

Alzheimer's  
Society

Leading the  
fight against  
dementia



## 15 years of the Research Network

Celebrating the impact of public  
involvement in dementia research

# Celebrating 15 years of Alzheimer's Society's Research Network

The Research Network is a group of over 250 dedicated volunteers who support Alzheimer's Society's research programme at every stage.

As carers, former carers or people with dementia themselves, Research Network volunteers use their experience and knowledge to inform research priorities, guide funding decisions and ensure that research has the maximum possible impact on dementia care.

Highly regarded by the dementia research community the Research Network provides a powerful impetus for driving forward the research agenda, both within Alzheimer's Society and beyond.

## Experts by experience

When the Research Network was set up in 1999, involving non-scientists but 'experts by experience' in research was a revolutionary concept. Since then it has vastly grown in both volunteer numbers and in the scope of its role.

As the Research Network turns 15, we take this opportunity to recognise this enthusiastic and passionate group of people. We celebrate the vital contribution they have made, and the impact they have had on dementia research, Alzheimer's Society and national policy and, ultimately, the care and quality of life of people with dementia.

'Alzheimer's Society's research programme has been and continues to be an inspiration to many organisations looking to develop public involvement in research. Their approach has influenced and been an example to others, both in the UK and internationally.'

Sarah Buckland, Director, INVOLVE

'The advent of the Research Network was a major step forward in dementia research. For the first time, meaningful and sustained involvement of people with dementia and their carers guided research, ensuring that it was of direct relevance and help to people with dementia and their carers.'

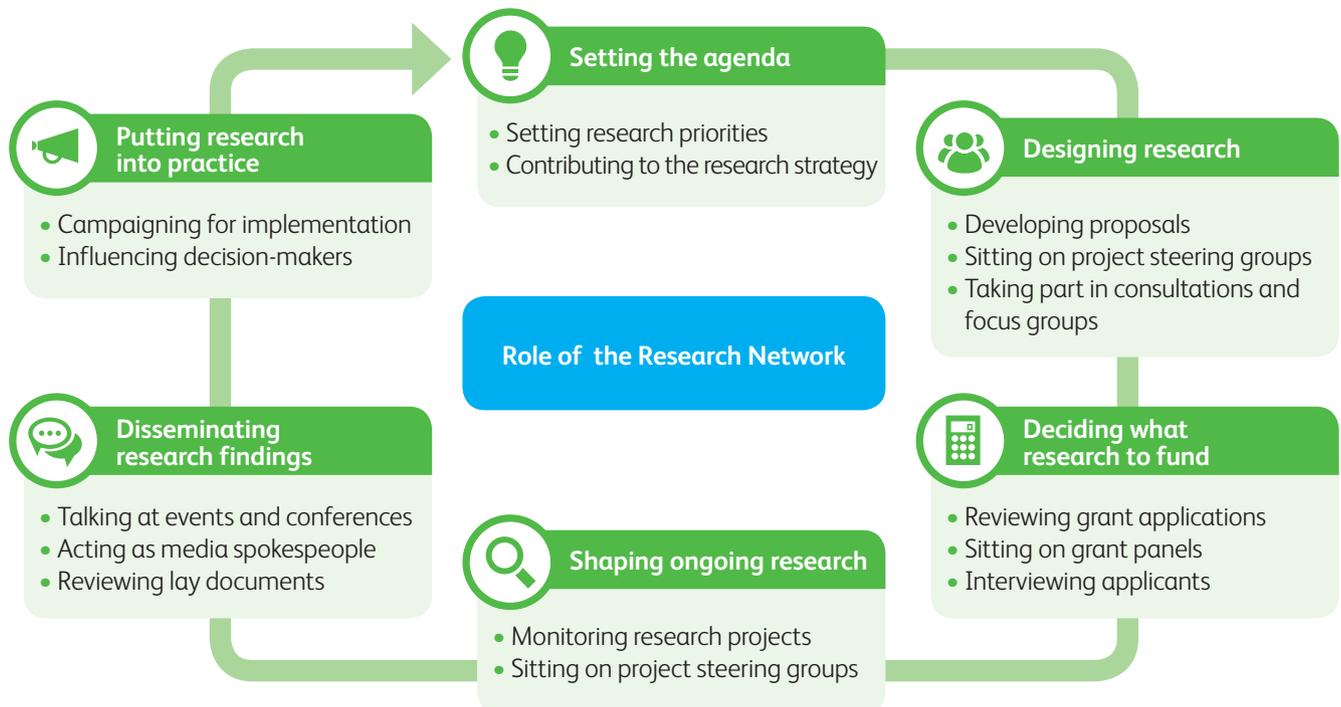
Professor Alastair Burns,  
National Clinical Director for Dementia, England

# The role of the Research Network volunteer

The core role of every Research Network volunteer is to read, comment on and prioritise applications from researchers seeking funding from Alzheimer's Society.

