

ALZHEIMER'S SOCIETY

A HISTORY OF THE RESEARCH NETWORK (QUALITY RESEARCH IN DEMENTIA)

FOREWORD



In this fascinating account of the 15 year history of Quality Research in Dementia the authors quote the chief executive of Research into Aging writing to the Alzheimer's Society in 1999 "This appears to us to be completely unrealistic... I think it very brave but you will live to regret it!"

What they thought was unrealistic was the active engagement of carers and people with dementia in the Society's research programme. As this history shows the doubters were wrong and the Society, the researchers and the many volunteer members of the Research Network have nothing to regret and much to celebrate.

There is no doubt that Quality Research in Dementia was innovative and controversial when it was established. It remains a beacon of patient and public engagement but the argument for the involvement of people who experience illness or disability in research about their condition is now well established both in charities and the NHS.

I was privileged to be part of the creation of this new approach to guiding and quality assuring research but the fact that QRD exists long after its founders have moved on is a tribute above all to all those carers and people with dementia who have been its champions and guardians and the researchers who have partnered them.

Shirley and Barbara have done a great service documenting the journey. But the work of researching dementia remains a challenging one and I have no doubt the Research Network will be needed for the next fifteen years or more.

Harry Cayton CBE
Chief Executive, professional Standards Authority for Health & Social Care
Chief Executive, Alzheimer's Society, 1992-2003

CONTENTS

PART 1: QRD: THE BACKGROUND	p 4
Planning the Research Programme	p 5
Setting up QRD	p 6
Applicants and Panel	p 8
QRD Up and Running	p 9
Early Years, Early Successes	p 12
The Three-year Report	p 13
The Research Office	p 15
QRD expands	p 16
PART 2: GROWTH AND EVOLUTION OF QRD/THE RESEARCH NETWORK	p 18
The Research Funding Process	p 18
What did QRD Consumer Members do in 1999?	p 20
What do Research Network volunteers do in 2015?	p 21
Events 1999-2015	p 25
Area Coordinators	p 28
Friends of Research	p 30
Delivering on Dementia	p 30
Partnerships	p 30
Collaborations	p 34
Evolution of the Research Network	p 37
Political influences at work	p 37
Future plans	p 40
PART 3: QUOTES	p 42
From Network Volunteers,	p 42
From Researchers,	p 45
From staff and others	p 47
PART 4: FACTS, FIGURES, FACES AND FOOTPRINTS.	p 48
The Changing Research Programme	p 48
Key research projects funded since 1999	p 50
Faces: The Team Leaders	p 54
Faces: The Research Office Team Over The Years	p 56
Research Network Numbers & Activity	p 61
QRD Network Surveys	p 62
Impact Report:- Cause, Cure, Care & Prevention	p 65
Footprints QRD Annual Round-Up Reports (Initiated By Clive Ballard)	p 66

PHILOSOPHY

“Alzheimer’s Society philosophy states that people with dementia and carers can make a unique and valuable contribution in every stage of research. We have continually pushed the boundaries of patient public involvement”.

MILESTONES

- 1999.** *Quality Research in Dementia (QRD), later called the Research Network, was set up to help shape the Society’s growing research programme.*
- 2000.** *First monthly newsletter printed to keep volunteers up to date with dementia research. First scientific symposium held to bring together Research Network volunteers and Society funded researchers.*
- 2001.** *Charity Awards: the Healthcare & Medical charity of the year award for ‘getting research from the lab into life’. Guardian /IPPR Public Involvement award for ‘developing a network of consumers who are involved in determining the Society’s research programme.’ First project Monitors appointed. First Training Day held.*
- 2002.** *QRD Hosted an international conference in London to bring together leading researchers from around the world to discuss the latest advances in dementia.*
- 2003.** *Full time Head of Research and part-time Director of Research appointed.*
- 2004.** *Publication of QRD Handbook for members of the QRD Advisory Network.*
- 2005.** *The Research Network reached 150 members.*
- 2006.** *First Alzheimer’s Society PhD Studentship awarded.*
- 2007.** *Head Office moved from Gordon House in Victoria to Devon House, St. Katharine’s Dock. The Dementia Knowledge Centre became the leading information and knowledge resource on all aspects of dementia in UK, including research.*
- 2008.** *Brains for Dementia Research project launched to support network of UK brain banks.*
- 2009.** *Research Network involvement in Ministerial Dementia Summit.*
- 2010.** *Research Office ran six Research Roadshows across the different regions.*
- 2011.** *Road map for Dementia launched. Workshop bringing together over 70 volunteers and researchers to develop proposals for the NIHR dementia call*
- 2012.** *Prime ministers challenge launched to advance dementia research and care by 2015.*
- 2013.** *Network volunteers played a key role in shaping the discussions at the G8 Dementia Summit.*
- 2014.** *15 years after the Research Network was created it reaches 250 volunteers.*
- 2015.** *Evolution of the Research Network two year plan completed.*

PART 1

A HISTORY – QUALITY RESEARCH IN DEMENTIA

BACKGROUND

The Alzheimer's Disease Society (ADS), as it was then called, was founded by carers, for carers, in 1979. In the 1980's the Society started funding a small number of research projects and fellowships and a Medical & Scientific Advisory Committee was appointed to review applications and prioritize for funding. However by the late 1990's increasing numbers of applications lead Harry Cayton, then Chief Executive of ADS, and the Council, to consider putting the research programme on a more formal footing aiming to a) improve the AS commitment to research allowing the Society to be seen as a serious research charity by raising more money that would be needed to fund the rising numbers of applications. b) re-focus the direction of research more clearly on research that would benefit people with dementia and carers and allow their voices to be heard so that they be more involved in the research programme.

Harry had been thinking about how best to go about this for a long time. There was some resistance to the concept of lay involvement and he needed to make sure any proposal of his was well thought through before putting it to Council and particularly to the Chair, Nori Graham, for approval.

THE EMERGING PPI MOVEMENT AND RELATIONSHIP TO QRD

The Standing Advisory Group on Consumer Involvement in the NHS Research & Development Programme was set up in April 1996. It was chaired by Ruth Evans, Director of the National Consumer Council and Iain Chalmers (then Director of the Cochrane Centre) was vice-chairman. The stated aim of the Group was "To ensure that consumer involvement in research and development improves the way that research is prioritised, commissioned, undertaken and disseminated."

One of the early tasks of the Group was to look at how consumers had been involved in the NHS R&D Programme to date and it commissioned a study to broadly identify examples of consumer involvement in health research. Membership of the Group included clinicians and researchers, representatives from academia, nursing, medical charities, social services, community healthcare NHS Trusts, NHS R&D directors, consumer groups, an observer from MRC (Dr Joan Box) and Harry Cayton, who (as a consumer member in the broadest sense of the word) chaired the planning group for their first conference.

In June 1999 the organisation changed its name to Consumers in NHS Research and Nick Partridge, CEO of the Terence Higgins Trust, took over as Chairman at around the same time. Bec Hanley had been a member of the Standing Advisory Group since 1997 and became Director of NHS Consumers in Research in 1999.

In 2003 it was re-named INVOLVE as a national advisory group that supports greater public involvement in NHS, public health and social care research. INVOLVE is funded by, and is part of, the NIHR and as one of few such groups in the world, it aims to 'share knowledge and learning on public involvement in research'.

When the Alzheimer's Disease Society was planning how to set up their research programme others on the Standing Advisory Group were aware that Harry felt he couldn't

be a member of a group that promoted involvement in research without doing something about it within the ADS, so in this sense Bec Hanley and other colleagues on the Group believed he was likely influenced by the Group. However, from the outset the programme the ADS established was unique and did not follow an 'off the shelf' model or anything Harry had seen as a member of the Standing Advisory Group. He admitted that being a member of the Group had given him confidence to believe that research would be better if scientists engaged with those who were to benefit from it and, in spite of grave misgivings expressed by a number of individuals and clinicians, Harry stood firm.

PLANNING THE RESEARCH PROGRAMME

In February 1999 the Society's Medical and Scientific Advisory Committee had discussed the proposed new research programme and this was formally approved by the Executive Committee as part of the business plan and budget for 1999 – 2000.

Once the decision to proceed was taken, the details were worked through as a group effort by clinicians, researchers and other interested parties. This included Dr Richard Harvey, then at the National Institute for Neurology. Richard too said that previously he had done a lot of thinking about consumer involvement, it being an issue "very close to my heart having been so involved with the cholinesterase inhibitor clinical trials and listened to so many carers and people with dementia who were so engaged, committed, interested, concerned, supportive and excited by the potential of research to change the inevitably terrible outcome they were facing".

Dr Richard Harvey recalls *"Just before QRD the Alzheimer's Disease Society had been given a legacy for research and it was decided to award it to one project. My idea for the legacy was to use the money for 'pump priming' a large number of projects – often funders want to see something before they give you more. I came up with the outline idea of QRD – developing consumer-endorsed ideas and using the legacy in this way to persuade funders to support the projects. It seemed like a great idea to multiply the effects of the modest legacy and gain a much bigger 'bang for the buck!'"*

"At this time I didn't really know Harry Cayton and indeed thought him a rather imposing and frightening figure! However, a mutual friend did know him and arranged a dinner party and invited both Harry and me, amongst other guests. I brought along my embryo QRD ideas in an envelope, hoping perhaps to talk to him, and possibly share what I had thought up."

"In conversation with him during the evening I got round to my ideas and began to give the very sketchiest intro around consumer involvement, the power of the consumer, the potential to raise funds. Harry being an incredibly ethical person immediately stopped me, said it was important that he didn't hear any more and wanted the envelope kept sealed but said that I should continue to think in that direction and that there may be an opportunity."

"A month or two later my then boss (Dr Martin Rossor), Nick Fox and I invited Harry to dinner to talk more generally about research and research funding. It's really important to understand that there was no collusion and no specific talk of the ADS was planned. We did find a meeting of minds around the importance of consumer involvement. Martin, Nick and I had been very much involved in

establishing the CANDID consumer support initiative largely from consumer engagement with its clinical and research activities. Again Harry revealed nothing other than that the Trustees were reviewing the way the Society supported research.”

According to Harry that meeting had served as a brain storming session in that they came up with a title **Quality Research in Dementia** and later Harry remembers it had been Richard's idea to have lay members review applications first and to insist there be lay summaries included within each application to help consumers, and scientists too; and to hold a pre-panel meeting with the QRD lay members who would be participating on the Grant Award Panel to allow them to clarify with the Research Director any queries they had regarding the shortlisted applications. Further, Harry recalls it was Richard's idea to have monitors for each project funded.

Prof Nick Fox recalls: *“I remember well the early discussions with Richard Harvey about the setting up of QRD At the time it was quite revolutionary, the idea of involving patients and carers in the assessment and monitoring of research projects. I think it was a visionary experiment which has really proved to be very successful, forming a link between researchers who might be distant from the problems that they are committed to solving and the patients and carers who know all too well what those problems are – often rewarding for both parties”.*

SETTING UP QUALITY RESEARCH IN DEMENTIA (QRD)

The name Quality Research in Dementia was approved by the ADS Council at their meeting in October 1998. At their meeting in February 1999 the Medical & Scientific Advisory Committee discussed the proposed new research programme and this was formally approved by the Executive Committee as part of the Society's business plan and budget for 1999-2000.

The last Fellowships to be awarded under the old scheme (1998-9) totalled £308,000 and brought the total value of grants for that financial year to £647,000.

There is a list on file of all the projects funded as of 23rd March 1999 but no individual sums mentioned. Incidentally, at this time Dr Richard Harvey was funded by ADS for a project titled 'The burden of fronto-temporal dementia' and given prominence on the list was the Dykes Project that aimed to improve the response of primary care practitioners to people with dementia and their families.

The proposed plan for the research programme was subsequently modified and it was decided to appoint a Director of Research, initially on a part-time basis, and the contract to host the programme would be awarded for 3 years, renewable. Interested applicants were invited to write to Lindsay Sartori, the Society's then Director of Finance and Support Services at ADS Head Office, Gordon House, SW1.

The brief included 'an international dimension':

“QRD will collaborate with international partners including Cape Western Research, University of Cleveland, Ohio (Peter Whitehouse), the Alzheimer's disease Research Centre at the University of Munchen, Germany. The

Alzheimer's Disease Society is the UK partner of the Ronald and Nancy Reagan Research Institute...in particular, QRD will strive to achieve the widest possible dissemination of research findings and will contribute to the Government's Public Understanding of Science and Technology Foresight Programme".

On querying the above with Dr Harvey, he said they did hold discussions with various of the above but could find no common ground although they did contribute to the Cochrane Collaboration in reviewing research summaries.

Following their meeting as far back as January 1999 Harry voiced in writing the Scientific & Advisory Committee's concerns about a conflict of interest with Alzheimer's Research Trust (ART) and wrote to four members of the Committee (Alistair Burns, Gordon Wilcock, Anthony Mann and Nori Graham (as present and former chairpersons of the Clinical and Scientific Advisory Committee) to ask advice on two issues of particular concern to them:-

- a. If the Society's research programme is based in one institution could it be objective in awarding grants?
- b. Would there be conflict with ART which has already approximately six Research Centres, several of whose directors are on the ADS Committee and if there is, does this preclude ART Centres from applying to host our grants programme?

Harry himself admits there is a conflict of interest – primarily as he saw it in fundraising and public profile. In his view there was certainly no conflict on what ADS have achieved and Harry thought those on the Committee who raised this issue were those already linked to ART! His view was that they should ignore the ART except in 'so far as it is a catalyst to improve what we do'.

All suitable institutions were encouraged to apply to host the research programme if they met ADS requirements for high profile, clear focus and suitable facilities. Harry was more concerned with criticism that basing the programme in an existing research institution would be seen as lacking objectivity and independence as a funder. If this were true it could be a serious blow to the proposal.

Safeguards:

- Director of Research would be managed by CEO of ADS and not the host institution.
- Priorities and strategy would be determined by Committee including researchers from many universities appointed by ADS.
- All grants would be peer reviewed. The Contract would be time-limited and could be shortened if necessary to act as an incentive to deliver.

Harry's response to the Committee's concerns was:-

"The QRD programme will only succeed if it is effective, objective and credible. So it has to be those things.... Surely it can prove itself by how it behaves regardless of where it is based?"

I will discuss with my senior management team colleagues the option of basing the research programme here (at Head Office). Even if it were possible I think it would be a dull and low profile choice. There is criticism that we do not get the

research publicity that ART do. However, we do have a story to tell and neither our research Fellows nor the way we present our work gives us one at the moment. I don't just want a quiet administrator to drive this forward, I want a research activist, someone who knows the field, can make contacts, win friends and influence people and in particular, sell our research to donors. Being in a research environment will make that much easier....."

APPLICANTS AND PANEL

A large Information Pack was produced detailing the proposal to provide an institutional base for the ADS Research Programme, a Person Specification for the Research Director and comprehensive guidance notes for applicants. The applicant was required to be part of an Institution that would physically **host** QRD.

In brief, the **aim** was:-

"To establish the Society's Quality Research in Dementia programme, to administer and monitor research grants, to establish new research partnerships, to disseminate research findings and to promote the Society's work as a research charity. As a member of the senior management team the Director would contribute to planning and policy development and the management of the Society."

The brief (on file) indicates that there were 11 Key tasks outlined, mainly around setting up systems, detailing which other departments within ADS the Research Director would be involved both for dissemination purposes and for promoting the Society as a research charity.

Of note here is **Key task No. 7** that was concerned with Patient & Public Involvement (PPI). *'To seek to ensure that when research is funded by the Society that the values of people with dementia and carers are central to determining the research priorities, methodologies and outcomes.'*

After many expressions of interest, full applications to host the QRD programme were eventually received from:-

- Martin Rosser, Professor of Clinical Neurology, Dementia Research Group, Institute of Neurology, Queen's Sq. / Imperial.
- Jim Edwardson, Institute for the Health of the Elderly, Newcastle General Hospital
- Professor Gordon Wilcock, Bristol University
- Alistair Burns, Professor of Old age Psychiatry, Manchester.

A letter of interest had been received from the head of another charity who was subsequently invited to be on the Award Panel but declined expressing concerns that the research to be funded by the new programme seemed to include social and health sciences research rather than just basic sciences and believing the job of Director as advertised could *"hardly be part-time given all the strands the one individual would be expected to operate... This appears to us to be completely unrealistic"* and in a later letter

to Harry: *“Sorry not to be more positive about your proposal. I think it is very brave but think you will regret it!”*

Although a number of prominent clinicians had apparently also expressed misgivings about the proposed programme, on questioning, Harry was adamant that he had no such misgivings and from the outset was confident that QRD would ‘work’ and in fact describes his ‘legacy’ as precisely what he had aimed for i.e.

“To take forward research in two ways - making it more relevant and better quality and opening up the caring community and scientific community to the wisdom of PPI.”

On file are bound copies of the two shortlisted Proposals to Provide an Institutional Base for the ADS Quality Research in Dementia Programme and Research Director:-

1. Alistair Burns, Manchester, where Dr Jane Byrne would be Research Director.
2. Martin Rosser on behalf of the Dementia Research Group and jointly with the Institute of Neurology (UCL) and Imperial College of Science Technology and Medicine proposing that basing QRD across both institutions would allow the Society to draw upon the unique strengths that each has to offer.

The latter’s team:-

Martin Rosser, Neurology
Richard Harvey, Psychiatry (proposed Research Director)
Elizabeth Warrington, Psychology UCL
Nick Fox, Clinician Scientist Imperial/UCL/Institute of Neurology.
Ron Isaacs, Research Nurse Manager
Katy Judd, Specialist Nurse CANDID, Institute of Neurology
Clare Morris, specialist counsellor
Nick Bosanquet, Professor of Health Policy, Imperial
Simon Cousens, Statistician LSHTM

There were pre-Panel site visits and on 11th May Martin Rosser wrote to Harry confirming that he and Richard Harvey would be present on 26th May and asked whether there were any other members of the team that Harry would like to meet for the informal discussion?

The Panel eventually took place on 11th July 1999 at Gordon House. The team from the Institute of Neurology invited a carer representative, Shirley Nurock, a family carer and member of ADS, to be on their team for the interview.

QRD UP AND RUNNING

ADS Chief Executive, Harry Cayton, wrote to Martin Rosser the next day to confirm

“ADS has awarded the contract to manage our new research grants programme (QRD) jointly to the Institute of Neurology and Imperial College. The selection panel was impressed by the presentation made by you and your colleagues and is positive about the opportunities for working together in this innovative way. We also have great confidence in Dr. Richard Harvey as the new part-time Director of Research”.

