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# JOIN DEMENTIA RESEARCH NEWSLETTER

## SUMMER 2018

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It's been an exciting few months. In July the NHS had its 70th birthday, and just before that Join Dementia Research celebrated an amazing milestone of its own - over 10,000 volunteers have now been placed in studies. NICE guidelines now recommend that everyone with dementia should be told about opportunities for research, and we should be proud of how Join Dementia Research is enabling that. I'm pleased to introduce our guest editor Simon Denegri, NIHR National Director for Patients, Carers and the Public, to reflect on these milestones.

**Professor Martin Rossor**  
NIHR National Director for Dementia Research

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It's a testament to the NHS and all those who work there that it has successfully adapted to meet changing demands and new challenges in the 70 years since it was established.

Dementia is an excellent example of a challenge that is now firmly on society's doorstep. Barely spoken about 30 years ago, in the UK today it affects 850,000 people, their loved-ones and families, communities and neighbourhoods.

Delivering better research is critical if our health and social care system is to stay on top of this challenge, developing treatments, improving the support we provide people, and working out ways in which dementia might be prevented in the future. The National Institute for Health Research (NIHR) is at the forefront of this endeavour: committing more funds than ever before and working closely with charity and industry sectors to maximise the impact of this investment.

But our most important partners are the thousands of volunteers who help us do research every day. Each year we pass important milestones that increase your opportunities for greater involvement and engagement in research - it's wonderful that 10,000 Join Dementia Research volunteers have already joined research studies.

I was honoured to attend the recent NHS70 service of celebration in Westminster Abbey and delighted that it included a prayer of thanks to those responsible for research which has improved patient lives. Research will be how we answer all our prayers for a world without dementia.

Thank you for your support.

**Simon Denegri OBE**  
NIHR National Director for Patients, Carers and the Public





## CELEBRATING 10,000 PARTICIPANTS IN STUDIES

We're delighted that over 10,000 volunteers have now taken part in studies through Join Dementia Research.

Thank you so much for getting involved. Even if you haven't matched to a study yet, you've already taken your first step towards participating in research when the right study comes along.

Since Wendy Mitchell was diagnosed with young-onset dementia in 2014, she has taken part in a number of studies.

Wendy says:



“ Taking part in research makes me feel as though I'm doing something which might help stop my daughters feeling the same inevitability a diagnosis currently brings.

It's my way of feeling useful and contributing to finding that elusive treatment which in turn will create a better world for my children. ”

The more researchers and volunteers we bring together, the more studies can make a difference to the lives of people with dementia - so let's keep up the momentum!

## NICE RECOMMENDS SPREADING THE WORD ABOUT DEMENTIA RESEARCH

Research is the only way to improve dementia treatment and care. Knowing what research opportunities are available empowers people to make their own decisions about getting involved.

According to new guidelines released in June by the National Institute for Health and Care Excellence (NICE), health and social care professionals should provide information about how to get involved in research to all people with dementia.

Spreading the word about Join Dementia Research is an ideal way to do this.



# 10,234

participants have enrolled in studies to date

These statistics are accurate as of 31 July 2018





## HAPPY BIRTHDAY NHS!

It was great to celebrate the 70th birthday of the NHS on Thursday 5th July this year.

The NHS is what it is today thanks to the research of the past. To mark the anniversary, The Guardian newspaper interviewed our champion Georgina Shomroni about her experience of dementia research and why it's so important.

Georgina said:

“ 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.

When it comes to trials we are scared of what? We can make life so much better.

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## CHOOSE HOW YOU HEAR FROM US

It's up to you how you choose to hear from us. You can change your preferences at any time:

- Phone any of the charity helplines on the back page of this newsletter.
- If you have an online Join Dementia Research account, you can login and manage your settings yourself.

## OUR PRIVACY POLICY

Data protection laws changed this year, so you've probably heard from other organisations recently about privacy policies. We're no different - we've updated ours too!

To find out how we're keeping your information safe, you can read our updated privacy policy by requesting a copy from any of the charity helplines overleaf or visiting our website at [www.joindementiaresearch.nihr.ac.uk/content/privacy](http://www.joindementiaresearch.nihr.ac.uk/content/privacy).



*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



**36,893**

total volunteers



**95**

studies are currently open to recruitment



**10,234**

participants have enrolled in studies to date



**219**

Studies have recruited

*Statistics accurate as of 31 July 2018*

## 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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Our mailing address is:

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



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