Volunteers also have the opportunity to help set priorities for dementia research, interview applicants, sit on project steering groups and monitor ongoing projects. They are often invited to speak about the impact of the research programme at Alzheimer's Society events and at national and international conferences.

Increasingly, Research Network volunteers play an active role in external research funded by the government and other major funders. They co-design research projects, sit on steering groups, take part in focus groups and act as co-applicants on grant applications.



# Deciding what research to fund

The Society's research programme is an active partnership between people with dementia, carers and the research community.

Network volunteers read and evaluate each research application, commenting on whether it is feasible, relevant to their personal experiences and likely to make a difference to people living with dementia. Scientific experts also peer-review each application. The comments and scores of the volunteers carry equal weight to those of the scientific experts when deciding which projects to fund.

To enable the Research Network's successful involvement, researchers are asked to write a lay summary that clearly sets out for non-scientists the rationale behind their proposal. Alzheimer's Society also provides volunteers with training in research methods, a monthly research newsletter and an invitation to their Annual Research Conference.

**'Joining the Network I found an amazing group of like-minded people all with a single commitment... most importantly, we are treated seriously by Alzheimer's Society and seen as an integral part of the research process.'**

Cathy, Research Network volunteer

## Setting priorities

Every two years, Research Network volunteers are asked to highlight areas of dementia research that they consider to be particularly urgent, relevant or neglected. These priorities are used to inform the Society's research strategy and to commission research into particular areas. For example, guided by the priorities of the Research Network, Alzheimer's Society has:

- Launched their flagship Drug Discovery programme to accelerate the search for new and better dementia treatments: [alzheimers.org.uk/drugdiscovery](http://alzheimers.org.uk/drugdiscovery)
- Funded the Brains for Dementia Research project to collect and preserve vital brain tissue from donors
- Increased the percentage of research funding spent on projects to improve the diagnosis of dementia from 1.7% before the Research Network was set up to 8% in 2014
- Funded important research into the care of people with dementia in hospitals and care homes.

# Designing and monitoring research

Research Network volunteers use their personal experiences of dementia to help with the design of research projects.

By commenting on research protocols, sitting on steering groups and monitoring the progress of research projects, volunteers help to keep researchers focused on the outcomes and next steps.

Their input ensures that clinical studies are realistic and able to recruit and retain the participants they need.

## Case study: Brains for Dementia Research

Human brain tissue is essential to finding a cure for dementia but it is in short supply. Brains for Dementia Research (BDR) is addressing this problem through a network of brain banks across the UK. BDR brain banks collect clinical information and brain tissue from people with all types of dementia and from healthy donors to use as a comparison.

**‘The role of a critical friend provided by the Research Network illustrates how public involvement in research works at its best. I am certain that BDR would be a poorer project without such a level of engagement and commitment.’**

Professor Paul Francis, Director,  
Brains for Dementia Research

Research Network volunteers have been involved at all stages of this 10 year project. They have:

- Developed accessible participant information and consent forms
- Helped recruit participants, by designing posters, writing articles and giving talks
- Monitored progress at each brain bank
- Presented to clinical staff at ethics study days
- Sat on the tissue request panel and continue to do so, approving and advising scientists seeking to access BDR brain tissue for their projects.

Research Network volunteers have helped the project team understand and consider the complex emotional and ethical issues surrounding brain donation. Their involvement has been integral to the scheme’s success, with more than 2,500 people already signed up to donate their brain to research.

## Case study: Reducing the use of antipsychotic drugs in care homes

Antipsychotic drugs are often used to treat complex or challenging behaviours in people with dementia in care homes.

**‘For those of us who have visited loved ones in nursing homes, the horror of finding them in a torpid, drugged state is one of the most upsetting experiences to be had.’**

Brenda, Research Network volunteer

Significant numbers of Research Network volunteers have been concerned about the severe and potentially harmful side effects of antipsychotic drugs and wanted to find ways to reduce their use.