Subsequently Harry indicated that there was no doubt in his mind that Dr Harvey was 'an innovator', one 'to make things happen' and these qualities came across well at the selection Panel.

The contract set out salary and terms: 3-days a week for Richard Harvey as Director of Research and an adjustment to his present ADS research Fellowship that would allow him to continue that work at Senior Lecturer level, this with effect from July 1999. There was provision for a salary for an administrative assistant, for a part-time IT administrator and for IT and office costs to those assisting Richard Harvey at his base within the Institute of Neurology at Queens Square.

QRD would have a new Research Advisory Committee and the previous members of the Scientific & Advisory Committee received letters from Harry thanking them for their advice given and wisdom shown in selecting candidates for grants.

During the interview Dr. Harvey had said that if they won the tender he would 'hit the ground running'. He did just that. The following day he telephoned Shirley Nurock to appoint her Regional Coordinator for London and said he would be recruiting members for the consumer network and appointing Regional Coordinators in the coming weeks.

Richard's philosophy in life is:

"that simple is always better, and as I recall, the priorities we put forward were:

- 1. Real genuine, engaged consumer involvement. None of this one poor consumer sitting alone on a panel of 20 scientists with little hope of any influence. The network seemed to me the key and the power would be in the numbers.*
- 2. Overheads must be low, it would have been very easy to create a giant administrative confection to run the programme and have no money to actually award grants.*
- 3. We had to support the best science."*

"So the priorities were to recruit a network (and we already had good access to a lot of consumers) engage them in real ways and get the funds flowing to research as quickly as possible".

He then embarked on a tour of all the Regions, meeting AS Regional Office staff and attending carers' groups in order to recruit members for the consumer Network and appoint Area Coordinators. Richard says

"my recollection was that everyone was enthusiastic, though some were uncertain of what they could actually contribute. I don't remember any volunteers being sceptical – unlike the research community who were mostly very sceptical."

"In most regions there were one or two very enthusiastic people who helped coordinate things, there were also regions where I had volunteers, but it was difficult to find coordinators and this meant it took longer to really get people involved. The enthusiasm of those recruited to the network was infectious and it was a very energising experience coming to work every day!"

“So yes, I did have a fairly clear plan of the apparently simple steps needed to ‘hit the ground running’ and I do seem to recall that we had a round of grants being advertised within a few weeks of the contract.”

RICHARD HARVEY INTERVIEWED:-

Q. How did you build trust within the research community about working with carers and consumers, particularly the idea of having lay reviewers and project monitors?

A. “This was more tricky. I was young, inexperienced, some would say naïve, and there was a high degree of scepticism and even some hostility about what the Society had done. Harry shared letters to him from some very senior and well known researchers that were highly critical of QRD and me personally... It was actually helpful to know this, and as I learned then and continue to practice now, the key to overcome the sceptics was to meet with them regularly, understand their issues and seek a common vision. This sort of interpersonal work was highly challenging but immensely fruitful.”

“The key to reassuring the community was to get the money flowing quickly, and to really high quality projects. Again the QRD network and their prioritisation of applications quickly bore fruit. I think most of the biological/basic science researchers thought that consumers and carers would only prioritise qualitative research, while in reality what they supported was high quality, leading edge research and projects ending up being balanced with Cause, Cure and Care all equally supported.”

“The project monitoring came a little later as things started to settle in. Here we had full control over the project as we were the funders. Grant applicants knew they would have consumer monitors and accepted this as part of the terms. I never had any resistance – I think researchers actually like being held accountable. I always tried to attend the first meeting of the researchers with their monitors and never sensed any hostility or guardedness from the researchers. They were usually delighted to have been accepted, were good communicators (their lay summaries had obviously been prioritised) and welcomed the consumer monitoring group.”

“Looking back over 15 years.... What impresses and gives me an enormous sense of pride and fulfilment is that 15 years later it all appears to be operating in much the same way. I find that the most remarkable thing. My suspicion is that the QRD network is so self-empowered and self-sustaining that the Society could not change direction (in terms of dropping consumer involvement) even if they wanted to!”

“I think the benefits were tremendous. Getting the researchers to explain clearly and in lay terms what they wanted to do is a very powerful thing. Research needs to be simple to be successful but all too often researchers think they need to be complex to impress funders. QRD changed all that. Similarly the monitoring held the researchers to account on what they said they would do and how they would do it.”

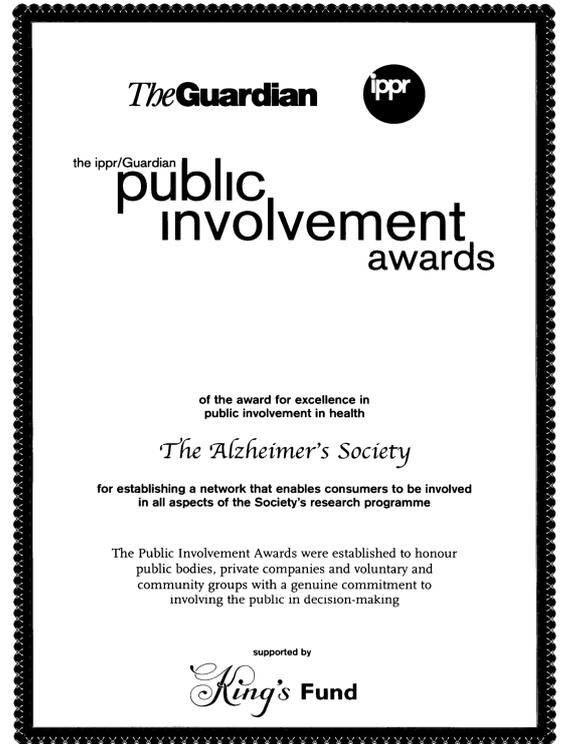
EARLY YEARS, EARLY SUCCESS

QRD took off rapidly and very soon its success was being recognized, winning two awards:

Guardian/IPPR Public Involvement Award 2001.
AS won the Health Award, supported by King's Fund, with the citation:-

“The AS for developing a network of consumers who are involved in determining the Society’s research programme.”

The award was collected by Lynne Ramsay on behalf of the Network. This was only the second year since IPPR had set up the awards.



Healthcare and Medical Research Charity of the Year Award 2001

Awarded for the QRD initiative.

Margaret Clark, Regional Coordinator for South West, recalls being asked by Richard Harvey to accompany him to the Awards Dinner in London, a very impressive event and she remembers Richard's great excitement when it was announced that QRD had won an award.

Other charities started to express interest in QRD and the concept of patient and carer involvement but very few took this further at that time, mainly because they lacked sufficiently strong or engaged patient and carer networks.

QRD went on to become an extremely successful example of consumer involvement in all stages of the research process – a 'pioneer' amongst medical charities and indeed other organisations. Lay members give presentations illustrating various aspects of their role at all the INVOLVE conferences from 2000 onwards and many other national and international research conferences on dementia.

“Since its inception many organisations in the voluntary and statutory sector have learned from its experience and many researchers and research organisations have benefited from the involvement of QRD members. QRD continues to innovate in the way it promotes effective partnerships between people affected by dementia and the research community. I’m in no doubt that the quality and quantity of dementia research has improved as a result of the development of QRD”.

Bec Hanley Twocan Associates

“The Alzheimer’s Society Research programme has been, and continues to be, an inspiration to many organisations looking to develop public involvement in research priority setting and grant selection panels. Their approach has influenced and been an example to others both in the UK and internationally with a thriving research network of over 200 carers, former carers and people with dementia who contribute to the research programme.”

Sarah Buckland, Director, INVOLVE Coordinating Centre

“INVOLVE have hugely valued the contribution staff and members of QRD in facilitating sessions, presenting their work and enthusing others at INVOLVE conferences since 2000. The expertise and commitment of members are invaluable in taking forward public involvement in dementia research”

Helen Hayes INVOLVE Coordinating Centre

THE THREE-YEAR REPORT

The first Three-year Report was published in July 2002. At that stage consumer network membership stood at 144 with a target of 150. 81% of members had attended a Day-One training workshop and 61% attended the Day-Two workshop.

The first Newsletter went out in March 2000 (all newsletters are in ‘Archive’) as a double sided A4 black and white sheet, with short articles on research, some written by members. It advertised for volunteers to help in the office and to join the network.

Previously only mailed to network members, by the time of the Report the monthly QRD Newsletters were also available to download. RH noted that although members were increasingly coming on-line, consensus at the network’s previous Annual Meeting was that they were not yet ready for mass electronic communication.

The Report stated that “a high priority is given to communication with the network which appears to have paid off in terms of the Network’s commitment to QRD and its ready response to consumer reviewing and calls for volunteers, noting that there has been no shortage of volunteers with more than twice the number needed volunteering for every project as monitor.” The Report concluded that “Generally members have a very good sense of personal involvement”.

N.B. At this stage the Consumer priority Survey was run annually. The Report recognised that Dissemination was an area that had the least involvement by consumers.



newsletter

QUALITY RESEARCH IN DEMENTIA NEWSLETTER OF THE ALZHEIMER'S SOCIETY

MARCH 2000

Welcome to QRD

This is the first edition of our monthly QRD Advisory Network newsletter. The newsletter is intended to keep you in touch with us, and up to date with developments and activities.

The QRD office is now fully operational at The Institute of neurology in Queen Square, London.

In January this year, we appointed our training partners who will be running empowerment workshops around the country for carers on our network from May onwards, see the article at the bottom of this page for more details.

January also saw the first of our grant awards, with a Commissioned Research Grant being awarded to Jan Dewing at the Royal College of Nursing Institute to carry out a project to identify what carers and people with dementia want from the anti-dementia drugs. Hopefully you will have seen more about this in the main Society Newsletter.



Queen Square in London, Home of Quality Research in Dementia

We are currently seeking volunteers from the QRD Network who might be able to help us in a number of ways.

QRD is a consumer led research programme, this means we need your help and involvement. Signing up to the Network is the first stage. We will

be using the newsletter to seek volunteers for a whole range of activities. If you would like to be more involved, even if you are not sure how, then get in touch. You are here for us and we are here for you!

Training partners announced

Training for carer members of the QRD Advisory network will be provided by two experienced training partners. From the VOICES in ACTION project at the College of Health Jane Bradburn and Gillian Fletcher will be focussing particularly on the needs of network members, and an introductory workshop.

Alison Hill and Elisabeth Buggins from the Critical Appraisal Skills Programme (CASP) in Oxford will be

developing the second and more advanced workshop on looking at research evidence.

Both teams are enthusiastic about working together, and much of the training and development is being undertaken jointly.

The training will be provided regionally, with the two workshops being repeated in each region. The first pilot workshop is planned for 24th May, and is likely to be in London. In the next edition of the newsletter

we will publish the full schedule of workshops. We will also be writing to the carers on our network asking which workshop you would like to attend. You won't be restricted to a particular region, you can simply pick the venue most convenient for you.

For those who can't get to meetings there will also be home study materials. The aim of the training is to be interesting, informative, empowering and FUN!

How you can help QRD

- ? If you live near London and have a few hours to spare, perhaps you could help us in the office?
- ? We need a newsletter editor and editorial team, would you like to volunteer?
- ? The QRD Network needs a steering group. We will be having election for this at the AGM on September 15th-17th, but we need volunteers to fill in until then.
- ? We will need help setting up regional training workshops. Could you help us co-ordinate other network members in your region?

If you think you can help out in any of the above ways, or have other suggestions, then please do give us a call. Our full contact details are on page 2.

Don't Forget!

- ? The QRD consumer training programme will commence in May
- ? Please complete and return the questionnaire enclosed with this newsletter as quickly as possible
- ? If you live close to London and would like to help out in the office, please call Ethan Cuthbert on 020 7837 3611 x 3804
- ? The next issue of the newsletter will be out on April 14th

ALZHEIMER'S SOCIETY HELPLINE 0845 300 0336 8:30AM - 6:30PM MONDAY TO FRIDAY

THE RESEARCH OFFICE

During 2003 this moved into a 'cupboard' at the Society's Head Office - Gordon House, 10 Greencoat Place, SW1P 1PH – in preparation no doubt for the fact that the next Research Directorate would be hosted within Head Office.

By March 2003 Alzheimer's Society was advertising for a Head of Research (full time) answerable to Richard Harvey, the Director of Research. Work would involve high quality administration of every aspect of the grants programme. And only a month later in April 2003 they were advertising for a new Director of Research flexible 2/3 days per week.

RICHARD HARVEY INTERVIEWED: -

Q. What eventually decided you to stand down?

A. “[My job] was never part time! It was a full time, evenings, weekends – totally immersive experience. I used to arrive at work at 5 a.m. and often not leave till late in the evening. This was probably a benefit of me being young and relatively free. I could immerse myself without hurting anyone else”

“The joy was seeing the huge response to grant review rounds, the passion and enthusiasm of the network, the joy of the researchers who received support, the warm welcome I received at branches and meetings. It was not hard on me at all!”

“The AS through its QRD programme has been a leading light in this process, acting like the proverbial David to fundamentally change the way Goliath-like organisations think and work”.

The contract to run QRD was for 5 years. As a young person who liked challenges 5 years is quite a big proportion of a 35 year- olds' life! Now as a 50 year old, it seems less”!

For personal reasons too..... “I have been here (Australia) ever since, initially as an old age psychiatrist, more recently as clinical director of a mental health service and head of psychiatry in the medical school. I continue to draw on my experience with consumers and with QRD and these are very powerful influences in everything that I do.”

“I was privileged to be involved in the conception and birth of QRD. Like an anxious Godparent I have continued to watch the progress from the far distant shores of Australia – where incidentally news and knowledge of QRD had spread long before I arrived!”

“My only half regret was not to have written more (formal articles). At the time I felt there was a big risk that if we studied QRD too hard or too closely it might cause it to fail – if nothing else than by directing energy to study rather than to simply making it work. It's only half a regret as I think I was right at the time, all of my energy was needed, like the first stage of a moon rocket, to get QRD into a stable orbit – and looking back, I think we did just that.”

N.B. Harry saw Richard's grasp of IT as key in helping the Society's senior management team and felt that 'his deliberately independent visibility fitted in well with the Society'.

After 12 years with AS Harry left soon afterwards to be National Director for Patients and the Public at the Department of Health. He felt he should stand back from the Society although stayed on for some time as a Friend of Alzheimer's Disease International to help with fundraising. Even now he maintains interest and keeps in touch with Jeremy Hughes and Nori Graham and is Patron of Arts4Dementia. Dementia is very much bound up with his personal life in that his father had already died of dementia when he took on the job with ADS. At the time of leaving he had been in talks with Alzheimer's Research Trust and Neil Hunt, as incoming CEO, was charged with carrying on finding ways of furthering closer ties, but this never happened!



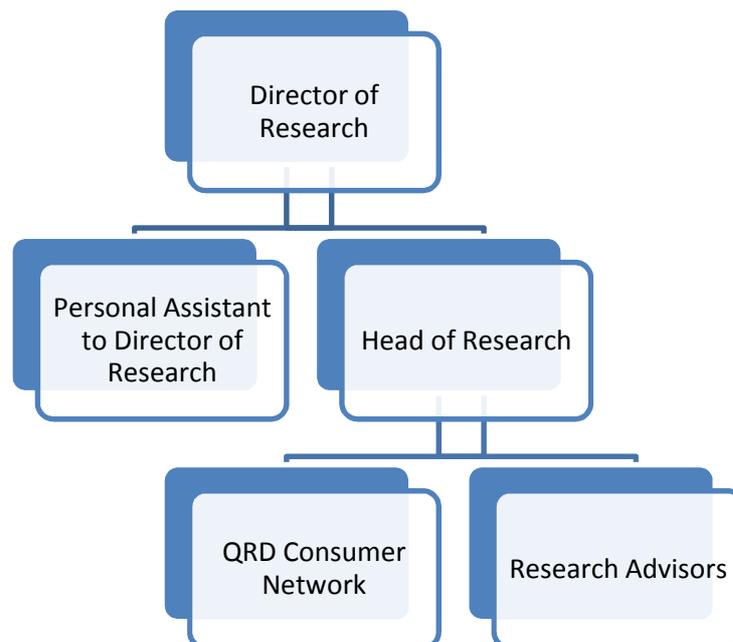
Richard Harvey, Harry Cayton and Cherie Blair



Richard Harvey and Martin Rossor at Gordon House

QRD EXPANDS

The 2003 Proposed Hierarchy:-



Dr Susanne Sorensen, Head of Research 2003-2011 writes:-

“At my interview for the job in 2003 I had to give a presentation on the benefits of consumer involvement in research. I had to use my imagination, as many experienced people in the field thought it was completely mad and I could find no evidence for any benefits anywhere. There was only a sense amongst a minority of people in patient organisations, that consumer involvement had to be right. Alzheimer’s Society was a trailblazer in this new movement and had developed the basic ‘how’ from scratch.

In my new job I met about 40 enthusiastic research volunteers telling me what they believed were the benefits and demanding my engagement and support. I also found that research was still on the margin of the Society’s activities and that, not only was there a discussion going on about what research to do and how to do it, there was a major debate raging about whether to do it at all. I began to fully understand and share the volunteers’ motivation and frustration.

During the following years the research volunteers pushed us on from success to success – always arguing for staff to support them to do more. The staff numbers grew and very satisfactorily, the budget grew too. It was a great day when we reached active research volunteer no. 200. We funded more and large and complex projects, research fellowships and studentships. We developed dissemination projects.

The longest and biggest project of developing a new type of brain bank finally launched in 2009. We led the way in training volunteers for research participation. Research staff and volunteers were invited to speak at more conferences and share our experiences with more advisory groups each year.

Volunteers were at the forefront in the campaign to make cholinesterase inhibitor drugs and memantine available on the NHS. Members of the group worked intensively together with the experts to influence the Dementia Strategy for England and, when we succeeded in getting research included in the list of priorities, they worked on the National Dementia Research Strategy. We partnered with well-known household name organisations to get more funding and more projects.

