



**‘We can make
our research
meaningful’**

**The impact of the
Alzheimer’s Society
Research Network**

alzheimers.org.uk
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Foreword

Alzheimer's Society is proud to have been a pioneer in patient and public involvement since the inception of the Research Network in 1999. When we created our Research Network the involvement of people who were affected by health conditions in the research process was often treated with suspicion and anxiety by members of the research community.

In 2018 patient and public involvement has been embraced by researchers, regulators and research funders, not just as something that is nice to have but as an essential part of ensuring that health research is of the highest quality. What we created at the Society has become the flagship of patient and public involvement within medical research charities. Our model has been replicated both in the UK and across the world.

We remain as committed as ever to ensuring that the research we fund is not only of the highest scientific quality, but also of high priority and relevance to all people affected by dementia. The special partnership we have nurtured brings the expertise of leading researchers together with people who have personal experience of dementia. We believe that this gives us the best chance of delivering on our vision of a world without dementia.

As the Research Network approaches its 20th year it is continuing to develop and deliver for the UK dementia research community. It is evolving in sync with the huge growth we have seen in our wider research programme which now exceeds £36 million of investment across more than 150 projects.

I have witnessed first-hand the positive impact of our Research Network during my years leading our Research & Development programme. I am also privileged to hear many stories from researchers and members of our Research Network about the value that our patient and public involvement programme brings to dementia research.



This report moves us beyond a position where patient and public involvement is done because of a belief that it's the 'right thing to do'. It means that we can now confidently say where and how the Research Network is having an impact. Our new focus on evaluating the impact of patient and public involvement will help build the evidence base, not just for involving people affected by dementia in research, but across all research.

The report tells us the positive impacts that the Research Network makes in four key areas. More than this, it also tells us how we can continue to improve our patient and public involvement to help maximise impact. Evaluation shouldn't just focus on 'proving' – it should also set an 'improving' agenda, which is something we are committed to. Taking forward the recommended improvements from this report will be important for all who are involved in dementia research.

Dr Doug Brown
Chief Policy & Research Officer

Executive summary

Alzheimer's Society has pioneered the active involvement of people affected by dementia in research since establishing the Research Network in 1999. 'People affected by dementia' includes people who have dementia as well as those who care for someone with dementia, in a non-professional capacity. We have always been aware of the influence that these dedicated volunteers have. This project aimed to collect their stories to understand and demonstrate the real impact that the Research Network has, in its broadest sense.

To collect this evidence, in January 2017 we conducted an online survey of the expert advisors who make up the Alzheimer's Society Research Strategy Council (RSC) and Grant Advisory Boards (GABs). In spring 2017 we went on to conduct semi-structured interviews with a number of Research Network volunteers and the researchers they have collaborated with. The output of these interviews was a series of detailed case studies. These demonstrate the range of mechanisms through which impact is achieved.

Thematic analysis revealed four key areas of impact which we expand on in this report:

- 1. Impact on volunteers**
- 2. Impact on researchers**
- 3. Impact on research**
- 4. Impact on Alzheimer's Society**

We also identified that people with dementia have a unique voice, which should be valued independently of that of their family or carers.

Our report found that there is overall recognition of a positive shift in researcher attitudes over time towards patient and public involvement (PPI). Despite this progress, in the online survey, PPI was seen as less influential in biomedical research than in care research. The case studies, however, demonstrate that there is a place for the Research Network in biomedical research: contributing to communication, accessibility and research impact.

The next steps for Alzheimer's Society are to increase the number of people with dementia volunteering in the Network, as well as the accessibility of all Research Network volunteer roles. As the Network grows, we will continue to assess these impacts, and understand which methods of involvement achieve good impact. We will make our evidence base publicly available to support shared learning and a greater understanding of best practice in PPI in both care and biomedical research.