In 2002, the Research Network prioritised for funding the FITS (Focussed Intervention Training and Support) trial, which asked whether enhanced care could reduce the severity of behavioural symptoms, improve quality of life and reduce the use of antipsychotic drugs in people with dementia. Three volunteers were appointed to the project steering group.

Results from the 12 participating care homes revealed that training staff to deliver person-centred care reduced the use of antipsychotics by 40%. The steep decline in negative behaviours showed that care staff who developed their knowledge and skills could greatly increase quality of life both for people with dementia and themselves.

### Developing resources for care home staff

With support from the Research Network, Jane Fossey, the Senior Clinical Psychologist on the FITS trial, was awarded the first-ever Alzheimer’s Society dissemination grant to produce an evidence-based training manual and CD of the FITS programme. ‘Evidence-based approaches for improving dementia care in care homes’ was published in 2007.

**‘It’s not rocket science but it does make all the difference in the world to those with dementia.’**

Jane Fossey, Clinical Psychologist, FITS trial

## Translating research innovation into everyday practice

‘There is an emerging body of evidence for the effectiveness of person-centered care but translating this into everyday practice is the real challenge.’

Professor Dawn Brooker,  
Director of Association for Dementia Studies,  
University of Worcester

To encourage this innovative research to be put into practice across the country, Alzheimer’s Society adopted a two-pronged approach. The first part involved working with the Department of Health, Royal College of GPs and the Dementia Action Alliance to develop a best practice guide on treating neuropsychiatric symptoms in people with dementia. Simultaneously a national campaign to reduce the use of antipsychotic drugs was launched.

Secondly, with encouragement from the Research Network, Alzheimer’s Society commissioned the University of Worcester to further develop and deliver the FITS programme to care homes around the UK. Led by Professor Dawn Brooker, the research team delivered and evaluated the training in 67 care homes. As well as validating the findings of the first FITS trial, this study also described how to feasibly deliver dementia training for care home staff on a large scale.



‘I had the privilege of working at Alzheimer’s Society during a tremendously exciting period where the participation of people with no scientific expertise but all the knowledge about living with dementia became central to research... Together we saw some really exciting dementia research come to fruition and begin to influence practice...’

Dr Susanne Sorenson,  
Head of Research, Alzheimer’s Society 2003-2011

A national audit reported a  
**52% decline**  
in the prescription of antipsychotic drugs  
for people with dementia between 2008  
and 2011.

# Raising awareness of dementia research

Research Network volunteers play a key role in sharing research findings with a wide range of audiences.

For research to have an impact, the findings need to be communicated to the right people. This isn't just other researchers but anyone working with people with dementia in health and social care, the government, the NHS and, increasingly, the public and patients themselves.

Alzheimer's Society funds projects that encompass all areas of research, from examining the biochemical and cellular mechanisms involved in dementia, to advanced brain imaging techniques, to the psychological consequences of caregiving. Regardless of how technical the topic, the Research Network volunteers play a key role in sharing research findings with a wider audience. Their role as project monitors equips them with the knowledge and expertise they need to talk to a lay audience, at workshops, conferences, policy events and in the media.



## Case study: Dr Amrit Mudher

Meeting regularly with Research Network volunteers can help researchers to better explain their work to non-scientific audiences.

Dr Amrit Mudher uses fruit flies to study the Tau protein and how it forms abnormal tangles in the brain of people with Alzheimer's disease. Funded through a series of Alzheimer's Society grants, Dr Mudher has worked with Research Network volunteers for nearly 12 years.

**'Meeting with the network volunteers is always immensely beneficial, helping me to break down complex scientific concepts into simple language. They always encourage me to take the research forward, find out what happens next and consider how it will be able to help people living with dementia in the future'**

Dr Amrit Mudher, Senior Lecturer in Neuroscience,  
University of Southampton

# Making dementia research a national and international priority

The Research Network has always been at the forefront of initiatives to bring dementia research into the spotlight for funders, industry and governments.

Volunteers have campaigned tirelessly for significantly more funding for dementia research. By lobbying politicians, influencing at committee-level, speaking in the media and working together with researchers, they have used their collective experiences of dementia to demonstrate the value of investing in research.

The Research Network has played a key part in the following major political and policy successes:

- Development of the first National Dementia Strategy in 2009, and monitoring its progress as members of the Ministerial Advisory Group on Dementia Research
- Shaping over £14 million of dementia research, funded by the National Institute of Health Research through workshops with over 70 Research Network volunteers and researchers in 2011.
- Publishing a Route Map for Dementia Research in 2011, which preceded the launch of the Prime Minister's 2012 Challenge on Dementia.
- Contributing to the discussions at the G8 Dementia Summit in December 2013, which brought dementia into the international spotlight. Research Network volunteers took part in an engagement event at the Cabinet Office, appeared in the media and attended the summit itself.