I had the privilege of working in AS in a tremendously exciting period where the participation of people with no scientific expertise but all the knowledge about living with a condition became central to research strategies, funding programmes, new research protocol development and the implementation of research outcomes. It is now mainstream and I believe the enthusiasm of AS’s research volunteers, the commitment of the small group of research staff and the willingness of some dementia researchers to consider new ways of working made it such a success and influenced the larger research agenda. We also together saw some really exciting dementia research come to fruition and begin to influence practice or form the basis for large scale programmes that could be taken on by larger organisations than us.”

PART 2

GROWTH AND EVOLUTION OF QRD / THE RESEARCH NETWORK

WHAT IS THE RESEARCH NETWORK? WHAT IS THE RESEARCH PROGRAMME? HOW ARE NETWORK VOLUNTEERS INVOLVED?

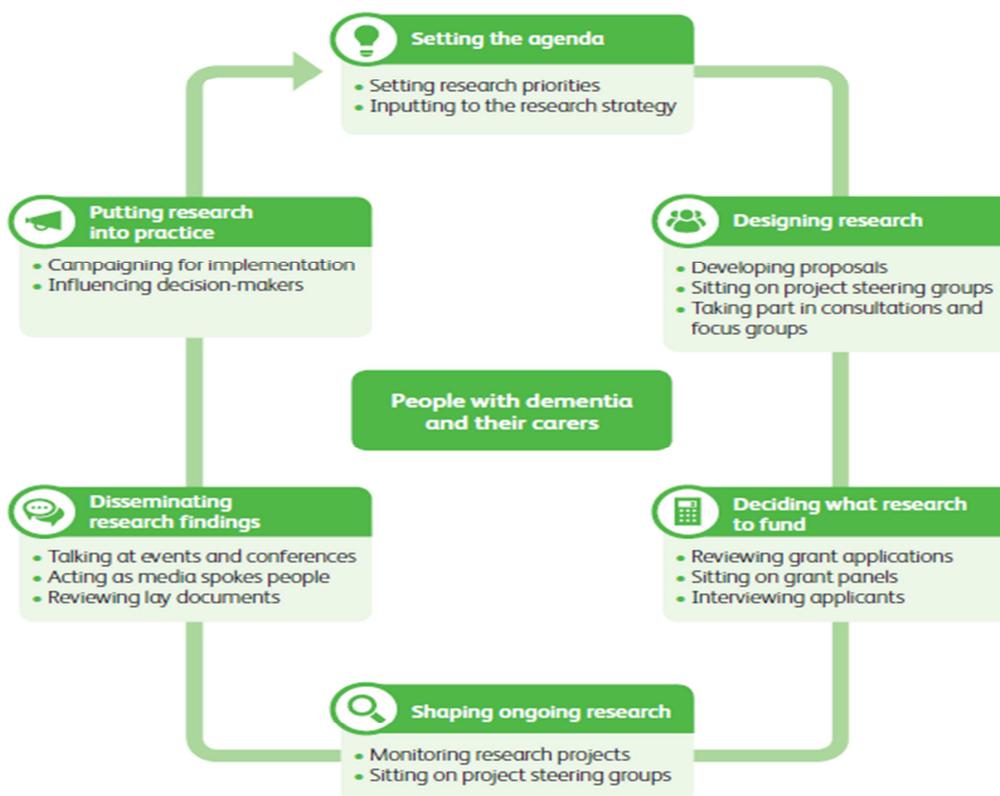
Since Alzheimer's Society made its first commitments to funding research in 1990 they have invested in cutting edge research into Cause, Cure, Care and (more recently) Prevention of all forms of dementia. The research programme covers the full scope of dementia research, from laboratory-based investigative science and clinical research to studies into social interventions and quality care for people with dementia.

The research programme combines the expertise of leading scientists and clinicians with the experience of people living with dementia. All funded research is approved by experts in the field as well as people with dementia and carers to ensure that only high quality research that influences practice and transforms lives is funded.

The Research Advisory Committee provided overall guidance to the research programme and included researchers and clinicians specialising in basic, clinical, public health and care research. In January 2015 a Research Network volunteer joined the Research Advisory Committee now called Research Strategy Council, to ensure that the views of the Research Network permeate at every level of advice and decision-making.

Over 500 scientists and clinicians in the dementia research community provide robust peer review and participate in grant selection panels and we consult with specialists who advise on specific streams of our work such as public health research.

THE RESEARCH FUNDING PROCESS



The Research Network volunteers contribute valuable insight into the design and delivery of research and influence dementia research funding at a national level.

The core role of Network volunteers (QRD Consumer members) was, and still is, to read, comment on and prioritise all applications submitted to the Society for funding and be involved in setting priority areas for research.

There are many other activities where RNVs can be involved if they wish and have the time, such as:

Setting the agenda: Volunteers participate in grant writing and ideas workshops and are consulted on their priorities for research.

Designing research. Volunteers help develop proposals, sit on project steering groups and take part in consultations and focus groups before researchers submit their **grant application** to AS

Deciding what research to fund. Parallel grant review and selection processes. Volunteers provide lay review of all applications received in parallel with scientific peer review and sit on Grant Award Panels.

Shaping ongoing research by Monitoring research projects, or as lay members of clinical steering groups. Three volunteers are assigned to each project funded.

Disseminating research findings. Volunteers speak at events to disseminate research and campaign for the implementation of research findings, act as media spokespeople and review lay documents.

Putting research into practice. Volunteers campaign for implementation and seek to influence decision-makers.

Putting research into practice has hitherto been the hardest, and least successful, part of the volunteers' role and indeed the role of the Research Team. Particularly in the area of Care research over the years there have been questions asked as to how and why good research isn't being put into practice. It took approximately 7 years for the FITS project to be implemented. Even now it has not been fully implemented. Some areas already have done so and others are in line for implementation. However it is perhaps the best example of RNV involvement in the entire Research Process.

In 2014 the Society appointed a Head of Research Development and Evaluation, as well as a Research Translation Manager to focus on ways to ensure effective translation of research into practice.

WHAT DID QRD CONSUMER MEMBERS DO IN 1999?

Read, comment on and grade applications from researchers who were applying for funding from Alzheimer's Society. The format and scoring forms we received have hardly changed since 1999 although in 2012 these became available for volunteers to review online. Once applications were rated by the QRD Consumer Network they went on to be peer reviewed by leading scientists, ensuring that the work AS funds is not only highly relevant to those who have been affected by dementia, but is also of the highest scientific quality.

Following a pre-Panel session with the Head of Research to clarify the projects under review, and agree questions they would be able to put to the applicants, three network members sat on each **Grant Award Panel** and in early days the shortlisted applicants for Fellowship and Project Grants attended the interviews in person and had time to give short presentation and answer queries relating to their application.

Help to identify and prioritize research that will make a difference to those with dementia and their carers with a **prioritizing exercise**, initially held annually, later, on alternate years.

Have access to training in research methods, two one-day sessions using external trainers held in London and regionally started in 2000.

"We led the way in training volunteers in research participation." Susanne Sorensen

Before he left Dr Harvey started writing, with consumer members' input, a **Member's Handbook** and this was followed up by Susanne when she became Head of Research. The first edition as a large loose leaf folder was sent to all members of the network in September 2004. The foreword by Richard Harvey stated "the member's handbook is the result of a great deal of hard work by everyone involved in QRD. It distils the essence of what a new member of the advisory network needs to know and will act as a source of reference for existing members". A committee of staff and advisory network members had contributed to the handbook with many quotes that eventually were used in the Speakers' Pack.

Funded to attend the Annual Research Conference that until 2011 ran alongside the AS AGM and Conference.

Monitor projects: This was Dr Harvey's aim right from the start of QRD but it took a year or so to take off. Three QRD network members are assigned to each project funded. They attend an initial meeting with the research team and meet those involved in the project and see round the labs if biomedical. Six-monthly or annual meetings followed after which both the research team and the monitors had to send a progress report to the Research Office.

These were good opportunities for young scientists to develop presentation skills particularly when addressing lay audiences and in the case of care projects often resulted in network members being invited to contribute to design and dissemination of the study.

Invited to Speak about the impact of the research programme at Alzheimer's Society events and at **national and international conferences** to explain the role of QRD network members.

Read: The monthly newsletter started its days as the QRD Newsletter, a simple paper supplement to the mailings received by the Network. Its purpose was to keep the Network members up to date with the activities of the research team which in the early years was a two-person band.

WHAT DO RESEARCH NETWORK VOLUNTEERS DO IN 2015?

In 2011 **QRD was re-branded as the Research Network** and QRD consumer members were henceforth known as Research Network volunteers (RNVs). This was in line with the re-branding of the Society from “AS (Dementia Care & Research)” to “AS (Leading the fight against Dementia)” with the intention also of allowing the Research Network to better integrate with the main functions of the Society. The core role of the Research Network Volunteers remains the same i.e.:-

Reading, commenting on and prioritising grant applications. The forms used for scoring remain much the same although in last five years there has been separate box for Public and for Private comments on the form as all Public comments are fed back to applicants. RNVs are now being encouraged to complete forms online.

Prioritising exercise alternate years. Priorities are displayed on website so that potential applicants for funding can see which topics are priorities although this should not prevent researchers from submitting proposals on topics not displayed. In 2012-2013 the AS convened a James Lind Alliance Priority Setting Partnership asking Research Network volunteers, members of the public, clinicians and health professionals to decide on the most important unanswered questions in dementia research.

Access to training in research methods. A one-day session for new members held a couple of times a year and a session during the Annual Research Conference. In 2010 a Monitoring Training Day was introduced to reflect that many more projects are being funded at universities covering a wider area of the UK including Scotland, hence more trained monitors are required. For those volunteers with time to spare, Monitoring is a popular activity allowing access to scientists and clinicians and insight into the way they work.

A workshop on Qualitative Research was held at KCL in 2010 run by Clive Ballard and Dr Joanna Murray.

“Joining the Network I found an amazing group of like-minded people all with a single commitment... most importantly we’re treated seriously by the Society and seen as an integral part of the research process!” Cathy

Member handbook – an upgraded version which covers most situations likely to arise when reviewing applications including how to review grants online. This is still available to all new volunteers and existing volunteers if required. The **Speakers Pack** includes a selection of presentation slides for us to pick and choose for use as appropriate at any events where we were speaking about research. A pilot of ‘Research Communications Training’ to support RNVs who speak at events was run in 2012 and is planned to re-launch in 2015.

In 2014 a new style of **Grant Award Panels** was introduced in response to increasing numbers of applications with the setting up of Research Network Grant Advisory Panels for the two newly created Biomedical, and Care Services & Public Health funding streams.

Fifteen volunteers were selected to serve on each Panel that meets two weeks before a Board and RNvs votes on those applications they think fundable, potentially fundable or unfundable. The role of four RNVs selected to attend the Boards, consisting of leading researchers, is to present the overall views of the Network and discuss and vote on the final selection of applications to be funded. In Biomedical research it is evident that 'Science is King' and the scientists and clinicians tend to have the last word if final decisions on funding are not unanimous due to likely flaws in methodology and validity issues. In Care research there is more deference to the volunteers and more equality in the decision-making given the personal expertise of the carers. The Chairs: Emeritus Professor Roy Weller chairs the Biomedical Panel. Emeritus Professor John Gabbay chairs the Care Services & Public Health Panel. They attend the Panel and answer our questions and queries.

Monitoring: Volunteers have opportunities to be one of the **three monitors** assigned to each project funded. Projects are more widely spread nowadays in universities right across the UK allowing local volunteers to monitor a more geographically well placed project. The number of projects funded has risen enormously so there are more calls for potential monitors particularly where projects are the result of a partnership or collaboration e.g. **BDR** have 16 monitors based at local collection centres, also represented on the **Joint Steering and Management Committees, Data Monitoring and Tissue Request panels.**



Respond to increasing numbers of email surveys/questionnaires from Head Office (including policy and service development) relating to strategy, or seeking comments from those with relevant experience on suggested topic proposals.

Help to identify and support research that will make a difference to those with dementia and their carers. **A Proposal Development Service** was launched in 2014 to help connect researchers to volunteers prior to submission of their applications. Researchers working on a proposal can ask to be put in touch with volunteers to obtain a lay perspective on their proposal before submitting.

Annual Two-day Research Conference: This for many Network volunteers is the highlight of the year. Most recently a sponsorship deal with Sunrise Senior Living supports the costs of the Network and this event in particular. From 2011 the Research Conference was a stand-alone event rather than run in tandem with AS AGM and Annual Conference. Leeds, Birmingham, Croydon and Nottinghamshire, have been recent venues with Manchester scheduled for 2015. Only in 2011 after the Society decided to discontinue its annual national conference, did the Annual Research Conferences become free-standing events. This is an indication of the growing importance of Research within the Society's remit, but some Network members regretted the loss of what was often their only contact with the work of the Society generally, the wider membership of the Society and

opportunities to hear from those involved in the running of the Society's services both nationally and locally. This situation was remedied briefly when following the One Society Review, Network Volunteers had opportunities to speak at the four-monthly Area Forums, indeed Research had a regular slot at these meetings. Initially many Society members of branches and area offices were very critical, often angry, that the Society was spending money (wasting money they called it) on research at a time when services were suffering from the reorganisation and budget cuts. Thanks to the efforts of Area Coordinators and local volunteers attending these meetings and with support and briefing notes from Susanne, interest in research gradually gained prominence and indeed in some cases Area Forums went on to be a recruiting ground for network volunteers. Unfortunately, Area Forums disappeared in the further reorganisation.

In 2014 **Volunteer Engagement Network** events were introduced across all areas as successors to Area Forums with RNVs having a defined role. These events aim to allow Society members to learn more about the Research Network and how they could be involved and at the same time allow RNVs to learn more about activities within the localities.

Attend Focus Groups on specific topics, e.g. end of life care, medication management, drug licensing

Sit on **Steering Groups and Trial Data** monitoring groups e.g. Brains for Dementia Research, The HTA-SADD trial looking at depression and dementia, Steering Group of BHiRCH looking at Better Health in Residents in Care Homes where the original pilot was "Avoidable Admissions to Hospitals from Care Homes".



Work with **DeNDRoN** (Dementia & Neurodegenerative Diseases Research Network). Examples of this: The DeNDRoN PPI Forum is populated by a majority of RNVs. The Dementia Clinical Studies Group (CSG) where 3 Network Volunteers attend twice-yearly meetings.

Act as **Co-applicants** on applications to NIHR, ESRC and other funders and **external lay reviewers** for NIHR, and ESRC

Alzheimer Europe: Angela Clayton Turner contributed to a project on ethics in dementia and Barbara Woodward-Carlton & Matt Murray presented on 15 years of the Research Network at the 2014 Conference. Daphne Wallace and Hilary Doxford have both been on the European Working Group for People living with dementia.

World Dementia Council- As a result of the G8 summit on dementia in December 2013 a World Dementia Council was convened with members from across the world. Hilary Doxford spoke to the group in 2014 and was formally appointed as the only member living with dementia in February 2015.

Lobby/Campaigning e.g. antipsychotics All-Party Working Group on Dementia, campaign to reduce prescription of antipsychotics and many RNVs joined the campaign to allow the anti-dementia drugs to be made available on the NHS to people in early and moderate

stages of AD and Memantine to those in later stages. This was finally cleared by NICE in 2011.

Presentations at local, national and international conferences (see under Events). When Annual Research Conferences were held in tandem with AS Annual Conferences and AGM, QRD volunteers manned the QRD stand and endeavoured to recruit new members.

Disseminate research. Write articles, contribute to edited books, give talks to local groups

Legacy Fundraising Events: A RNV speaker at each of these events across the country.

External Opportunities afforded through the experience of being on the Research Network:

Stem Cell Bank Management Committee, Cochrane Collaboration, Access to Understanding Science Judging Panel, Ministerial Advisory Group on Dementia Research (MAGDR), Prime Minister's Challenge on Dementia.

READ: The AS monthly magazine Living with Dementia. Each issue now includes an article on research.

Research Network Publications:- The **Monthly RN Newsletter** has evolved in the last few years, changing design and format and reaching a much wider audience. The readership includes members of the public, health professionals, Area managers and regional operations managers and wider Society audiences as well as the Research Network and Friends of Research. The readership grows in number every month. In 2010 the 100th issue was published. At the end of 2014 in response to feedback from RNVs the Newsletter became a quarterly magazine "Care and Cure" with in-depth articles on dementia research and background information to understand better the latest findings.

2008 Launch of online QRD Journal A twice-yearly e-journal presenting up-to-date reviews of cutting edge research as parallel articles for both scientists and the public. This was available on the website, the edition of February 2010 edition focused on BDR. The e-journal was discontinued in 2011.

The image shows the cover of the QRD newsletter, titled "Quality Research in Dementia". It features the Alzheimer's Society logo in the top right corner. The main headline is "Report from a completed research project: Behavioural and functional analyses of the X11 proteins in a mouse model of Alzheimer's disease" by Dr Declan McLaughlin, Institute of Psychiatry, King's College, London. A small portrait of Dr. McLaughlin is on the left. The text describes a Morris water maze test where mice with high levels of X11 proteins learn to find a hidden platform more quickly than normal mice. The newsletter footer includes contact information for the Alzheimer's Society and its registered charity status.

Network News was launched in September 2014 and includes short articles written by Network volunteers and is circulated to Network volunteers every two months.

EVENTS 1999-2015

In **January 2000 QRD had held its first Scientific Symposium** at Head office, Gordon House, in Victoria, when all the current researchers and grant holders were invited to a reception, to give brief descriptions of their work and allowing time for discussion. It was the first time that so many of the Society's research and scientific advisers and grant holders were together in one place and many commented how useful it was to have this as a forum to discuss research progress.

A **'Meeting of Minds' Conference** was held in London at the Queen Elizabeth Conference Centre in 2000, being the ADS 20th Anniversary Conference. Originally this event was intended to launch QRD but the organisation and ambitious scale of the conference delayed it somewhat. The main purpose was to launch QRD and re-position Alzheimer's Society as a research charity and raise the profile of scientists. Perhaps, as Harry admitted later, this launch was prompted by some alarm that Alzheimer's Research Trust was being set up apparently in competition.



Taken at the first Scientific Symposium. Many familiar faces, all looking somewhat younger than now!

John Snow opened the conference and the then Health Minister Frank Dobson spoke at one of the sessions.

Peter Whitehouse from University of Cleveland, USA, opened one of the plenary sessions and over the course of the event QRD consumer members were encouraged to chair or co-chair the various workshops and sessions.