Glossary

- GAP – Grant Advisory Panel
- GAB – Grant Advisory Board
- RSC – Research Strategy Council
- DRI – Dementia Research Institute
- PPI – Patient and Public Involvement

The Research Network at a glance

Our Research Network volunteers fall into two groups:

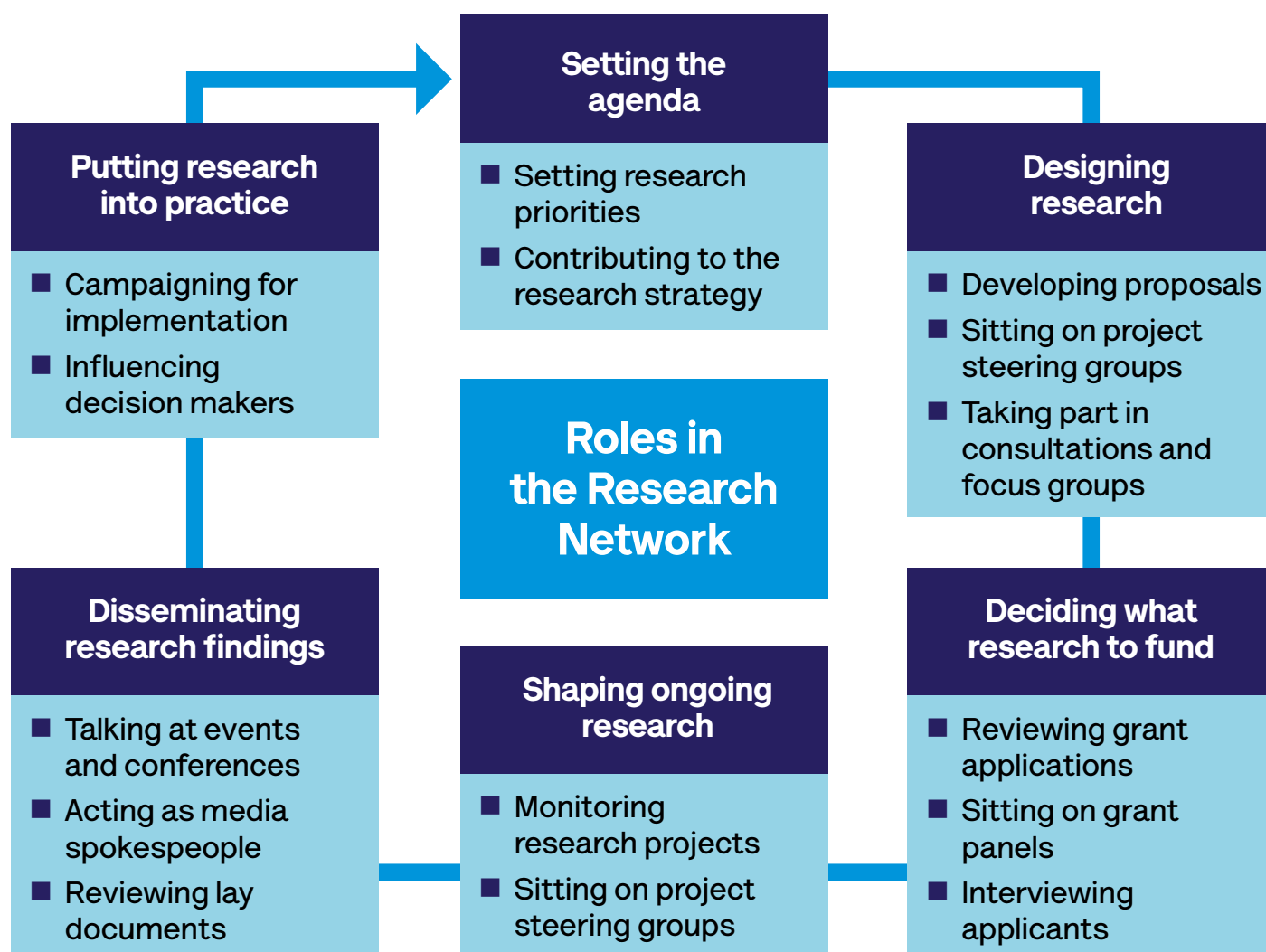
- people with dementia
- people otherwise affected by dementia, who have experience caring for a family member or loved one.

Volunteers can choose to be involved in several ways, and to give as much or as little time as they wish.

Volunteer roles include:

- lay reviewer
- monitor
- Grant Advisory Panel (GAP) lay member
- Grant Advisory Board (GAB) lay member
- Research Strategy Council (RSC) lay member
- Research Network Area Coordinator

The diagram below demonstrates how volunteers influence our research programme throughout all stages:



270 volunteers

5,367

reviews submitted in 2016/17

137 monitors

48 Grant Panel members

Over **150**
projects supported since 2010

Methods

Monitoring role review

In 2015, we conducted a review of the Research Network monitoring role. In this role, volunteers monitor research projects as part of the 'shaping ongoing research' element of the programme (see diagram on page 4). Surveys were sent in online and paper form to current and previous monitors. They were also sent to researchers who were grant holders and received funding between 2008 and 2013 (with end dates between 2011 and 2016).

