in-depth analysis of the UK’s attitudes towards dementia and research.

More than half of the UK population (52%) has been affected by dementia, with a family member or someone else close to them diagnosed with the condition.

The results show widespread support for prevention and cure research, but more must be done to engage people with how they can personally support research efforts.

Promisingly, 50% of people would hypothetically be willing to take part in medical research for dementia. Spreading the word about Join Dementia Research is the best way to make this happen.

Full findings of the survey are available at www.dementiastatistics.org/attitudes/
What’s it like to volunteer for dementia research?

Everyone’s research experience is unique. After signing up to Join Dementia Research, Jude Clarke (left, with researcher Dr George Savulich) was selected to take part in a study called SENDeR, looking at brain connections (synapses) and how their loss leads to dementia and other brain illnesses.

Tests included a series of tests on memory, language, vision and attention, as well as an MRI scan - accompanied by ‘90s rave music! Jude chose the music as she knew it would help keep her awake.

“Taking part in this research project was a fascinating, worthwhile and most of all straightforward process.

I had the satisfaction of knowing that I was contributing, in a small way, to the progress of vital dementia research. Willing volunteers taking part in research are vital to help make much-needed breakthroughs possible.”

40,000 volunteers sign up to Join Dementia Research

We’re delighted that over 40,000 people have now registered as volunteers with Join Dementia Research.

As of the end of July this year 42,783 of you are signed up, helping us to bring more researchers and volunteers together. This means that more studies can reach their potential.

Thank you so much for all for your support so far. Please continue to spread the word about Join Dementia Research and help us reach the next 40,000 volunteers.

If you’d like to read the full version of the stories featured in this newsletter, please request a copy from any of the charity helplines overleaf.
Join Dementia Research in numbers

43,256 volunteers registered
87 studies are currently open to recruitment
20,167 participants have joined a study
300 studies have used the service

Statistics accurate as of 30 July 2019

Get in touch

To update your information on Join Dementia Research, please call one of the charity partner 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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NIHR National Institute for Health Research

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