ANNUAL CONFERENCES

The first Annual Conference was held in 1999 and subsequently ran in tandem with AS AGMs; 2002 at Loughborough University and the 4th in 2003 at York University. The QRD Annual Conferences were originally one-day events tacked on, or running in parallel with, the Alzheimer's Society AGM and annual two-day Conference. Subsequently there were five held at Warwick University.

Network Volunteers have also spoken at: **seminars and local events** from the earliest days and one-day informal **RESEARCH MEETINGS**: In London these became a regular event and also in other regions, notably West Midlands. Increasingly these were organised and chaired by Area Coordinators.

Pictures from the Annual Conference 1999-2014



REGIONAL CONFERENCES: Following the One Society Review, research staff and network members were encouraged to attend AS local conferences and wherever opportunities were available to run presentations about The Network, to promote awareness of the AS research programme and the value of consumer involvement in research.



Alzheimer’s Disease International (ADI) conferences: In 2012 ADI held their conference in 2012 where Matt Murray spoke about the Research Network with many Network members in attendance.

International Events Including

ALZHEIMER EUROPE Conferences

International Event explaining PPI, Stockholm

European Stem Cell Conference 2005



International ICAD Research Conference. The AS organised and hosted an evening symposium at the ICAD 2011 conference in Paris. Securing the symposium at such a large event was an achievement for AS helping to raise the profile of AS Research and included the first ever presentation by a carer at such an event.



INVOLVE conferences. Network members have spoken or presented posters at every INVOLVE conference since these started in 2000.



Annual UK DEMENTIA CONGRESS.

AS RESEARCH ROADSHOWS– between 2010 and 2011 the Research team hosted six events across the UK to promote the latest research, with talks by research staff and by local researchers. RNVs were invited to attend and speak about their role.

Launch in 2011 of the DRUG DISCOVERY PROGRAMME at the House of Lords hosted by Society ambassador Lord Julian Fellowes.

LEADERSHIP TOURS held since 2012 bring together Staff and Research Network volunteers, and other volunteers at local meetings to discuss progress in AS strategy and have an open forum for questions and discussion.

AREA COORDINATORS

It was Richard Harvey's idea to appoint Regional Coordinators as they were then called. Originally 15 regions, now 12 and re-named Area Coordinators, this due to the re-drawing of AS boundaries to better reflect the changed political landscape. With more responsibilities, the Coordinators now get together with Research staff for three one-day meetings a year including one during the Annual Research Conference. Since 2011 Coordinators are responsible for running introductory induction sessions for potential new members in their area, and part of their role is to channel information from Head office to their area members, and vice versa, and often seek views from their members about agendas, focus groups, local issues, policies, and other relevant topics. The vast majority of Network Volunteers are now on email which makes life easier for Coordinators. The role of Coordinator is a fairly individual one depending on area, demographics, time available etc. They are 'first port-of-call' for network volunteers.



Research Network Area Coordinators Meeting, 2004

List of Area Coordinators

Area	Name
London	Shirley Nurock
South East	Aubrey Milstein, Barrie Randall, Lynne Ramsay, Angela Clayton-Turner, Julie West
Northern Ireland	Valerie Megraw, Kieran Hanna
Yorkshire & Humber	Bill Peberdy, Barbara Woodward-Carlton
North East	Donald Thomas, Lesley Rickerby, Marshall Ward
North West	Margaret Edmonds, Jean Town, David Ford
Scotland	Joyce MacFarlane, Kate MacGowan
Wales	Roy Hughes, Tricia Best, Victoria Morgan, Merridy Cameron
East of England	Sue Maskell, John Hill, Francis Weiss, Barry Plumpton
South West	Bill Mitchell, Margaret Clark, Stephen Hatch, Sue Lawrence
West Midlands	Chris West, Sue Boex, Sarah Gillespie
East Midlands	Sid Rees, Ted Freer, Peter Riley

-AWARDS: William Brooks Volunteer Awards: Jim Ellis; Shirley Nurock 2009; Barbara Woodward-Carlton 2010; Lynne Ramsay and Angela Clayton-Turner 2011. Alzheimer’s Society People Awards: Bob and Sylvia Kahn, Yorkshire Research Network, Matt Murray 2013; Keith Oliver 2015.

FRIENDS OF RESEARCH

The brainchild of Victoria Morgan, Coordinator for North Wales, and set up in 2007 this aimed to encourage more Alzheimer's Society members, staff and members of the public to become better informed about our research programme. This was especially useful for those unable to join the QRD Consumer Networks because either they did not fit the criteria, or did not have the time to scrutinise the many research applications that members of the Network receive to review. All Friends receive the monthly Research Newsletter and invitations to local events and to Annual Research Conference, although expenses are not paid for attending these.

It has been immensely successful, increasing from 50 Friends in 2008, 425 in 2010, 695 in 2011 and at the end of 2014 membership stood at 1,627.
(see quote from Victoria in Part 3.)

DELIVERING ON DEMENTIA

In 2012 the Society launched a new 5 year strategy called **Delivering on Dementia**, aimed at changing the face of dementia research with increasing investment in research and leading the way in partnerships and best practice. This has led to the Society increasing its investment in exciting new projects and driving through areas of work that are relevant to its strategic priorities. Fellowship grants and PhD studentship budgets were raised to enable AS to support more researchers and build a stronger dementia research community particularly to increase capacity encouraging existing researchers and new young researchers to enter into dementia research. Other new elements of the Strategy include the Drug Discovery Programme, new co-funding partnerships and a focus on Research Development, notably in the translation/implementation of research into practice.

PARTNERSHIPS WHY PARTNER WITH OTHER ORGANISATIONS?

*In 2007 the **QRD PARTNERSHIP FUNDING PROGRAMME** was launched. With more topics than Alzheimer's Society can address on a limited funding budget one of the ways to encourage research in areas we cannot fund directly is by entering into partnership with other funding bodies or researchers themselves.*

The Research Network have been involved in a number of different partnerships enabling an increase in the quality and quantity of research in the UK.

Some of these are funding partnerships and some involve Network volunteers in a variety of different ways.

FUNDING PARTNERSHIPS:

BUPA FOUNDATION: In 2010 AS teamed up with the BUPA Foundation to fund the year's project and fellowship grant rounds. Both charities contributed £1.5 million to the budget and worked together to review research funding applications from across the UK and around the world. Nine new project grants (the majority biomedical) all of a very high standard, were awarded. Following a focus group held at Devon House the previous week involving a number of Network members, two Network volunteers read all 60 full

applications, the lay reviews and scientific peer reviews, and sat on the Grant Award Panel.

N.B. This grant award procedure provided the inspiration to change the way the AS Grant Award Panels and Scientific Advisory Group functioned, bringing it more into line with other major funders in the sense that the Panels do not generally actually interview all shortlisted applicants (other than Fellowships) as had been the case until then.

THE STROKE ASSOCIATION. In 2007 the Alzheimer's Society hosted a joint workshop with DeNDRoN (Dementias & Neurodegenerative Diseases Research Network) and the Stroke Research Network to discuss research into vascular dementia. From this sprung the AS Hearts & Brains Project - an initiative to raise awareness of vascular dementia and the risk factors associated with it. The group agreed there were potentially excellent opportunities to prevent or delay the onset of cognitive decline in people with existing cerebrovascular disease. However at that time the level of investment in this area lagged substantially behind other common conditions affecting the brain.

The group commissioned systematic reviews and promoted awareness of the statistics showing that approximately 30% of people who survive a stroke will develop impaired memory and thinking and then dementia within the next five years making this a priority area of research. The group nominated facilitators to lead workgroups responsible for developing the four highest research priorities in this area.

One of these groups, led by Professor Philip Bath (University of Nottingham) was awarded joint funding by the Stroke Association and AS to look at Prevention of Decline in Cognition After Stroke Trial (PODCAST) a grant of £399,145 for research into stroke and dementia. Known as an intensity trial it does not measure the result of treatment against no treatment, but rather, of some treatment against more treatment. The trial ended in 2014 having examined whether rigorous treatment by lowering blood pressure and cholesterol can influence cognitive decline in people who have had a stroke, with participants being regularly monitored over 3 years. It experienced major recruitment problems and the trial formerly closed with inconclusive evidence but sufficient to warrant further research particularly where lowering cholesterol (lipid) levels were involved.

This 'taskforce' approach appeared to be a successful mechanism to galvanise research particularly in areas which have received the least investment to date.

BRITISH HEART FOUNDATION. In 2007, following on from the Hearts & Brain project, AS launched an initiative to raise awareness of vascular dementia and the risk factors associated with it and questioned why it was not being investigated.

In 2013 a clinical trial co-funded with the British Heart Foundation was announced looking at a common type of vascular dementia. As part of the Drug Discovery programme the £2.25 million trial will take a commonly used BP drug and test whether it may be used to treat dementia (PI: Professor Peter Passmore, Queen's U. Belfast) recruiting 600 participants from several centres around the UK. The Trial will run for four years. The application was developed in collaboration with RNVs with experience of vascular dementia.

NON-FUNDING PARTNERSHIPS

The JAMES LIND ALLIANCE (JLA)

The James Lind Alliance partnership with AS was instigated by the Public Health Steering Group led by Professor Carol Brayne. In 2012 JLA announced the launch of a Dementia Priority Setting exercise in partnership with AS to identify gaps in current research for dementia and the priorities for future research into the prevention, diagnosis, treatment and care of dementia. The robust prioritisation process involved extensive consultation with people affected by dementia, clinicians, professionals, Network Volunteers and stakeholder organisations to identify uncertainties and provide researchers with an evidence-based framework within which to position their work.

Impact value: in 2013 a list of the ten top priorities was published, these being made available on the website for funders, policy makers and commissioners to direct future research according to the most critical issues. Subsequently there has been a NIHR commissioned call on the back of the JLA results.

NATIONAL INSTITUTE OF HEALTH RESEARCH (NIHR) DEMENTIA THEMED CALL

was launched in May 2011 to provide increased government spending on dementia research. A one-off workshop in May 2011 was hosted by AS in London to bring together researchers who were writing applications for this funding, with RNVs, to improve the quality and relevance of the planned research. The event was a great success and provided a unique opportunity for researchers to discuss their ideas with volunteers. It brought together RNVs with top researchers with the aim of driving forward and supporting high quality research applications in priority areas.

In total the Society supported 40 applications submitted to the NIHR, playing a key role in making the most of this opportunity to increase national investment in research. RNVs were able to provide valuable information to researchers, helping them to develop high quality research proposals and was an excellent example of patient and public involvement in action – as pioneered by AS.

Forty RNVs attended the event. The outcomes from this funding round were announced at the end of December 2012. In total, £22 million of research was to be awarded and 21 research projects funded. AS is involved as partners with 10 of these projects, thus having an influence on £14 million of the research with many RNVs involved either as co-applicants or lay advisory group members.

Impact value

Following this and the subsequent NIHR/ESRC Themed Call, some 80% of projects with partnered PPI were shortlisted compared to 30% which weren't partnered. The quality of the applications was so high that the Government awarded extra funding.



Researchers meeting with Research Network volunteers at the NIHR Themed Call event in 2011

PARTNERSHIPS WITH UNIVERSITIES ON INDIVIDUAL PROJECTS

MARQUE PROJECT, UCL – Managing Agitation and Improving Quality of Life .

BHiRCh PROJECT, Bradford - Better Health in Residents in Care Homes

PROMs, London School of Hygiene and Tropical Medicine – Patient Reported Outcome Measures to improve the management of long term conditions in primary and residential care.

PREVENT programme, Imperial College London - cohort study to identify earliest signs of change in brain while people still in good health..

Deep & Frequent Phenotyping, KCL and others- Feasibility study to test whether it is acceptable to gather a large amount of data from people with dementia to accurately match them to drug trials

IDEAL, Bangor/Exeter- looking at ways to live well with dementia

PROVIDE, School of Optometry- Prevalence of Visual Impairment in Dementia - Investigating the prevalence and causes of visual impairment in people with dementia.

SHARED, University of Warwick- Research Network volunteers trained to interview people with dementia discharged from hospitals as well as their carers to create recommendations on improving the discharge experience.

DeNDRoN PPI and AS End-of-life care. The **SEED** project is an example where a researcher has taken an AS priority topic, run a focus group with RNVs and collaborated for a large grant: - Instigated by Susanne in 2010 AS collaborated with DeNDRoN to host a forum into End of Life care attended by several QRD network members where issues raised were taken forward to a further meeting to inform the research that is needed in this area. This led to the SEED project currently taking place at Newcastle University, led by Prof Louise Robinson.

Developing a dementia register: Two members of the QRD Network had been instrumental in the development of a project to provide access for people with dementia to a database of clinical trials into dementia. This valuable resource was made possible by NIHR and the DeNDRoN Network. As lay members of the DenDRoN Clinical Studies Group two volunteers had some years previously suggested that a database of clinical trials be set up that people with dementia and their carers could use. They had noticed that while it was difficult for people to find out about clinical trials in their area, many trials were struggling to reach their recruitment targets. A couple of local initiatives took place, notably in Scotland, and North Thames but a central, accessible database was the obvious solution.

AS started working with DeNDRoN in 2009 to set up this database – A Dementia Register - which could be accessed via a link on the AS website. A Lay champions group was set up, hosted by DeNDRoN, with many RNVs involved in attending meetings between 2012 and 2014. Initially named RAFT, the Register was piloted early in 2014. With a formal name of **Join Dementia Research (JDR)**, the project launched nationwide in December 2014 and the register also allows people to self-refer by entering their own details so that

when a suitable trial starts, researchers can contact them. It is also accessible via AS Helpline. By May 2015 more than 6,000 people had registered with JDR.

Impact value: *“Research Network volunteers have worked tirelessly to achieve their goal of a functional database so that people with dementia and their carers can have the opportunity to proactively search for trials. They were not just actively involved in supporting initiatives like this, they actually make them happen!”* Piers Kotting, Assistant Director of DeNDRoN

OTHER EXAMPLES OF FOCUS GROUPS

2010 **Assistive Technology** focus group in collaboration with DeNDRoN led by Prof Rupert McShane, Oxford.

2011 Roche/KCL focus group on **Clinical Trials for Prodromal AD**, London.

2011 Rob Howard, KCL - discussing **ethical issues around the use of morphine/cannaboids** to control symptoms of agitation in dementia, London.

2011 **Medication Management** led by Ian Maidment

2013 **Population Screening** in AD and other dementias, Cambridge.

2013 **Deep & Frequent Phenotyping** for Experimental Medicines in dementia. This group also contributed to an information sheet design and ethics submission. Prof Simon Lovestone, KCL/Oxford

2014 **Sleep disturbances** - Dr Anne Corbett, KCL

AS formed a working partnership with **Alzheimer Nederland** in 2012 to work collaboratively on a project that aimed to reach a Delphi method consensus on treatment of people with dementia with antipsychotic drugs in care homes. One of the focus groups to inform the work was with RNVs, following a parallel consensus process with volunteers which included a questionnaire to Network volunteers with experience in this area. A paper outlining the innovative methods used was published in 2015. Through this and other projects the Research Network is shining a light for best practice in Europe and around the world to lead the way in involving people affected by dementia to guide the work

COLLABORATIONS

BRAINS FOR DEMENTIA RESEARCH (BDR)

A £10million ten-year collaboration with Alzheimer’s Research UK launched in 2009 BDR is an initiative to address the shortage of brain tissue available for research through prospective recruitment. BDR has developed a gold standard in brain donation procedure in order to provide researchers with fully categorised tissue with, where possible, a full medical history.

When BDR was in the process of being set up, two lay members of QRD were on the Award Panel in Cambridge and others were involved in developing protocol for recruitment to BDR. Network volunteers were also represented on the ethics groups, at workshops to train brain bank staff regarding recruitment, at recruitment drives.

RNVs sit on the Joint Management Steering Committee and the Ethics group and act as monitors at the 6 regional Centres i.e. Oxford, Cambridge, London, Newcastle, Bristol, Manchester.

Network volunteers are on the Tissue and Data Request Panels alongside the scientists and brain bank managers and review all applications coming in from around the world for BDR tissue.

Impact value: *“Involvement of the QRD/RNV has been crucial at all stages of the development of BDR, from the recognition of the need for people with dementia and their families to be involved in dementia research to assisting the applicants developing the original bid. Furthermore and alongside scientific reviews, lay members helped identify strengths and weakness that have ultimately lead to a project more fit for purpose. Once the project started in 2008 after some years in the development stage, QRD/RNV members have been an integral part of each BDR Centre’s management and steering committees as well as contributing to overall oversight of the project. One invaluable role was helping develop the participant information sheets, consent forms and recruitment posters for the project ethics application at start-up.*

The mid-term review and the renewal process again saw key contributions to shaping and evaluating the application. Lay members continue to make increasing contributions to the project through membership of the tissue request committee and talks at ethics study days, culminating in a lay study day in 2012 where all aspects of involvement were celebrated and new ideas discussed. An often overlooked contribution is to recruitment of participants by word of mouth, articles written and meetings attended.

In my view the partnership with scientists and role of a critical friend provided to BDR by the QRD/RNV illustrates how PPI works at its best and I am certain that BDR would be a poorer project without such a level of engagement and commitment.” **Professor Paul Francis, Director BDR**

THE BBC. In 2009 in partnership with the BBC and King’s College London a trial was launched to carry out the first large-scale clinical trial into the benefits of Brain Training. The Brain Test Britain trial was launched by the BBC on the TV programme ‘Bang Goes The Theory’ on 7 September 2009, open to anyone over 18 and under 60 with the aim of answering important questions about whether Brain Training could help improve or stabilize brain function in older adults by participating in a ground-breaking online medical trial of brain training software. More than 11,000 people participated in the UK. Professor Clive Ballard presented some initial findings from the Brain Test Britain trial at ICAD 2010 in Honolulu. Results indicated that brain training games do not improve brain function, a disappointing but important finding. The study received wide attention and was published in Nature.

In 2010 Alzheimer’s Society in partnership with the BBC convened an expert panel to review the evidence for lifestyle factors in reducing the risk of dementia. Based on this consensus process a number of lifestyle factors were highlighted and an opinion given regarding the most likely lifestyle and medical factors to reduce the risk of AS and other dementias.

Cochrane Collaboration: RNVs review papers for the collaboration.

Carer Reference Panels. Bradford University, Professor Murna Downs .