We received 40 responses from members of the Research Network and 23 responses from researchers. Survey responses were analysed by Alzheimer's Society's Research Engagement Officer. The purpose of this review was to evaluate the monitoring process, but it also allowed us to assess the impact of monitoring on both researchers and Network volunteers.

Qualitative interviews

In spring 2017 we used the monitoring review data to identify potential impact case studies. We then invited the researchers and volunteers involved in these selected studies to interview. To capture different aspects of the Network role, we also contacted RSC, GAP and GAB members to take part. Research Network volunteers were invited to take part in a semi-structured individual or group interview. They were also given the option to speak either on the phone or in person at Alzheimer's Society's offices in London, according to their preference. Of those who took part:

- two were volunteers with dementia
- eight were volunteers with other experience of dementia
- five were dementia researchers who had experience of working with Research Network volunteers. They took part in individual phone interviews lasting between 30 minutes to an hour.

The interviews were facilitated by Alzheimer's Society's Research Engagement Manager and Evaluation Manager. All conversations were recorded using written notes and a digital recorder. All participants were asked for their permission to be recorded, and their responses quoted in this report. In this report, quotes are attributed using first names, followed by the person's role in brackets.

Notes and transcripts were analysed thematically by the Research Engagement Manager and Evaluation Manager.

Survey of Grant Advisory Boards and Research Strategy Council

The Research Strategy Council (RSC) is a committee of expert advisors which informs the strategic direction of Alzheimer's Society's research programme. Grant Advisory Boards (GABs) are committees of expert advisors who approve funding decisions in each grant round. The four GABs are:

- Biomedical
- Care, Services and Public Health
- Implementation
- Care Programme.

These boards are informed by Grant Advisory Panels (GAPs) of Research Network volunteers. Between two and four GAP representatives attend each GAB meeting to contribute to the decision.

A survey of both the RSC and the GABs was conducted online (using SmartSurvey) between 16 January and 3 February 2017. It achieved a response rate of 70% (39 out of 56) with a good spread across the different boards. The survey included questions on various strategic topics, however this report considers only those findings relating to the role and impact of the Research Network.

Survey findings were exported from SmartSurvey and analysed by Alzheimer's Society's Evaluation Manager.

The key findings from both our qualitative and quantitative research are outlined on the following pages.

The background is a solid light green color. Overlaid on this are several thick, dark green, hand-drawn style lines that swirl and loop across the page, creating a sense of movement and organic form. These lines intersect and curve, filling the background with a dynamic pattern.

Key findings



1. Impact on volunteers

**'I got such a lot from
knowing that we had
been part of helping
to develop this
research project...'**

The feeling of contributing to something worthwhile

The Research Network volunteers interviewed each had their individual reasons for joining the Network. However they all share a motivation to make a contribution to dementia research and, ultimately, to improve life for people affected by dementia.

‘I got such a lot from knowing that we had been part of helping to develop this research project, and that they were going to use the virtual reality to help people with daily living.’ – Elizabeth (volunteer)

‘I didn’t want to be a participant in a drug trial, I didn’t feel entirely comfortable with that role, but I did want to do something linked to that, so the Network was an ideal way of doing that. I wanted to broaden the Network to include people with dementia like myself.’ – Keith (volunteer)

All those interviewed reported feeling that their contribution is valued, and that this gives them a sense of purpose.

One volunteer, Wendy, related her sense of purpose to a practical benefit she feels she gets from her involvement. She explained that her role not only gives her a sense of contribution to the future, but also enables her to keep her brain active, as if she were completing a Sudoku puzzle:

‘I always say that it’s my way of feeling like I’m giving hope to my daughters, by being involved... and I always call it my Sudoku’ – Wendy (volunteer)

Learning about dementia research

Some volunteers spoke about their interest in finding out more about dementia and building their knowledge base. They said they found that this empowered them to cope better with their own experience of dementia, and to feel positive about the potential to help others with dementia in the future.