**'To have all political parties united in this cause has been a huge source of satisfaction to those of us who have pushed for this for so long.'**

Barbara, Research Network volunteer

**'I think we were very successful in increasing the impact of research through campaigning, policy and media... and an enormous part of that success was due to the tremendous influence of the network volunteers.'**

Professor Clive Ballard, Director of Research, Alzheimer's Society 2003–2013

# History of the Research Network

By the late 1990s, Alzheimer's Society was receiving increasing numbers of applications for research funding.

Under the leadership of CEO Harry Cayton the Society set up the Research Network as part of the Quality Research in Dementia (QRD) programme to formally administer and monitor research grants, establish new research partnerships and promote the charity's research work.

In line with the NHS's emerging concept of patient and carer involvement, the new programme was to refocus the direction of the Society's research towards topics that would directly benefit people affected by dementia.

In 1999, the National Institute for Neurology at Imperial College was awarded the tender to host the QRD programme and Dr Richard Harvey, Consultant Psychiatrist, was appointed as the first Alzheimer's Society Director of Research.

Dr Harvey 'hit the ground running', visiting the Society's regional offices and carers groups across the country to recruit volunteers. By the end of the year more than 100 carers, former carers and people with dementia had joined the Research Network, eager to help shape the growing research programme.

**'I hope the Research Network transformed research in two ways: to improve its relevance and its quality. But I also hope it opened up the caring community to the values of research, and the scientific community to the wisdom of carers and consumers.'**

Harry Cayton,  
CEO, Alzheimer's Society 1991–2003

**'The pleasure was seeing the huge response to grant review rounds, the passion and enthusiasm of the Research Network volunteers, and the joy of the researchers who received support...'**

Dr Richard Harvey,  
Director of Research, Alzheimer's Society 1999–2003

# Looking to the future

Alzheimer's Society is the leading UK support and research charity for people with dementia.

Since 1990 the Society has spent almost £30 million on cutting-edge research into the cause, cure, care and prevention of all types of dementia.

Since the Research Network was founded in 1999:

- The number of active volunteers has more than doubled from 120 to over 250.
- The Society's research budget has grown from £647,000 in 1998/9 to £5.3 million in 2012/13
- The number of applications received each year has increased from 20 in 1989/9 to 91 in 2012/13

At the G8 Dementia Summit in December, world leaders committed to finding a disease modifying treatment or cure for dementia by 2025. To support this ambition, Alzheimer's Society is significantly increasing their commitment to dementia research, and will continue to rely on the expertise of people affected by dementia to guide their research activity.

**'We're pledging to spend at least £100 million over the next decade on an ambitious programme of research that will improve the care of people living with dementia today, while also searching for a cure for tomorrow.'**

Jeremy Hughes, CEO, Alzheimer's Society

**'The Research Network has been inspirationally innovative from the outset... It has been a privilege working with some of the world experts in scientific research... Major changes for the benefit of patients have been enabled by having the scientific professionals working together with the public'**

Lynne, Research Network volunteer

### Get involved

Are you are living with dementia or do your have experience of caring for someone with dementia? Are you interested in helping shape Alzheimer's Society's research programme? Find out more about joining the Research Network, at [alzheimers.org.uk/researchnetwork](http://alzheimers.org.uk/researchnetwork)

### Get informed

Anyone with an interest in dementia can become a Friend of Research – you don't need to be a carer or living with the condition. Friends receive regular newsletters and invitations to research events. They are important ambassadors for dementia research and can help spread the word about Alzheimer's Society's work. Sign up at: [alzheimers.org.uk/researchfriends](http://alzheimers.org.uk/researchfriends)

### About the authors

Shirley Nurock and Barbara Woodward Carlton joined the Society's Research Network at its inception in 1999; Shirley as a carer for her husband and Barbara as a former carer for her mother. Having seen the Research Network evolve considerably, they felt the 15-year anniversary was an opportune time to look back and reflect on its impact and achievements. This booklet accompanies a longer 'History of the Research Network' report which can be found at [alzheimers.org.uk/researchnetwork2014](http://alzheimers.org.uk/researchnetwork2014)

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