RNVs are providing high levels of PPI through membership of Carer Reference Panels in Yorkshire and London in this ongoing 3-year project looking at Better Health in Residents in Care Homes (BHiRCH) and avoiding unnecessary hospital admissions. Two RNVs are co-applicants on this project. The group in Bradford also support a number of other research projects carried out by the Bradford Dementia Group.

MRC: The DOMINO TRIAL Professor Rob Howard, KCL. Co-funded by MRC with involvement and some partnership funding from the AS, the trial studied the effects of continuing the AD drug donepezil into the moderate to severe stages of AD. This project also studied the value of adding memantine to donepezil. (2007- 2012)

“For the first time we have robust and compelling evidence that treatment with these drugs can continue to help patients and the more severe stages. It means a lot to doctors and carers to see the differences like that”.

Prof Rob Howard, KCL.

Impact Value: *A collaboration that has influenced practice and improved access to drugs.*

UKARF (UK Age Research Forum). Set up in 2008 it is a strategic partnership between government, research councils and relevant charities that aims to make a positive difference to the lives of older people through well co-ordinated research.

2014 saw the launch of UK Dementias Research Platform, a collaborative project between the MRC, several Universities and industry that will place the UK at the forefront of research into dementia treatment and prevention. The £50 million investment will bring together over 22 different British cohort studies to allow researchers to compare and compile evidence. The information covers over 2 million people over the age of 50 from these cohorts who can be followed over time and will enable researchers to conduct large, high-impact studies into cognitive ageing and dementia. It will form the world’s largest group of dementia research participants.

Alzheimer’s Society and other charities play an important role making the platform a success and some of AS funded research, such as the PREVENT study is already part of the Dementias Platform and in future years the Society will be considering how to add further research to this tremendous resource.

THE DRUG DISCOVERY PROGRAMME

Launched in 2011, this is a pioneering and exciting new approach to fund phase III trials and develop better cheaper treatments for AD. It draws on the highly successful approach of drug repositioning and repurposing to identify existing off-patent compounds with the potential to act as disease modifying treatments. This approach has the potential to develop cheaper treatments for dementia that could give people benefits for up to five years longer than present drugs by fast-tracking (initially six) drugs to the point at which they can be clinically tested. The most promising three drugs will then be tested in clinical trials over the next 5-10 years.

In 2014 AS announced a funding partnership with **Alzheimer’s Drug Discovery Foundation** (USA) to use our funding to leverage additional funding from other organisations. By pooling together funding in this way we are increasing the amount of collaboration and resources available. Although AS are joint funders, the ADDF have led the grants administration and review processes, originally by-passing RNV involvement at

this early stage, although this has since been rectified. However four new drug discovery trials were announced which will take place in the UK with input from RNVs.

These are:

- Following demonstration that the diabetes treatment **Liraglutide**, a GLP-1 agonist, decreases AD pathology and improves cognitive function in pre-clinical studies, this led AS to fund a clinical study (ELAD) to investigate if these benefits are also seen in patients with early AD. The original pre-clinical study was also funded by the Society, awarded to Dr Christian Holscher, Ulster U. (2010).
- The **Tadalafil trial**, approved for funding in 2014 and based at St. George's, London University (Dr Atticus Hainsworth) will explore whether tadalafil (a Viagra-like drug) which works by dilating blood vessels, could help prevent vascular dementia by increasing blood flow to the brain.
- The third grant is to Prof Giovanna Malluci, University of Leicester, who will be testing **three drugs** to see if they have potential as dementia treatments. The repurposed drugs target the unfolded protein response to prevent neurodegeneration in dementia
- In 2015 a grant was awarded to Prof Joanna Wardlaw, Edinburgh University to investigate whether finding a drug to treat small vessel disease will help in the treatment or prevention of some forms of vascular dementia.

EVOLUTION OF THE RESEARCH NETWORK 2013-2015

This two-year plan was launched in 2013 with the aim of ensuring that the Research Network was equipped to meet the demands of a growing research grants programme, keep the Research Network at the heart of the research programme by improving existing involvement activities, improve the volunteering experience by increasing support and resources available to it (including the appointment of a Research Engagement Officer to support Matt Murray in running the Research Network) and to increase the amount of opportunities for Research Network volunteers to support the Society in areas other than research. Examples of improvements made as a result of the plan include linking Research Network volunteers to the Volunteer Engagement Network events, creating the Grant Advisory Panels, bringing a Research Network volunteer onto the Research Strategy Council, improving the Research Network Area Coordinators meetings, review and improve monitoring and volunteer training and introduce a Proposal Development offer for researchers to access PPI before submitting their applications.

POLITICAL INFLUENCES AT WORK

Alzheimer's Society was involved from the very beginning in 2007 in developing a new **National Dementia Strategy for England**.

The **Five-year National Dementia Strategy** was launched in 2008. Priority No. 16 was Research into dementia when Department of Health would work with the Medical Research Council (MRC) and other funders to develop a plan for dementia research in the UK.

Hosted by MRC, the first **UK Dementia Research summit (2009)** came out of responses to the Draft National Dementia Strategy to inform the final **National Dementia Research Strategy** and brought together major research funders to establish an agreed way forward for UK dementia research. The (Labour) Minister of Health, Phil Hope, spoke and the event was attended by five network members, one of whom spoke.

There were major policy developments in research between 2011 and 2012. The government continued to show its commitment to improving the lives of people with dementia and investment in research has been a key feature in subsequent government policies.

2009-2011 Ministerial Advisory Group on Dementia Research (MAGDR) was chaired by Phil Hope (Labour Minister) until the 2010 General election when the Chairmanship was taken over by Paul Burstow (Lib Dem).

Professor Sube Banerjee was Co-leader of the Strategy Group.



Barbara Woodward-Carlton, Sue Boex and Angela Clayton-Turner are three of many Research Network volunteers to visit Number 10 Downing Street.

2010 Five subgroups of MAGDR were established to take forward work begun at the 2009 Ministerial Summit. Groups included RNVs with the brief to report back by 2011.

- Priority research topics in care, cause and cure
- Raising public awareness
- Securing available funding and support
- Better ways of working
- 'Translation' of research findings into better treatment and care.

2011 National Institute for Health Research Dementia themed Call was launched seeking proposals for research into the cure, cause, care and prevention of dementia. In response to this AS hosted a workshop in May 2011 to bring together RNVs with the best researchers with the aim of driving forward and supporting high quality research applications in priority areas. In total the Society supported 40 research applications submitted to the NIHR, playing a key role in making the most of this important opportunity to increase national investment in research. (see more detailed account on page 33).

Building on published research by Prof Sube Banerjee to lobby against the use of antipsychotics the Research Network played a pivotal role in setting up an **All-Party**

Parliamentary Group on Dementia (APPG), a group of influential MPs and Peers interested in dementia issues that meets regularly.

Members of the Network appeared before the group and submitted evidence on a number of issues. The earliest was on the over-prescribing of antipsychotics and subsequently the Group went on to investigate the level and quality of dementia care skills and training of social care staff. AS submitted evidence to the inquiry on (over)use of antipsychotics and in 2013 hosted a research discussion as part of the UK's contribution to the G8 summit.

June 2011 Route Map for Dementia Research launched outlining new commitments, (derived from the MAGDR sub-groups), from the government to prioritise dementia research. The commitments included increased investments in the NIHR through £20million of new biomedical research units, creating a national register of patients to aid trial recruitment (leading to the development of Join Dementia Research).

In **March 2012 the Prime Minister's Challenge on Dementia was** launched by David Cameron building on the MAGDR findings. It underpinned the PM's personal commitment to improving the lives of people affected by dementia. The challenge was divided into three work streams: driving improvements in health and care: creating dementia friendly communities: and better research. The Challenge aimed to push further and faster to deliver a major improvement in dementia care and research in England by 2015 to ensure people with dementia, their families and carers get the services and support they need.

The PM's Challenge commits to more than doubling government spending on research from 26.6m in 2009/10 to an estimated £66.3m in 2014/5. This will directly increase the budgets of bodies that award research grants such as the MRC, and the Economic and Social Research Council (ESRC) for research into dementia at institutions across the UK.

Money would be made available to fund a specific aspect of the UK BioBank, a large, long-term project that aims to understand what happens as we age. The MRC will fund the brain scanning of a subset of the participants, so that additional information with regard to brain structures and the development of dementia can be collected and analysed alongside the information that will be collected from all participants. The government is also keen to encourage people with dementia to participate in research and offering people the opportunity to participate in research will become one of the conditions for accreditation of memory services.



U Hla Htay meeting Prime Minister David Cameron in 2014

In December 2013 London hosted the G8 summit on dementia research where world leaders committed to finding a disease modifying treatment or cure for dementia by 2025. To support this ambition AS is significantly increasing its commitment to dementia research, pledging to spend at least £100 million over the next decade. Research Network volunteers were present at the summit and associated events, also contributing to media work. Prior to the summit itself a discussion group was hosted by the Department of Health where Research Network volunteers contributed items and ideas which were taken forward in the agenda.

G7 Legacy Events have been taking place following the G8 summit to build on the momentum which had been achieved. Alzheimer's Society staff have been present at all of these events, including one in 2014 which focused on research.

World Dementia Council This was set up in 2014 to support the delivery of commitments made by the G8/G7 events and is chaired by Dr Dennis Gillings, who was also named the World Dementia Envoy. Originally there were no places on the council for people with dementia but following an address made by a Research Network volunteer, Hilary Doxford to the group she was offered a place to represent people living with the condition in 2015.

FUTURE PLANS

Matt Murray (Research Engagement Manager, 2010-present) outlines some of the ways in which the Research Network will develop in the future:



In 2014 Alzheimer's Society committed to investing at least £100million in research over the following 10 years, marking a significant increase in its investment. This is undoubtedly in part due to the successful lobbying of Research Network volunteers over the past 15 years to increase the Society's expenditure in research.

A fundamental part of delivering this increased investment in research will be the involvement of the Research Network at the heart of all of this work. As new opportunities open up to fund research in bigger and more creative ways, the Society will continue to invent, innovative and influence the successful involvement of people affected by dementia in research at all stages of the research process.

In some cases this will involve re-formulating how the Research Network supports research. For example, new national and international funding collaborations mean that the involvement of the Research Network might be in conjunction with other involvement groups, or require reviewing different styles of applications. Wherever possible the Society will push for the maximum level of involvement which is appropriate for the activity and will seek to complement rather than duplicate any involvement activities which exist.

The Evolution of the Research Network two year plan began a cycle of refinement and improvement of how the Research Network runs and there will undoubtedly need to be more improvements made over the coming decade to effectively support the £100million investments that will be made. To effectively embed the involvement of people affected by dementia throughout the research programme we must achieve these outcomes:

1. Research funded by the Society better addresses the priorities of people affected by dementia
2. Research findings are effectively translated into tangible benefits for people affected by dementia
3. Dementia Research in the UK is strengthened by access to PPI throughout the research process
4. The impact of involving people affected by dementia in research is measured and communicated
5. Alzheimer's Society remains a leader and innovator in PPI
6. Alzheimer's Society's strategic mission is achieved with the support of the Research Network

The work that the staff team and Research Network volunteers will do over the coming years will fit within these themes. Examples of planned activity in the upcoming years include the development of robust impact measurements, creation of sub-groups which will allow Research Network volunteers to better personalise their involvement and reviewing the role that volunteers play in biomedical research.

PART 3 QUOTES

FROM RESEARCH NETWORK VOLUNTEERS:-

Research Network volunteers are of all ages and from all walks of life, the following comments range from a university student to people in their eighties....

Anne. "It has been a real pleasure to make a contribution.... Watching the charity grow and expand has given me hope for more research and eventually a cure"

Gillian. *"I have been privileged to enjoy being involved in a range of activities, working with researchers, other lay and professional volunteers as well as Society staff.....I really feel that being able to take part in something constructive in the face of such a cruel and destructive disease has helped me personally as well as possibly benefiting others"*

Angela. Ted, my husband, was probably the first person with dementia to join the network. He came to the early conferences and joined me in monitoring the ginkgo biloba project. I was told that his being there reminded the scientists what it was about... Joining QRD has been a catalyst to a rich and rewarding life".

Cathy. *"Joining the Network I found an amazing group of like-minded people, all with a single commitment... most importantly we're treated seriously by the Society and seen as an integral part of the research process... One particular memory is being part of an interview panel for post- doctoral fellows alongside some extremely eminent professors, yet we 3 Network members were treated with equal importance and our views carried real weight when it came to making choices"*

John. "I joined the AS Research Community in 2008 after reaching out to the Society for a way to help... The QRD network proved a great introduction to the Society and in particular the opportunity to meet and talk with both former carers and the scientists working away, gave a great balance to both angles to the issue... From the QRD starting point, I have been lucky enough to assist the Society in a range of aspects, from the campaigning side and meeting my local MP in the Houses of Parliament, to evenings in the House of Lords, through to arranging meetings for the fundraising team with key contacts from my 'day-job' in the financial services community... I have found the whole experience interesting, at times challenging, and always very rewarding".

Lynne. *"The QRD network has been inspirationally innovative from the outset. All patients and carers know that only implemented change and advancement benefit patients. The group has never been tokenistic but has always been able to influence the strategy and delivery and act as ambassadors for patients. It has been a privilege working with some of the world experts in scientific research."*

"Carers can easily become isolated but being part of such a group constantly reinforces the tireless efforts being made by professionals and can significantly assist psychologically. At the same time carers are the experts in care and can particularly influence the actual research in this area. This has been facilitated by some exceptional Alzheimer's Society staff who have had equally strong communication skills with scientists and the public alike. Major changes for the benefit of patients have been enabled by having the scientific professionals working together with the public."

Jeanette "It has been interesting as a new member to attend a meeting and listening to researchers. Looking through all the funding applications has been most informative and makes reading newspaper articles, TV programmes more interesting."

Brigid *"Attending a discussion on screening for dementia and whether it would help or hinder sufferers made me realize how little, still, most of us know about dementia until it affects somebody we love."*

Marshall "Like all of us who have lost loved ones to AD, I was determined that those who were still battling with the disease should have a far better experience than those who have gone before.... Monitoring ongoing research funded by the Society has helped me maintain my belief in the progress being made..."

Mary *"Even for those of us without the remotest understanding of what is being done in the lab, being a project monitor can give a real sense of participation. Taking part in a visit to an early-stage researcher can show them that AS is not just another possible source of funding and their work a possible route to publication of research papers, but out there are real people to whom the potential of their research matters deeply and who are willing them to succeed"*

The first event I attended on joining the RN was the two-day research conference. Being updated on research was interesting but by far the most memorable impression was from that evening's conference dinner. Round the table a group of people who had never met before aided by very adequate supplies of wine and an evening away from their responsibilities, felt able to share sometimes very intimate feelings about the stresses and rewards of caring. They all knew next evening would see them back on the treadmill, but just for the moment there was an overwhelming sense of empathy and mutual support"

Htay "Minnie and I joined AS in 1997 to learn what medicines would be needed a year after Minnie was diagnosed with early onset AD type of dementia.... When QRD was formed we both joined and attended AS workshops.... Then Minnie dropped out after 2 years. I continued..... I joined Cochrane Consumer Group in 2001, learned Critical Appraisal Skills for Cochrane Reviews then became a CCNet representative at the International Association of patients' organizations (IAPO) in 2006, presented research findings at Involve Conferences, contributed to PPI (Patient and Public Information Packs), joined MRC Public Panel in 2005, gave regular talks at Dementia UK training courses since 2001 and Mental Health Nurse Training run by Admiral Nurses.... Through my MSc studies at UCL I am involved in various dementia studies (iCST, SHIELD, START (NIHR) and participate at research programmes at the Mental Health Foundation..... poster presentation at Patients for patients' Safety (PFPS) and EMA (European Medicines Agency). Without Minnie's dementia caring and above all QRD members support throughout the years I would not have such achievements or involvement in dementia campaign today. It is due to our involvement at the QRD from the beginning".

Sylvia *"Although my father is no longer living, I want to 'give back' something to Alzheimer's Society for the support I received for so many years. Through my experience of being a carer I do have a wealth of first-hand information to share with researchers."*

Ted "I joined the Society in 2000 soon after my wife had moved into full time residential care and I was looking for a new direction. In 2001 I joined QRD and took on the role of E. Midlands Regional Coordinator working with the inspirational Dr Richard Harvey. In 2010 I remarried and retired from my active involvement with QRD... Although I come from an

academic background in engineering, research in biomedical sciences presented a new and stimulating experience. The discussion with the scientists and other lay people concerning the philosophy, practicality and constraints of the research programme were very rewarding whether they were high value large-scale projects like the Brain Bank or relative small PhD proposals.

Apart from the assessment of research proposals and the monitoring of projects two other areas of activity opened up. The first meant preparing and delivering presentations on the Society's research programme to a wide range of outside bodies from scientific symposia to local AS groups and fundraising teams, to charity organisations like Rotary International and Lions and to Nursing Home staff. In the second area I found my QRD work opened doors in the local NHS Mental Health Trust where I joined committees concerned with care of those with dementia. I was also involved with ward inspections and in working to improve procedures and communications between staff, patients and carers."

I found the range of activities fascinating and the interaction with people from so many different backgrounds very stimulating. It rejuvenated me and set me off in the new direction I sought."

Victoria *"Excuse me but do you know if anyone else from Wales is here? Instantly three pairs of hands grasped me tightly and before you could say Dementia I was appointed the Regional Coordinator for QRD in Wales. I should have known better than to identify myself for earlier when I had contacted to Dr Harvey to ask what were the qualities required for QRD members, back came the reply by return 'Thank you' it said, 'for joining QRD'."*

And so began over ten years of the most rewarding voluntary work. I scored applications for funding, listed priorities for research, sat on panels choosing which applications to support and monitored projects' progress. I attended Regional Coordinators' meetings, represented the Society at external dementia meetings. I spoke to AS branches, Mother's Union meetings and the WI, etc. disseminating the work of QRD and the wide field of dementia research."

"It was during the latter that I kept meeting people who longed to join QRD but were neither a dementia sufferer nor a past or present carer. It seemed foolish to let all that empathy, enthusiasm and commitment drain away. It was disappointing for the applicant and frustrating for the network. And so the idea of a group of Friends to support the network became a reality. Each Friend receives a copy of the monthly research magazine informing them of the latest research into cure and care in dementia and all that goes on in that world".