‘I’ve always felt that information is power, and the more I knew the more I would be able to deal with my dementia. I saw it as a learning experience by reading what is out there and finding out about what could potentially help other people as well as myself.’ – Keith (volunteer)

‘Just seeing the development of the research from the beginning... how encouraging that it was actually going to fulfil its potential.’ – Elizabeth (volunteer)

‘People need to remember, we all had talents before dementia – and we still have them.’

Another aspect of this is the opportunity to learn more about Alzheimer’s Society research and how our funding processes work. Volunteers who represent the Network at the GAP, GAB or RSC said they benefit from gaining knowledge about how research funding decisions are made at each level.

Cathy described gaining a unique overview of the research process. This, she feels, improves her skills as a volunteer and makes her a better lay reviewer:

‘It makes me a different [Research Network volunteer] because I have a wider picture, I react in a different way. It makes me better at looking at some applications because I understand more about the consequences and the people involved and what it would mean.’ – Cathy (volunteer)

An opportunity to use existing skills

Research Network volunteers bring with them a personal experience of dementia, but also a varied array of skills and abilities from their professional and personal lives. Several volunteers reported valuing the opportunity to put these skills into practice:

‘People need to remember, we all had talents before dementia – and we still have them.’ – Wendy (volunteer)

‘We speak about our own experience, you’ve been there, seen it, done it and you would do it again. [Researchers] have a particular point of view – a scientific point of view, but we are coming from a personal level to something that is very close to us.’ – Kieran (volunteer)

‘I am able to bring to the panel some of my education background as a head teacher and primary school advisor. Being on boards and panels has been part of my DNA for the past 20 years. The format is very comfortable to me and I can understand and respect differing points of view.’ – Keith (volunteer)

In one study, Barbara A, a monitor, drew on her experience as an occupational therapist in acute hospitals. She suggested a number of novel lines of enquiry for approaches to pain management (the focus of the study). She found the familiar environment empowering.

‘It felt like an easy relationship. Because of the hospital setting it was a situation and environment I knew.’ – Barbara A (volunteer)

Peer support and friendship

Several volunteers described how they have benefited from being part of a community of people with similar experiences, both of dementia and being involved with research projects.

‘You get to know the people you are working with, including the other monitors. You get to know people; you learn about their situation and that’s part of being a monitor.’ – Barbara A (volunteer)

‘It’s also about meeting other people in the same situation.’ – Wendy (volunteer)

Elizabeth was able to learn from other volunteers, and gain their support in developing her monitoring skills:

‘They helped me survive... it was a fantastic support and it’s great to know that it’s developed. We’ve always kept the friendships, and I think if you’ve got communication with people who are in the same situation, and you can do something positive at the same time, as we have done and still are doing, then fantastic stuff.’ – Elizabeth (volunteer)

‘You get to know people; you learn about their situation and that’s part of being a monitor.’

This sense of community extends further, as volunteers have the opportunity to join networks of researchers and spend time on various committees which they may otherwise not have been able to access.

‘You get the opportunity to go to places and meet people...that would not have been a possibility if I wasn’t in the Network.’ – Kieran (volunteer)

A gateway to further opportunities

For several volunteers, the relationships they have built with researchers through the Research Network have led to further opportunities for involvement in dementia research, both inside and outside Alzheimer's Society. They have been able to use their new knowledge and skills in different projects.

'We have built up a relationship with researchers so they feel more able... to ask us "can you look at this?" before submitting an application.' – Kieran (volunteer)

'It has opened other doors. I was involved with the interviews for the Director of the Dementia Research Institute [DRI] and I'm meeting Doug Brown (Director of Research and Development, Alzheimer's Society) to discuss the future for the DRI. That stuff I am very privileged to be asked to do and I am very pleased to do. I wouldn't have had these opportunities if it wasn't for the Network.' – Keith (volunteer)

In some cases, volunteers have co-ordinated other people with experience of dementia to team up with researchers elsewhere.

'I help the Alzheimer's Society with their research programme, assessing applications covering all sorts of dementias at all different stages, whether it is cause, cure or care, but also support the other government and National Institute for Health Research [NIHR] funded projects. Especially because I am linked with carer support groups in my area, I want to make sure I keep them up to date with research.' – Frank (volunteer)

Research Network volunteer, Barbara B, has partnered with researcher Murna on numerous studies. She has been able to offer her own perspective as a former carer of someone with dementia, and has also co-ordinated extended networks of Experts by Experience to inform dementia research. She recognises the positive impact this has on volunteers:

'It makes the family carers feel they have a right to be involved and that we welcome their contributions... the training that we had from Alzheimer's Society meant we could use that knowledge with other groups. We've now worked with other researchers. I do think we've made a difference to making PPI more important.'
– Barbara B (volunteer)

'We have built up a relationship with researchers so they feel more able... to ask us "can you look at this?" before submitting an application.'