"Few initially saw that as being a major movement. They were wrong. 1600 of you are right. Use your voice"

Elizabeth *"We shared a common passion – to use our experience of dementia in furtherance of research. On reflection it feels that I have been on a roller coaster journey since joining this fantastic research group. Reviewing a scientific project with my human biology 'O' level standard knowledge back in the early days felt to me like Latin or Greek! I remember Dr Richard Harvey assuring me that my opinion really was valued when I attended a grant panel in London in 2000. His advice was to remember the reason for being invited to become a lay volunteer member – my practical 'hands on' day to day experience of caring for someone suffering with dementia. This is what mattered and still does. My enthusiasm for the cause of research if anything is stronger than ever and I have*

huge admiration for the scientists who are involved in the many innovative projects taking battle forward against this dreadful disease

Being able to take part in new research helped me to cope with the stress of knowing that there was at that time little understanding of the causes of the disease....”

Barbara *“As AS monitors we were deeply moved by the case studies”.*

“It is a joy to be involved in a group such as RNVs and to know that finding the cause... and finding a cure or curers is nearer... and that for a significant number of people with dementia good quality care is already a reality”

“I am constantly impressed by the quality of work done by researchers, by their dedication and passion to make life better for those with dementia and their carers: likewise by the knowledge, passion and commitment of Research Network volunteers”

“I just want to help in any way I can”

Anon *“The chance to highlight... the special problems of deaf people and problems elderly couples have.... The dilemmas facing carers and the need for there to be available funding”.*

Molly “I loved it. I loved the people, we became friends. It was all so interesting. The insights gained were complex but it was all so good”.

“I’ve met lots of wonderful people many of whom I now regard as good friends”.

Vivian “The AGM’s have been a vital date in my yearly calendar... when I look back I conjure up images of wonderful hospitality, shared experiences and the getting of knowledge and understanding.... most of all the bonds I have formed, the friends I have made, plus the exciting research I have been involved with have been a vital part of my own life experiences. I feel the progress that has been achieved is a lasting legacy”

QUOTES FROM THE RESEARCHERS

Professor Alistair Burns, University of Manchester. “The advent of QRD 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 the research was of direct relevant and help to people with dementia and their carers. From a personal point of view, QRD increased the quality of research proposals that I submitted!

Professor Linda Clare, University of Bangor. *“The involvement (of 3 research volunteers as monitors) was really interesting to get their perspective and they were very helpful to us in various ways... Today we think about PPI as an integral part of all our projects... We benefit from the very well– developed network of RVs and other aspects of the Society’s work. In case we are inclined to take this for granted it’s good to look back and remind ourselves how very innovative QRD was at the outset and what a tremendous impact it has had on involving carers and people with dementia in research.”*

Professor Gill Livingston, UCL. “I’ve found it very helpful to have input into developing proposals, enabling me to add relevant qualitative and quantitative questions... I think that as well as specific guidance, questions and inspiration, they have shaped our groups’ thinking and become part of what we think about research.”

Professor Steve Gentleman, Imperial College, London quotes on a scientist's experience of sitting on interview Panel:

"If I'm honest I approached my first mixed review panel with a certain degree of scepticism and some trepidation because I didn't know what to expect in terms of group dynamics. Would it be us against them, would we agree on anything? Well, thankfully my fears were unfounded because it soon became clear that the review process benefits a great deal from the two very different perspectives provided by the panel members.

"Problems reduced to the pathological, biochemical or molecular biology level can become rather abstract and, as scientists, we love nothing more than to debate the details to the nth degree. It can therefore be a bit of a shock to the system when somebody on the panel turns round and poses the question: "What has this got to do with AD and how is it likely to affect the lives of patients?" With some projects it is not always easy to see what the immediate benefit of the work is likely to be but this type of question has a wonderful way of focussing the minds of applicants. The members of the panel are realistic enough to realise that progress towards a viable therapy for AD is an incremental process but it is important that this type of reality check is in place.

Personally, after sitting on these panels, I invariably end up going back to the lab with a renewed sense of purpose."

Professor Murna Downs, Head, Bradford Dementia Group, Bradford U.

"The network has been instrumental in helping researchers ensure their areas of focus are both relevant and accessible to people affected by dementia. In developing our research proposal, to develop and test ways to reduce avoidable hospital admissions from care homes, we have worked closely with a Carer Reference Panel comprising 8-10 family carers from the Volunteer Network. All have been able to bring their experience to bear on agreeing the focus and approach of the study."

Professor Robert Howard, Institute of Psychiatry, London. On the topic of monitors. "Our study was a simple one in principle, but when we first met our monitors we had not decided exactly what data we needed to collect and how we were going to do it. I remember being struck by how pleasant and thoughtful they seemed. As the meetings progressed it became clear that our monitors had some very positive things to add which, if we listened to their experiences as carers and observers of life in care homes, could add an extra perspective to our study measures. Our monitors became participating members of the research group and influenced the choice of instruments that we finally adopted in the study. They helped us to think of extra things that we should look at and measure

They weren't really 'monitors' at all – instead they behaved like partners in a process whose successful completion we all felt to be a common cause. So when a colleague asks me about my experience with consumer monitors, I know what my response will be: 'Maybe I was very lucky with the three I was allocated, but they are great to work with and can add a very real extra dimension of thought and experience to what you do.'

Professor Sube Banerjee, Lead Investigator HTA-SADD trial (funded by NIHR). "The Research Network volunteer was critical to our ensuring that the voice, experience and preferences of people with dementia and carers were effectively incorporated into the trial at all stages from the design, to its conduct and analysis. I am very pleased that she is a co-author on our Lancet paper and she and the Society richly deserve this".

Professor Sergio Della Sala, Edinburgh University. *“The monitors on our project were able to give us a unique insight into the sort of difficulties people with dementia experience and provide constructive feedback to our research plans, enabling us to tailor our research appropriately”.*

Dr Atticus Hainsworth, St. George’s, London University. *“As a laboratory-based neuroscientist I have found the input provided by my three Lay monitors extremely helpful and motivating. Their involvement gives a direct contact with dementia and how it touches peoples’ lives. I know that my colleagues and the team share this view”.*

Professor Nick Fox, UCL remembers well the early discussion with RH about the setting up of QRD.

“At the time it was quite revolutionary, the idea of involving patients and carers in the assessment and monitoring of research projects. I think it was a visionary experiment which has really proved to be very successful forming a link between researchers who might be distant from the problems that they are committed to solving and the patients and carers who know all too well what those problems are – often rewarding for both parties”.

“It is an exciting time for dementia research. Finally dementia research is moving up the political agenda and with increasing awareness from the public, I think the focus will be sustained. Recent advances offer real hope of progress. There are however some formidable challenges, from improving the quality of care to finding treatments – all of which will need a great effort in basic and translational research. I think the AS, together with the RVN, will make a major contribution to these efforts”.

Anon: *“It was extremely valuable getting input on my research from the Research Network volunteers and they were a big motivation to be around”.*

Anon: *“I found the poster session very useful because it’s a great opportunity for researchers to meet carers/volunteers and talk about their experiences”*

QUOTES FROM STAFF AND OTHERS:

Bec Hanley, TwoCan Associates *“Since its inception many organisations in the voluntary and statutory sector have learned from its experience, and many researchers and research organisations have benefited from the involvement of QRD members. QRD continues to innovate in the way it promotes effective partnerships between people affected by AD and the research Community. I’m in no doubt that the quality and quantity of dementia research has improved as a result of the development of QRD”*

Phil Taverner, Asst. Director of the NIHR Evaluation, Trials and Studies Coordinating Centre *“The NIHR themed call on dementia in 2011 led to a significant new investment in dementia research. The partnership formed with Alzheimer’s Society was a notable feature of the call, they were able to provide crucial help to applicants in the form of workshops which brought together researchers and people with direct experience of dementia. The result was research that is grounded and relevant to the experiences of people living with dementia”.*

Harry Cayton, CEO Alzheimer’s Society 1992 - 2003 *“I hope QRD transformed research in two ways:- to make it more relevant and to improve its quality but I also hope it opened up the caring community to the values of research and science and the scientific community to the wisdom of carers and consumers”.*

PART 4: **FACTS, FIGURES, FACES AND FOOTPRINTS**

THE CHANGING RESEARCH PROGRAMME

GRANT TYPES IN 1999

- **Research Fellowships**

Building on the success of Alzheimer's Disease Society's Research Fellowship programme, QRD will continue to offer personal fellowships to talented junior researchers. Awards will be made by competitive, peer-reviewed application with one deadline for applications each year.

- **Innovation Grants**

The objective of the innovation grants scheme is to provide small amounts of funding to high-risk, potentially high-gain projects. Funding will be primarily for basic science research. Applicants will need to demonstrate a good chance of attracting other major grant funding if the project supported by the innovation grant is successful. Applications may be made at any time, and will undergo fast-track review if they fulfil the objectives of the programme by being truly innovative.

- **Partnership Grants**

The partnership grants scheme will offer funding for research projects in all areas of research into cause, cure and care in dementia. There will be three deadlines per year for applications, which will undergo a rigorous peer-review and selection process.

- **Commissioned Research Contracts**

-

The QRD Programme will seek to commission research to answer specific questions, and deliver high quality evidence. Funding and commissions under this programme will come both internally from the Alzheimer's Disease Society, and from external organisations.

KEY CHANGES 1999-2015

PhD STUDENTSHIP GRANTS

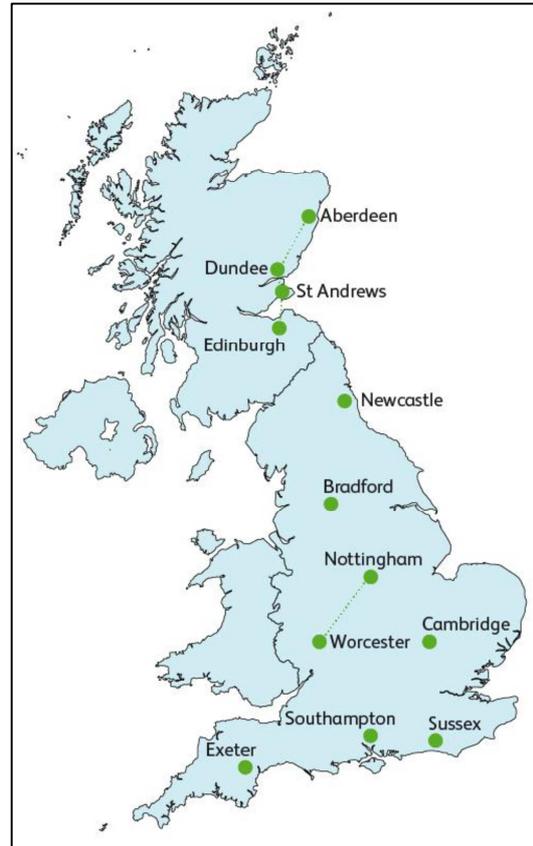
"Alzheimer's Society first began funding PhD students in 2006 through specific grants and sees potential in the PhD students and Fellows. Their enthusiasm and commitment to dementia research is tremendously encouraging ... we are confident they will develop into the top dementia scientists of the future. We continue to look for new ways of providing support to young researchers and committed to increasing the number of funded PhDs."

This led to the **LAUNCH in 2014 of PhD DOCTORAL TRAINING CENTRES** – This is a £5 million commitment to early-career researchers in dementia to create a network of doctoral training centres at universities across the UK to encourage young scientists to study dementia.

At the end of 2014 eight doctoral training centres were announced covering both biomedical and care research, recruiting 53 PhD students from a variety of academic and clinical backgrounds. Over £3.2 million of the investment was provided by AS with an additional £1.6 million awarded through matched commitments from universities.

GRANT TYPES in 2015

- **Project grants** are the biggest grants awarded and can be up to £400,000. Established researchers can apply for funding for projects of up to three years that target a research priority as published on the website.
- **PhD grants** of £85,000 fund doctoral students in successful dementia research groups. These grants aim to attract young scientists into dementia research at an early stage of their career.
- **Junior Fellowship grants** are a maximum of £225,000 for up to 3 years (full time) or 4 years (part-time), and are awarded to post-doctoral researchers who have shown exceptional promise at the start of their research career. These grants may include salary, materials and consumables and the appointment of part-time technicians or administrative support.
- **Senior Fellowships** of up to £400,000 for a post-doctoral researcher who wishes to build on a number of successful dementia research projects to become an independent investigator after completion of the grant. Senior fellows will have an established track record in an area of dementia research. The higher budget reflects the career progression, complexity and size of the project.
- **Clinician and Healthcare Professionals Training Fellowships** of up to £225,000 to support practicing professionals working in dementia health and care services to undertake study towards a higher research degree (usually a PhD) and who wish to develop a dual career that combines research and practice.
- **Dissemination grants** are up to £30,000 and are awarded to researchers who wish to communicate findings from a piece of dementia research, not necessarily funded by Alzheimer's Society, in specific ways beyond that of scientific papers.
- **Undergraduate bursaries**



Map showing the location of each of the 8 new Doctoral Training Centres funded in 2015

KEY PROJECTS FUNDED SINCE 1999

CAUSE

“Amyloid plaques and tau tangles are part of the underlying changes that occur in the brain to cause Alzheimer’s disease and other dementias and is critical to the development of new drugs and therapies. By 2012, 39% of our total research investment had been dedicated to understanding the causes of dementia.”

Furthering our understanding of the role that amyloid plays in the development of Alzheimer’s Disease

Alzheimer’s Society funding over the past 25 years has played an important role in developing the understanding of the role that amyloid plays in causing Alzheimer’s Disease. Funding dates back to a PhD Studentship awarded to John Hardy. The student on this grant co-authored an important paper published in the journal *Nature* in 1991 which reported that a mutation of the beta-amyloid precursor protein gene was found to cosegregate with familial Alzheimer’s disease in a single family. Subsequent work completed by Dr Ritchie Williamson, a research fellow at King’s College London examined the mechanisms involved in cell death caused by amyloid b-peptide and hyperphosphorylated tau.

Dr Amrit Mudher, Southampton University has been funded by AS for the last nine years starting with a fellowship grant in 2005 and subsequent project grants to continue her work on the tau protein. During her research she has developed a fruit fly model for investigating the role of the tau protein in AD and has used it to show how tau acts during the disease. In her most recent research Dr Mudher tested the effect of Lithium a known drug, on tau. She has found that treatment with Lithium not only protects cells from the effects of tau but it also causes the abnormal tau to accumulate in rounded clumps which are then less likely to cause damage to the cell.



Other projects around **untangling tau** by research Fellows include: Hanger (1998), Lovestone (1999), Noble (2005), Williamson (2002)

DIAGNOSIS

BIOMARKERS:

Research has established that Alzheimer’s and dementia-related pathologies develop many years before emergence of symptoms, requiring a need to identify biomarkers sensitive enough to predict at-risk individuals, and enable earlier diagnosis and a clearer differentiation between subtypes of dementia. This is particularly critical in the identification of suitable participants for clinical trials. Priority areas include development of neuropsychiatric tests, neuroimaging techniques and refinement of biomarkers in cerebral-spinal fluid and blood.

IMAGING TECHNIQUES

MRI scans play a vital role in diagnosing AD. Professor Nick Fox who was an AS Research fellow between 1993 and 1997 developed the now standard imaging technique used in diagnosis of AD and drug trials internationally, using MRI scans.

Dr Jonathan Schott continued this important work as an AS funded research fellow in Professor's Fox's group at the Institute of Neurology in London resulting in publications in Lancet (1999) and Neurology (2005).

BIOMARKERS

Professor Simon Lovestone's laboratory at King's College London:

Dr Madhav Thambisetty was a past research fellow of AS in this laboratory. His fellowship was devoted to a search for a blood biomarker of AD – a protein that could be detected in blood and that could be used to identify when someone had the disease. PhD's at King's College London continue the work on biomarkers e.g. Sarah Westwood (Pictured), AS is particularly proud to note the progress of this line of work which began so successfully as a result of AS funding.



AS is particularly proud to note the progress of this line of work which began so successfully as a result of AS funding.

CURE

As of 2015 there are still only two main types of medication that are licensed to treat AD – cholinesterase inhibitors e.g. Aricept, Exelon and Reminyl, and one NMDA receptor antagonist Ebixa. These slow the progression of symptoms in some people with AD. There are no drug treatments available that target the underlying disease pathology. Currently there are very limited treatment options for other forms of dementia.

Inflammation project at Southampton University.

Professor Clive Holmes (Pictured with his monitors) ran a project (2003-2006) that discovered that high levels of the inflammatory molecule TNF-alpha is a predictor of increased cognitive decline in patients with dementia. The work attracted industrial investment for a phase II clinical trial of a TNF-alpha inhibitor Etanercept in patients with AD and encouraged many other projects looking at the role of inflammation.



Including research funded by AS, published in Neurology found that people who develop an infection need to be treated as soon as possible to prevent it worsening their dementia. There was much publicity in press around this finding. Project grant: Chronic stress as a risk factor for the development of AD.

Post-operative decline- Dr Daqing Ma (Imperial College London) was funded between 2010 and 2013 to investigate ways to prevent the onset of Alzheimer's disease induced by surgery. Dr Ma found that surgery-induced cellular stress could hasten cognitive decline but that short-term treatment with drugs used to lower blood cholesterol or celastrol (found in Chinese herbal remedies) appeared to prevent these changes in mice. More research is

now needed to understand why these particular drugs had these effects and how they might be used safely to prevent the development of post-operative cognitive decline in humans.

Gingko-biloba trial (Warner 2008) proved that this is not effective for patients with mild to moderate dementia.

Linda Clare (Bangor U) A RCT to illustrate the benefits of **cognitive rehabilitation** to help those in the early stages of dementia to maintain quality of life and potentially delay the need for further specialist care.

Drug Discovery Programme to accelerate development of drug repositioning to identify existing off-patent compounds with the potential to act as disease-modifying treatments by funding Phase III clinical trials with the aim of developing cheaper, more effective treatments that could be available in less than 10 years..... as against the 20 years and £billions that it takes to develop a totally new drug.
e.g. Liraglutide, tadalafil trials underway, with more starting in 2015.

Stem Cells. Dr Virginie Sottile, Nottingham University. An AS Research fellow, later supervising a PhD studentship. The student has now gone on to get post-doctoral funding from the Society at Nottingham. "In understanding how stem cells are influenced by their environment, we can gain insight into how to protect or stimulate them in case of damage in order to promote repair. We hope our research will contribute to the design of new treatments to counteract the effects of disease or damage to the brain".

CARE

A 10-month training programme (FITS) Focussed Intervention Training and Support trial for care home staff reduces the use of antipsychotic drugs in residents with dementia. (Howard 2006).

Jane Fossey was awarded the first Society Dissemination Grant to produce a Manual. Professor Dawn Brooker (Worcester University) was funded by AS to implement the findings of the original FITS project ("FITS into Practice") to roll it out into 67 care homes.
FITS was the first project to have its evidence-based findings implemented and funded by AS.

Prof Murna Downs was funded between 1999 and 2003 to improve the **response of primary care practitioners to people with dementia** by trialling different educational interventions (a workshop, a CD and specialised computer software). This was tested with nurses, GPs and care workers against a similar control group which received no intervention. Prof Downs found that the workshop and software interventions were more effective than the CD and that it was feasible to increase the knowledge of dementia for all people responsible for diagnosis and care of people with dementia.

Prof Murna Downs, Bradford University- Better Healthcare in Residents in Care Homes. This followed on from a pilot to Avoid Unnecessary Hospital Admissions from Care Homes and was funded by NIHR. Research Network volunteers have been very **actively involved in the development and management of this research** which will begin in 2015.

Prof Gill Livingston START Dissemination Grant (2014- 15). This funding is to train clinical psychologists to train graduate psychologists in the START manual, which is an **intervention designed to reduce anxiety and depression in carers** of people with dementia.

A study jointly funded by AS and BUPA foundation led by Dr Elizabeth Sampson UCL, looked at pain in acute hospital settings (BEPaid). Research Network volunteers played a **crucial role in ensuring that this study received ethical approval** as the original ethics application was rejected due to concerns over the consent process, which was eventually refined through involvement of the monitors.

Prof Linda Clare- cognitive rehabilitation- GREAT. Research funded by Alzheimer's Society at University of Bangor showed that **goal-based cognitive behavioural therapy** can potentially have cognitive benefits aside from improving quality of life. The ongoing involvement of Research Network volunteers has resulted in Prof Clare receiving follow-up funding from the NIHR for a larger trial called GREAT.

PREVENTION

Systematic Reviews: Prof Carol Brayne. To explore the best way to maximise epidemiological work and utilise innovative technology to build knowledge on how dementia might one day be prevented.

Reducing the Risk: In partnership with the BBC AS convened an expert panel to review the evidence for lifestyle factors in reducing the risk of dementia, highlighting a number of areas.

PREVENT: Prof Craig Ritchie was funded between 2013 and 2016 to better understand the factors in mid-life that increase the risk of developing dementia. This exciting project will add crucial knowledge to a school of thought that the pathology of dementia starts to develop many years, possible even decades, before dementia is diagnosed. The project will identify groups at the highest risk of developing dementia (in their 40s and 50s) by identifying which factors are present that increase the risk of dementia

Dementias Platform UK. This will involve large groups of cohort studies inc BioBank and retrospective data across millions of UK population to look at risk factors.

FACES: THE TEAM LEADERS



Dr Richard Harvey, First Director of Research 1999 – 2003 (see Interview In Part 1)

Dr Susanne Sorensen, Head of Research 2003- 2011 (see Susanne's Interview In Part 1.)



In 2003 when Susanne Sorensen was appointed **Head of Research** a small office, more a cupboard really, was found for her in Gordon House next to the library.

Jean Harding was her delightful part-time assistant with responsibility for the consumer network. Eventually they were allocated a corner in the main office.



Professor Clive Ballard, Director of Research 2003 – 2012

Seconded on a part-time basis from King's College London where he leads a research team at the Wolfson Centre for Age-related Diseases . At AS he took responsibility for the overall strategy and was often the public face of the research programme.

Q. What led you to work with AS?

A:“The huge gap between research evidence and changing what happens in real life – the AS has to be the organization to bridge that gap... AS represents ‘The voice of people with dementia’”.

“QRD/RN was probably the biggest surprise (in a really good way). It was and is such a tremendous group of individuals and the drive and enthusiasm to take things forward – together with considerable expertise was both inspiring and provided a tremendous platform to achieve influence.”

[My role was two- fold]:-“To increase the impact of research and practice through campaigning, policy and media – I think we were very successful in all of those areas... And an enormous part of that success was the tremendous influence of QRD/RN in all of those areas.”

“As a moderate size funder of research my view was (and still is) that the Society has to be particularly smart to create the best impact from the funding available. My aim was to use my own expertise and that of QRD/RN re the issues that are particularly important for people with dementia and advisors to the Society to create Society-led projects, as well as continuing the usual external funding programme. Again, I think this worked well – QRD/RN advocacy internally was vital in enabling the next generation of the FITS project,

and I think we had notable successes with several high impact systematic reviews which have been extremely influential (e.g. re pain, antipsychotics, drug discovery). I also think the on-line CBT trial will be an extremely important piece of work”.

“I had very little experience of PPI before joining the Society and the development of my thinking re the value and optimal impact of QRD/RN was really an iterative process based on gaining a fuller understand of what could be achieved by such a unique group.”

“I think the appointment of Matt in particular was really important enabling more professional coordination of the group and ensuring proper processes were in place for on-going training and for succession planning... I think he’s done a terrific job... with a lot of support from QRD/RN”.

Q. By the time you left how did you feel about the progress of the Network – its successes and its legacy?

A: I feel very positive about the value of the network – and I think the organization/coordination etc has now become more sustainable. My slight personal concern is that there seems to have been a move away from the campaigning/influence re specific research issues and a move away from supporting projects based on what the Society is uniquely placed to achieve. I personally don’t think this is utilizing the full potential of RN or the uniqueness of the Society and there is a danger with the general increase of funding available that the voice of the Society will be drowned out as one of a number of ‘modest research funders’.”

QRD/RN was vital in enabling the next generation of the FITS project, and I think we had notable successes with several high impact systematic reviews which have been extremely influential (e.g. re pain, antipsychotics, drug discovery).

Q. What did you think were the benefits to researchers and their research projects form involving QRD/RN?

A: “I think it brings researchers closer to people with dementia, and if done well is a really powerful tool to really engage young researchers as dementia researchers. I think as well with the right QRD/RN members assigned to the right projects – the combination of personal knowledge of dementia with other relevant skills has made really important contributions to specific projects.”

“It also makes researchers much more aware of the urgency for dissemination and implementation.”

Q. Any other comments

A: “I have generally positive feelings about the Society, with some regrets over the last 18 months of my role. None of those regrets though were about the RN volunteers who were an inspiration and a joy to work with. I am also very personally grateful for the warmth that I was received with and the support that I was given in my role... I think together we did achieve some really notable things”.



Dr Doug Brown
Director of Research & Development 2013-present

Back in 2013 I met some lead members of the Research Network on day 3 of my time at Alzheimer's Society and was instantly inspired. You may be shocked to hear that this actually wasn't a surprise for me, but during my previous 5 years in the charity sector the Alzheimer's Society Research Network was seen as the gold standard of patient & public involvement in research, so I was expecting to be inspired and wasn't disappointed!

And that inspiration I get has continued to grow. Our Research Network volunteers truly are the beating heart of our research programme. I remain amazed at the amount of time, commitment and expertise each of our volunteers give to our programme from reviewing, to participating in panels to monitoring projects. And in recent times we have now expanded our reach nationally and internationally bringing the voice of people affected by dementia in to numerous high profile initiatives, including the World Dementia Council!

The Research Network volunteers really do have an impact. I have seen many examples of where volunteers have helped make the right decisions about the research we fund and even improving the research that is done. They have also been the real drive behind our unique approach to improving how we can get research into practice. As a leading charity we are not just here to fund research but to also make sure the effective interventions actually become available to those who can most benefit – something our volunteers have been incredibly passionate about! And rightfully so!

As our programme goes from strength to strength I can be confident that we are going to deliver meaningful impact because of the unique partnership we foster between Research Network volunteers, researchers and practitioners. This really is special and something we will absolutely be committed to going forwards – how can we not?! Working with the Research Network is one of the biggest highlights of my job and I know the wider team feel the same. We really wouldn't be able to do what we do without them, and we will be eternally grateful for their commitment.

**FACES:
THE RESEARCH OFFICE TEAM OVER THE YEARS**

Ian Cuthbert and **Moira Young** assisted Dr Richard Harvey, based Queen's Square
Jean Harding was Susanne's part-time assistant, 2004 – 2007
David Bugler followed Jean as QRD Liaison Officer, 2007 - 2009
Dr Ayesha Khan, Scientific Liaison Officer, 2007 - 2009
Nick Dingwall, QRD Liaison Officer, 2009
Brett Kerrigan, QRD Liaison Officer then Executive Administrative Officer 2009-2010



Moira Young, Jean Harding & Brett Kerrigan

Dr Anne Corbett, Research Communications Officer, 2009 - 2010 then Research Communications Manager 2010-2012. Edited Newsletter.
Dr Anne Hale, Head of Public Health Research 2009 – 2010



Ayesha Khan & Ann Hale

Dr James Pickett, Research Grants Officer, 2009 - 2012. Senior Research Manager 2012-2013. Head of Research 2013 - present
Matt Murray, Executive Administrator of RN 2010 – 2011; RN Volunteer Coordinator 2011 – 2013; Research Engagement Manager 2013 - present
Alistair Scott, Research administrator and the UKARF Executive Administrative Officer 2010 - present
Dr Jerome Boyd-Kirkup, Research Communications Officer 2010 - 2011 (edited Newsletter 2010 -11)
Jess Smith, Research Communications Officer 2011 - 2015 editing Newsletter
Steve Dewar, Interim Director of Research Management 2011 - 2012
Nicola Hart, Project Support Officer 2011 – 2013
Dr Claire De-May, Research Grants Officer 2012 – present
Keara Allen (néé O'Connor), PA to the Director of Research & Development and department Coordinator 2013 - present
Becky Driscoll, Research Engagement Officer 2013 - 2014
Dr Clare Walton, Research Communications Manager 2013 - present

Katherine Gray, Research Grants Manager 2013 - present
Dr Bethan Hamilton, Research Grants Officer/BDR support officer 2013 - present
Dr Jacqui-Ann Hanley, Research Grants Officer/BDR support officer 2014 - present
Dr Ian Le Guillou, Research Communications Officer, editing Newsletter, 2014 – present
Colin Capper, Head of Research Development & Evaluation 2014 - present
Malayka Rahman, Research Translation Manager 2014 - present
Dr Anna Grinbergs-Saull, Research Engagement Officer 2014 - present
Dr Louise Walker, Research Communications Officer 2015 – present
Jess East, Research Grants Officer 2015 – 2015

The Research Team in 2011

Left to right: Susanne Sorensen, Alistair Scott, James Pickett, Matt Murray, Anne Corbett



Team in 2012

Left to right: Jess Smith, Debora Miranda, Nicola Hart, Matt Murray, Alistair Scott, James Pickett, Steve Dewar, Clive Ballard, Anne Corbett



Team in 2014

Left to right: Doug Brown, Matt Murray, Malayka Rahman, Claire De-May, Katherine Gray, Jacqui Hanley, Clare Walton, Ian Le Guillou, Erika Moisl, Anna Grinbergs-Saull, Jane Tooke, Colin Cooper, Jess Smith



THE MEDICAL & SCIENTIFIC ADVISORY COMMITTEE (1998- 2006)

This group had a membership of 20 individuals selected according to needs for advice from the Society on clinical and research matters. The group was reorganised in 2006 to meet new challenges with a smaller, core group which aligned better with QRD priorities and liaise with the QRD volunteers.

The Research Advisory Committee in 2006

Professor Alistair Burns (Chair), Professor Carol Brayne (Vice chair), Professor Brian Anderton, Professor Esme Moniz-Cook, Professor Nick Fox, Dr Steve Gentleman, Professor John O'Brien, and Professor Murna Downs

The Research Advisory Committee In 2010

Professor Alistair Burns (Chair), Professor Carol Brayne (Deputy-chair), Professor David Allsop, Professor Esme Moniz-Cook, Professor Nick Fox, Professor Steve Gentleman, Professor John O'Brien, and Professor Murna Downs

Quotes from Research Advisory Committee members explaining why they generously give their time to working with AS research programme

"The rate at which progress can be made is determined by the amount of funding available and historically, there has been a gross underinvestment by the government. For this reason, the role of AS in supporting research has been, and remains, highly significant and important." **Professor David Allsop.**

"During the 4 years of my fellowship I learnt from the Society's members and repeatedly felt humbled and impressed by the carers I met. I think the Society can do much to inform (and push) government policy. Involving patients and their families in research is critical to progress." **Professor Nick Fox**

"My AS fellowship effectively launched my independent scientific career and so I have always felt a huge affinity for the Society. When sitting on grant review panels it is always rewarding and educational for me talking to my fellow lay and scientific panel members, each of whom brings a unique perspective to the table" **Professor Steven Gentleman**

"I have always had tremendous respect for the work AS has undertaken, both with regard to service provision and support, raising the profile and de-stigmatising dementia and its vigorous support of research". **Professor John O'Brien**

In 2010 Professor Alistair Burns was appointed National Clinical Director for Dementia. "As Chairman of the Society's RAC executive, Professor Burns plays a crucial role in helping decide the direction and focus of our research. I am delighted that he has been appointed to this important position to lead the future of dementia research in England. His knowledge, expertise and passion for this work makes the future of dementia research all the more promising". **Professor Clive Ballard**

THE RESEARCH STRATEGY COUNCIL, 2014- present

Co-Chairs: Professor Nick Fox and Professor Carol Brayne.

Members: Professor Simon Lovestone, Professor Pat Kehoe, Professor Steve Gentleman, Professor John O'Brien, Professor Esme Moniz-Cook, Professor Murna Downs, Professor Clive Holmes

Grant Advisory Board Co-Chairs: Professor Roy Weller and Professor John Gabbay

Lay member: Cathy Bird (Research Network) appointed in January 2015

GRANT ADVISORY BOARDS 2013-2016

Biomedical Grants Advisory Board:- Chaired by Prof Roy Weller

Chair	Professor Roy Weller	University of Southampton (Emeritus)
1	Professor Stuart Allan	University of Manchester
2	Professor David Attwell	University College London
3	Professor David Brooks	Imperial College London
4	Dr Joanna Collingwood	University of Warwick
5	Dr Trevor Crawford	University of Lancaster
6	Professor Klaus Ebmeier	University of Oxford
7	Professor Frank Gunn-Moore	University of St Andrews
8	Dr Diane Hanger	King's College London
9	Professor Paul Ince	University of Sheffield
10	Professor Kevin Morgan	University of Nottingham
11	Professor Peter Passmore	Queen's University Belfast
12	Professor Bettina Platt	University of Aberdeen
13	Dr John Powell	King's College London
14	Professor Louise Serpell	University of Sussex
15	Professor Maria Grazia Spillantini	University of Cambridge
16	Professor Alan Thomas	Newcastle University
17	Professor Joanna Wardlaw	University of Edinburgh
18	Professor Gordon Wilcock	University of Oxford

Care, Services & Public Health Grants Advisory Board:- Chaired by Prof John Gabbay

Chair	Professor John Gabbay	University of Southampton (Emeritus)
1	Dr Tony Bayer	Cardiff University
2	Professor Linda Clare	University of Exeter
3	Professor Claire Goodman	University of Hertfordshire
4	Professor John Keady	University of Manchester
5	Professor George Kernohan	University of Ulster
6	Dr Iain Lang	University of Exeter
7	Professor Gill Livingston	University College London
8	Professor Jill Manthorpe	King's College London
9	Professor Jan Oyeboode	Bradford University
10	Professor Marcus Richards	University College London
11	Professor Craig Ritchie	University of Edinburgh
12	Dr George Savva	University of East Anglia
13	Dr Denise Taylor	University of Bath
14	Professor Alison Wray	Cardiff University

NB: Each Grant Advisory Board meeting has 4 Grant Advisory Panel members in attendance, who have full voting rights. The Grant Advisory Panels consist of 15 Research Network volunteers, appointed for 3 year terms.

RESEARCH NETWORK NUMBERS & ACTIVITY

In 2001 there were **123** volunteers, rising in the following year to **144**

Membership of the network remained steady as in **2005** there were **150 volunteers**.

In 2007 - 8 there were over **180 volunteers**, reading over 40 detailed research applications and contributing approximately 11,000 hours of volunteering. Friends of Research set up:

In 2008-2009 there were **176 volunteers** who reviewed a total of 44 grant applications. Of these 32 were approved by the Network with nine going on to receive funding and a further ten awaiting scientific review. Friends of Research membership 95.

In 2009-10 there were **173 volunteers** reviewing a total of 64 applications and helped to approve 47 applications for shortlisting with 17 going on to receive funding. Friends of Research membership rose to 244 in April 2010.

In 2010- 2011 there were **210 Research Network volunteers** who provided 4,169 reviews, participated in 800 hours of training, gave over 9,500 hours of their time to support AS research programme and contributed to 30 funding applications from UK researchers to the NIHR dementia themed call as co-applicants or consultants.

RNVs were involved in over 20 different steering groups, board committees or patient representative groups and participated in 800 hours of training to enable them to fully engage in research. Friends of Research membership rose to 425.

In 2011-12 there were **225 volunteers** including 76 new members recruited in 2010. They gave over **9,500 hours of their time** to support AS research programme. Average hours per volunteer – 50! Twenty-three RNVs have become co-applicants on external grant programmes and many more have been actively involved in consultations and focus groups. Friends of Research membership rose to 695.

In 2013-14 there were 52 new volunteers were recruited bringing the total to **262 active volunteers**. They provided 5,216 reviews for grant applications and participated in 170 hours of training. They gave 480 hours of talks raising awareness and vital funds for research and contributed 932 hours of consultation, review and input to 25 Partnership projects. Estimated total **12,803 hours** of support provided by Research Network!! **101 active Monitors** and a further 16 monitors on BDR.

By the end of 2014 there were 264 RN volunteers. Membership of Friends of Research had risen from 1,627 during 2014 to 1,720 in early 2015.

Postscript: It was calculated that those RNVs that sit on the two Grant Advisory Panels have spent 1,456 hours helping select the most important and relevant research to fund.