2. Impact on researchers

'In a single interaction the wealth of knowledge, information and feedback that you can gather is incredible.'

Motivation and a sense of purpose

All the researchers interviewed spoke very positively about the contributions of Research Network volunteers.

‘In a single interaction the wealth of knowledge, information and feedback that you can gather is incredible.’ – Mario (biomedical researcher)

Researchers said they value the volunteers’ contributions and they remind them why they do the work they do.

‘As academics, we tend to be thinking about our careers a lot, and you know we’re receiving money from Alzheimer’s Society and yes that’s good for our careers. But that is not the primary driver, it’s far from the primary driver... it takes me back to the point that we’re engaging with society, with people... who are directly involved with these diseases and we should be reminded of that all the time.’ – Sean (biomedical researcher)

Academic GAB members also recognise the important role that the Network plays in grounding the researchers.

‘The involvement of people affected by dementia keeps the work accountable and grounded in the issues that people affected by dementia face.’ – GAB member

‘The involvement of lay members ensures that the panels stay focussed on whether the grants funded will really be relevant to patients.’ – GAB member

‘She feels like part of our team. The relationship and mutual respect we share is really important to our work. She’s been the wind behind us, supporting us to have an approach which values the experience of people directly affected by dementia.’

Understanding the ‘real world’ realities of dementia

Furthermore, volunteers raised issues about how things work in the ‘real world’ rather than a theorised, academic representation of dementia.

‘[The researchers] views of dementia can be sanitised because they can discuss it as an academic issue rather than day-to-day, gruelling, tough and incredibly guilt-ridden, all those emotions, and they need to be reminded of that.’ – Cathy (volunteer)

‘Academics, when they are considering their applications, think of an ‘NHS world’ which they think is happening. Sometimes they need us to step in using our experience and say “well actually if you think that this is, or will happen, in the real world, it isn’t, or won’t, or at least not everywhere.” It’s about the effectiveness of the project and ensuring this has an impact on the real world.’ – Frank (volunteer)

Network volunteers feel passionately about the role they play in this.

‘We represent the face of dementia, we are real people. This isn’t science – it is everyday life. We are trying to tell [the researchers] that they can make a real difference to people. It’s not just a research subject – it’s real people and real people’s lives they can affect.’ – Kieran (GAP member)

‘It is their job [researchers] and they have to do it – we are volunteers and we do it for a different reason. They might have the passion, but it is still a job – whereas it is a different passion that we bring.’ – Wendy (volunteer)

The close working relationship of Murna, a care researcher, and Barbara B, a volunteer, offers a great example of this grounding taking place on an ongoing basis:

‘She feels like part of our team. The relationship and mutual respect we share is really important to our work. She’s been the wind behind us, supporting us to have an approach which values the experience of people directly affected by dementia. She helps us to ensure we ground our research in people’s real life experiences. As an excellent convener and conduit for other people’s experiences, she broadens the frame of reference beyond what we know ourselves.’ – Murna (care researcher)

Focusing on the impact of their research

Researchers described how working with the Research Network has helped them to focus on the long-term impact of their body of work. The Network helps to validate current ideas and inform the future focus of their work.

This is particularly significant for biomedical researchers, who describe shifting their focus from answering a biological question to contributing to understanding of dementia as a whole:

‘Because we engage with the lay panel, it keeps us in a better mind space of trying to understand the disease and for a purpose... instead of just answering the biological question we’re trying to address.’ – Sean (biomedical researcher)

‘Applicants are increasing the range of ways to work with people affected by dementia.’

Through conversation, this wider understanding spreads beyond the individual researchers and into the research community.

‘It helps me think in terms of answering questions when I talk to other biologists. If they ask, “Why did you do that?” or, “Why is that piece of data appropriate?” I can tell them it’s because that’s the piece of data that you care about if you’re a patient, or dealing with a patient, with this disease.’ – Sean (biomedical researcher)

Developing lay communication skills

Lay communication refers to researchers’ communication with people who may not be familiar with scientific terms and theories (lay people). Researchers said that drafting lay summaries and receiving honest feedback from volunteers has helped them to improve their written lay communication skills and understand more about how people understand and interpret their work.