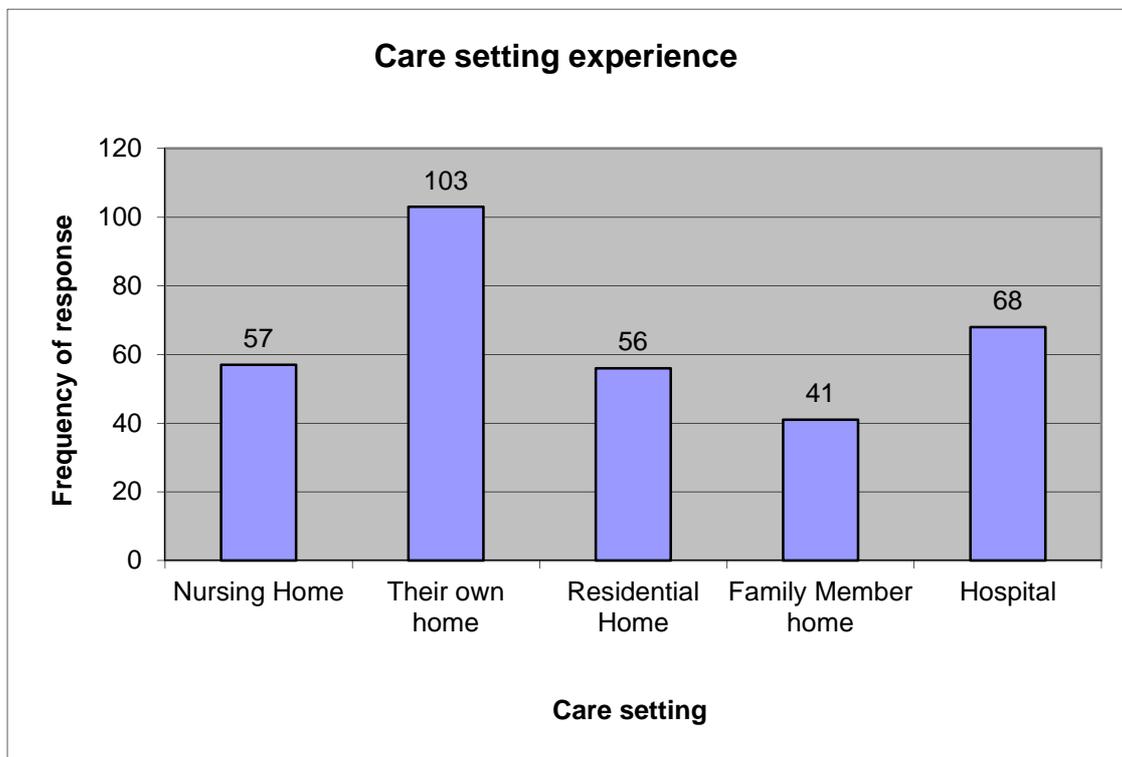
QRD NETWORK SURVEYS

The Survey is carried out at intervals to ascertain information re demographics of the Network, to highlight skills that members have that could be better utilized and to gather honest feedback on what areas need improvement; why some members have been unable to be involved in activities such as Research Days and monitoring, or training and what further training they would like.

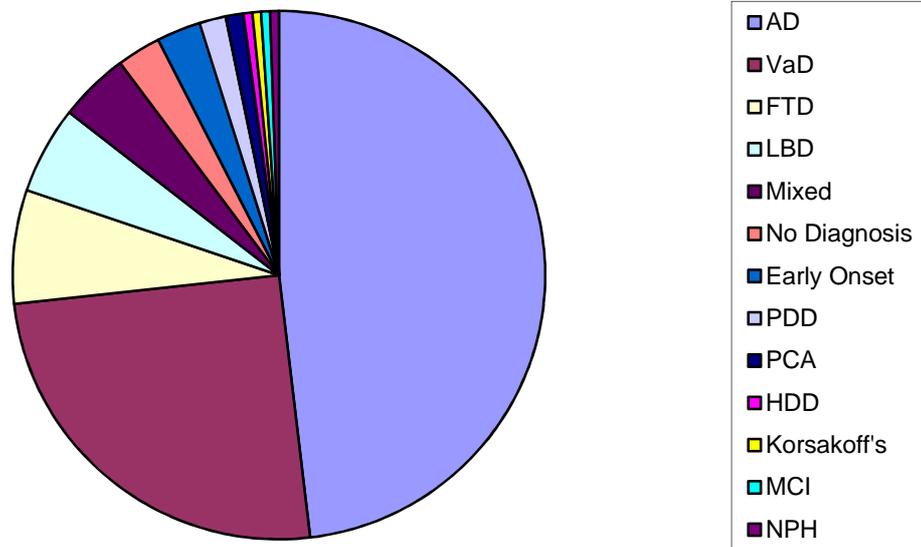
QRD Network Survey 2010 indicated that the majority of members are female, former carers, retired, degree educated and average age 64. However there is a large variety of ages (between 26 and 90), backgrounds and experiences. Members have worked in a wide range of employment sectors and attained different levels of academic achievement but what is perhaps most important is the variety of caring backgrounds that people have.

The 2012 Survey showed that 25% of Research Network volunteers were current carers and that there were only 3% with a diagnosis of dementia. The current % of people with dementia in the Research Network is 4%, showing that there are many more former carers than people with current experience of dementia. Some Network members have multiple experience of caring for someone, across different generations or are both a current and a former carer. Network volunteers are twice as likely to have cared for someone from an older generation than a spouse.

The experiences of dementia itself varied as seen in the graphs below:

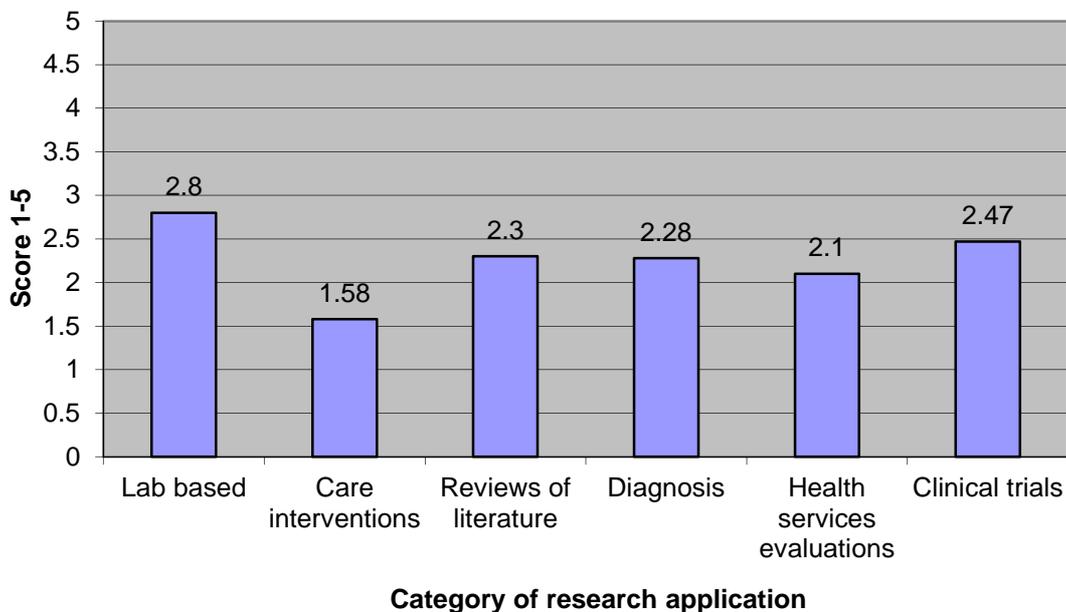


Diagnosis of dementia experienced by Research Network volunteers



The survey also asked how confident Research Network volunteers are in scoring different types of application (where 1 is most confident and 5 is least confident).

Confidence in scoring research applications



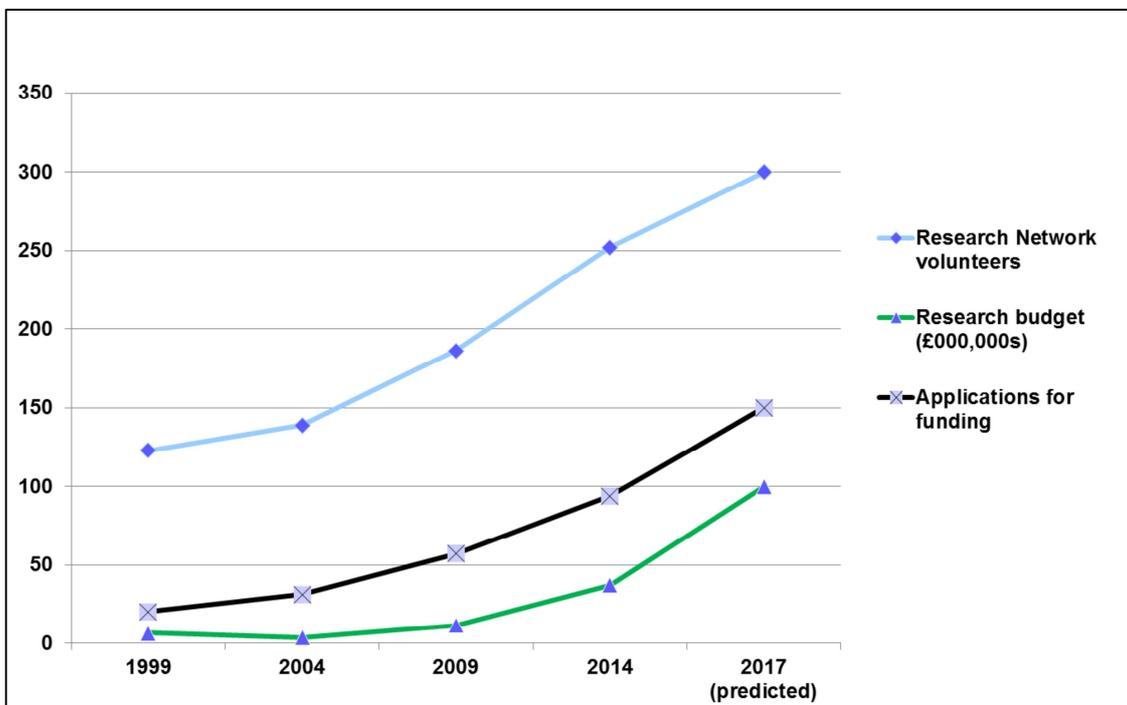
In recent years the Society has moved to administering detailed surveys every 2 years for all staff and volunteers. In 2014 we received 96 responses. Almost all of the metrics on the Workforce Engagement Index show a significant improvement from 2012. Areas that increased the most included:

- My initial welcome and training gave me the confidence to carry out my role (+34% from 2012 survey)
- I feel I have developed skills from the training I have received through the Society (+27% from 2012 survey)
- My ideas and opinions are given serious consideration by the Society (+26% from 2012 survey)
- The Society keeps me informed about matters affecting me (+25% from 2012 survey)
- Alzheimer's Society provides effective support for volunteers (+24% from 2012 survey)

Feedback from staff & volunteer surveys are now discussed in joint workshops between staff & volunteers, with actions agreed to address the key areas of improvement.

THE RESEARCH BUDGET

When QRD was set up in 1999 the budget that year was £647,000. In 2014 it was £6million. It is projected to be £10million by 2017.



Grateful thanks to the many donors to the Research Programme over the years, Including:

Donations are secured from charitable trusts, companies, individuals, and legacies. Key research supporters include Airbus, The BACIT Foundation, Barbara Charlton, The Barcapel Foundation, Catlin Group, Charles Wolfson Charitable Trust, Deloitte, Edward and Fiona Hayes, The Foster Wood Foundation, Healthcare Management Trust, The Henry Smith Charity, The Ingram Trust, Mrs Janet Fullarton, The John and Sally Reeve Charitable Trust, King & Wood Mallesons, SJ Berwin, Lloyds Banking Group, Professor Miriam Glucksmann, Phil and Jenny Perlin, QBE Foundation, Rosetrees Trust, The R S Macdonald Charitable Trust, Societe Generale, Tesco, Mike Gooley Trailfinders charity. ICAP plc., the Robert Luff Foundation, the Eranda Foundation, the Hartley Charitable Trust, the Steel Charitable Trust. Henry Lumley Charitable Trust, Sir Samuel Scott of Yews Trust, the Edwin George Robinson Charitable Trust, Edward George Robinson Charitable Trust, Lord and Lady Lurgan Trust, Mr David Mayhew, Mr Charles Hunt, Ms Joy Phillips, Credit Suisse (Charity of the Year 2011 -12) partnership raised £78,854 for the research programme.

DoH, Nominet Trust, Stavros Niarchos Foundation, KPMG (Charity of the Year 2009-10). Mr Edwin Harry Lea, Rhoda Patricia Fraser, Miss Margaret Curtis, Mary Kathleen Bourhill, Dr Christopher Beels, the family of William Scott Trust, BUPA, Dr Jaeger, Mrs Davies and two other major legators who between them contributed nearly £680,000 through gifts in their wills.

**IMPACT REPORT:- CAUSE, CURE, CARE & PREVENTION
ALZHEIMER'S SOCIETY'S DEMENTIA RESEARCH PROGRAMME 1990 - 2012**

Clive Ballard authored this report to demonstrate the impact and achievement of AS dementia research programme. N.B. 1990 pre-dates QRD but Alzheimer's Society made its first commitment to fund research back in 1990 and setting up QRD put the programme on a more formal footing.

Impact Value: "Our achievements go beyond the publication of results in scholarly papers and scientific journals. People with dementia and their carers are at the heart of our research. They are involved throughout our research programme, ensuring we fund research that addresses the needs and concerns of people living with dementia today. We are committed to taking promising research findings and translating them into real and tangible benefits for people with dementia, through policy, campaigning, training and education.....We are proud of the academic achievements of the scientists and researchers we have supported".

N.B. 60% of completed Fellows have gone on to be independent group leaders in dementia research.

Some key statistics:-

In the last 20 years AS has awarded over 250 research grants, investing over £25m.

AS –funded research has produced over 250 peer-reviewed publications, resulting in Citations in 7,500 journal articles, 40 publications of impact factor 7 or higher, Hirsch index number of 46 (46 publications that have been cited 46 times or more)

Distribution of funding

60% AD, 30% All types of dementia, 10% Other causes of dementia.

AS is the only charity that funds research into the cause, cure, care and prevention of dementia.

There is a chart of Areas of dementia research funded on page 26 of the Impact Report.

Portfolio History

Grant type	Numbers funded
Biomedical	179 (67%)
Care, Services & Public Health	88 (33%)
Project grants	102
Fellowship grants	64
PhD Studentships	38
Dissemination Grants	13
Doctoral Training Centres	8
Innovation grants	8
Other grant types	18

FOOTPRINTS

QRD ANNUAL ROUND-UP REPORTS (INITIATED BY CLIVE BALLARD)

ANNUAL ROUND-UP REPORT 2008-9

£2.9 million was spent on research in 2009, up from £1.6 million in 2008. Three new PhD students funded, two fellowship grants

ANNUAL ROUND-UP REPORT 2009-10

£2.1 million was raised towards AS research.

BDR was launched in October 2009 with five centres across England and Wales. Since its inception QRD members have been involved throughout, some acting as monitors for one of the five centres. Angela Clayton-Turner was particularly active, speaking at ethics training days and giving presentation about the user/carer perspective on brain donation at ADI.

173 volunteers in the QRD Network reviewed 64 grant applications of which 47 were approved by the Network with 10 going on to receive funding. 2009/10 saw over £1.7 million raised towards funding all areas of the research.

ANNUAL ROUND UP REPORT 2010-2011

Key highlight was an exciting research funding partnership with the BUPA Foundation which meant that together we were able to invest £1.5 million in new project grants. We also funded fellowships and PhD studentships to the tune of £859,000, plus the collaboration with the Stroke Association. Series of roadshows to inform local communities about research and the opportunities we provide for carers and former carers and pwd to engage with the research programme.

Over the year there was a focus on re-launching the RN, improving procedures and communications. As part of this the Coordinators elected its first chair.

Ministerial Advisory Group on Dementia Research convened to maintain the momentum begun by the 2009 Dementia Research Summit and develop a vision for the future of dementia research.

- £2.5 million was raised towards all areas of the Society's research.
- £565,767 secured from trusts and statutory organisation.

Impact Factor: Publications in 2011-2012. AS was acknowledged as a funder of 50 new scientific publications.

ANNUAL ROUND UP REPORT 2011-2012.

Over £2.7 million was secured through fundraising for the Society's Research programme through donations from charitable trusts, companies, individuals and legacies. A number of major foundations and charitable trusts secured £900,000. Individuals donated £234,605 and one donor who donated £25,000 towards the Society's Drug Discovery Programme. Another individual who donated £10,000 towards Clive Holmes' research into chronic stress as a risk factor. During this period Legacies totalled £689,000.

Impact factor: Publications in 2011-2012. AS was acknowledged as a funder of 68 new scientific publications.

Record numbers of volunteers attended training events, including introductory training delivered collaboratively with Asthma UK, Epilepsy Action and Parkinson's UK.

23 RNVs have become co-applicants on external grant programmes and many more actively involved in consultations and focus groups.

ANNUAL ROUND UP REPORT 2013-14

73 active projects worth £12.9 million. £1.1million new funding spent on care research, doubling last year's investment.

Over 26 new grants awarded. 25 early careers researchers supported by the Dementia Research leaders programme that was launched in January 2014 in response to growing concerns about the relatively small number of researchers working in all disciplines of dementia research.

ANNUAL ROUND UP REPORT 2014-15

The financial year 2014-15 was a record-breaking one for the research programme with investment doubling from last year to £8.1m. We also funded a record 10 Research Fellowships, which are given to promising young researchers to help them become more independent. These awards, along with our ground-breaking Doctoral Training Centres, mean that we're making excellent progress in our Dementia Research Leaders programme, helping us to attract bright research talent to the field of Dementia.

This 'History' was authored by Barbara Woodward-Carlton and Shirley Nurock (both then carers and members of the Research Network since its inception in 1999) as a record of the Alzheimer's Society research programme - a pioneering and innovative concept for its time, that of allowing those affected by dementia to have their voices widely listened to when it came to funding research and prioritizing topics that really mattered to families and people with dementia. It aims to chart the progress, expansion and success of the Network and highlight some of the key projects funded, as seen through the eyes of the volunteers themselves and of the research community.

Note From the Authors

We had much more material available and simply couldn't include everything, but thank everyone for all their contributions. If you would like to suggest amendments, please let us know.

Our thanks to Matt Murray, Anna Grinbergs-Saull and Clare Walton for their help and patience with the writing of this archive.