‘The lay abstract is one of the most difficult things to write, but it is also the most rewarding thing to write... it’s good to see the comments as well. It’s good to see people really want to engage with the material, which is difficult to engage with. It tells you how much people actually care.’ – Sean (biomedical researcher)

This is validated by the fact that long-standing Network volunteers have noticed an improvement in lay summaries over time.

‘I saw a difference over the years. It changed, you know. On the whole, all of the proposals that came to us were so much clearer to understand because the researchers understood the importance of writing in lay person terms.’ – Elizabeth (volunteer)

Furthermore, working with Network volunteers as monitors and interacting with them at events, such as the Alzheimer’s Society Annual Conference, helps researchers to improve their verbal lay communications skills.

‘Working together with the Network has educated the researchers to talk to the public in a way that can be understood by people. Researchers can find it difficult to tell their stories to people outside their normal research context. So the Society has been pushing, and the monitors particularly push you, to make your ideas clear.’ – Mario (biomedical researcher)

‘[We have to] think closely about how we explain what we’re doing. Not just what we’re doing, but why we’re doing it as well. Meeting the monitors has made myself and the student better communicators.’ – Sean (biomedical researcher)

Learning how and why to involve people affected by dementia

Researchers explained how Alzheimer's Society has helped them to learn about the importance of PPI, and how to go about involving people.

Mario (biomedical researcher) had previous involvement experience. However, funding from Alzheimer's Society provided him with the opportunity to combine his research with his involvement skills, and he has become a key advocate for the approach.

Mario thinks that involvement has particular benefits for early career researchers:

'We need to continue working, educating our new researchers and ourselves as to how we can best incorporate these activities and evidence in our actions. It is really relevant.' – Mario (biomedical researcher)

'It's just so interesting because I regularly meet the PhD students with the researchers and we make comments on their work. The idea is that we, as people with experience of caring for someone with dementia, can bring our experience to that...'

He has facilitated this by holding joint events with the members of his lab, allowing researchers who are earlier in their career to get the monitors' feedback and input.

This focus on early career researchers is shared by Network volunteers. Barbara B values the opportunity to meet researchers at various points in their career and to contribute to their work:

'It's just so interesting because I regularly meet the PhD students with the researchers and we make comments on their work. The idea is that we, as people with experience of caring for someone with dementia, can bring our experience to that. The PhD students are just delightful. They are really great to work with.' – Barbara B (volunteer)

This has not gone unnoticed by Murna, a researcher who works closely with Barbara:

'Barbara is supportive to junior researchers and aspiring researchers. She gives as much, if not more, attention to them as to senior colleagues. They greatly value the interest she shows in them.' – Murna (care researcher)

Comments from the survey of RSC and GAB members suggest that this investment in early career researchers is paying off, with an observable improvement in the ways researchers involve people affected by dementia.

'Applicants are increasing the range of ways to work with people affected by dementia not only in the design but also in the conduct (data collection, analysis and write up) and dissemination of the study.' – RSC member



3. Impact on research

‘They ask questions that make you think about how you can increase the scope and validity of the methods, and I did!’

Researchers have described the impact of the Research Network on their work, particularly through initiatives such as Research Network monitoring. Researchers reported impacts throughout the design, delivery and evaluation of the research process, and on the results of the research.

‘There have been two major... actions that I have implemented consistently throughout my research programme thanks to the input of my monitors from the network.’ – Mario (biomedical researcher)

‘Whenever we get any written material to read, people are always very sensitive to the language which is used...’

Changing methodology

As well as describing the impact on research outcomes, several researchers shared examples of the impact that the Research Network has had on their research methodology. Mario (biomedical researcher) described the changes he made to his first Alzheimer’s Society funded project as a result of conversations with his monitors:

‘They visited me and they started questioning the methodology. For example, I developed a task that required colour vision, so people had to see colours to be able to do the task, and they asked, “Well what about colour blind people?” So I said, “You know that’s true, we are not covering this population”. And then they asked, “But what about the visually impaired?” They ask questions that make you think about how you can increase the scope and validity of the methods, and I did!’ – Mario (biomedical researcher)

Solving ethical issues in research methods

Others discussed the broader impact of volunteer input on research methodology. For example, Liz (care researcher) experienced delays to her work due to a lengthy ethical approval process. She described the benefits of being able to ask people affected by dementia for advice on her participant consent processes, supporting her ethics approval application:

‘When someone is in an acute hospital we don’t have the time for someone to read through a consent sheet and wait for a relative to sign the consent form. We requested from the ethics committee that if a person with dementia wasn’t able to give consent for themselves, the researcher contacted a next of kin who could give verbal consent over the phone, under the Mental Capacity Act. We could then send a consent form and get that back. It sounds like a simple thing but it was a huge barrier and we wouldn’t have been able to do the study if we couldn’t do that. So because we could run that idea past the panel of carers and they said, “That wouldn’t bother us, we can’t see another way to do it and we are happy to support you [with] that approach”, we were able to do the project.’ – Liz (care researcher)

Liz suggested that without the input of Research Network monitors, she may not have received ethical approval for the approach, which would have significantly impeded the project.

Providing advice on ethical approval materials has become an important part of the Research Network monitor role. Barbara B (volunteer) chairs a carer reference panel. She described the impact that the panel had when reviewing information sheets:

‘Whenever we get any written material to read, people are always very sensitive to the language which is used, the way things are expressed. We also make things accessible, ensuring the guidance in the research manuals for staff in care homes is sensible and achievable’ – Barbara B (volunteer)

As described above, Research Network volunteers are able to provide guidance to researchers on presenting their work in an accessible way. Here, this impact has practical implications on the research methodology: making sure participant information sheets as well as research manuals are appropriate to the intended audiences, and supporting recruitment and retention to the study.

Impact on data collection and analysis

The Services after Hospital: Action to develop Recommendations (SHARED) study, funded by the National Institute for Health Research (NIHR), was supported by a group of lay co-researchers. Half of these researchers were recruited from the Research Network. This PPI element emerged as a particularly impactful area as the study developed.

The lead researcher, Carole, described the process of involving people in collecting and analysing data, and the impact this had on their results:

‘I don’t know if the data would have been the same or not if we had not involved the co-researchers, but their approach to interviewing was certainly different to mine as they would readily share their own experiences. They understood what people were going through. It was generally a more relaxed, friendly approach.’ – Carole (lead researcher)

The lay co-researchers joined the lead researcher on three analysis days. They shared ideas about what they thought the issues were, and developed these into themes from which the recommendations were developed.

‘The group analysis took a bit of thinking as none of them had done anything like this before. I would have gone through the analysis line by line and gradually developed common themes and sub-themes from what I was finding, but this was not practical with the group in the time we had. So they did it the other way round: they each read some of the anonymised transcripts of the interviews, and after a lot of discussion they agreed on the themes and sub-themes first.’ – Carole (lead researcher)

‘Their friendly but professional approach put everyone at ease and discussions between the lay co-researchers and the study participants were very lively and ultimately successful.’

In follow-up focus groups, some of the study participants returned for further discussions, which were led by the co-researchers. It is a rare opportunity for study participants to be further involved after being interviewed, but participant involvement is a growing area of PPI.

‘Focus groups were planned when we first designed the study but we didn’t know if any lay co-researchers would still be involved towards the end of the study two years later. Of course, we had five very enthusiastic lay people to lead the focus group discussions. Their friendly but professional approach put everyone at ease and discussions between the lay co-researchers and the study participants were very lively and ultimately successful.’ – Carole (lead researcher)

In fact, involvement became a key output of this project. Sue, a Network volunteer, presented at several conferences, and co-authored publications describing the approach.

Producing more useful outputs

In a survey sent to our GAB and RSC members, we asked how important various Research Network activities are to ensuring that Alzheimer’s Society’s research is relevant to people affected by dementia. These were the results:

- 94% said that lay reviews are either very important or essential to ensuring relevance.
- 93% said GABs are either very important or essential to ensuring relevance.

This suggests that an important impact of the various roles performed by the Research Network is ensuring that the outcomes of our research produce useful benefits for people affected by dementia.

- 78% said monitoring is very important or essential, even though this takes place after funding decisions are made.

This is partly because the Research Network has encouraged researchers to think about the impact of their research. For more discussion on this, see page 14.

Researchers have also told us that this increased focus on long-term impact has led them to change the focus of their research. For example, Sean (biomedical researcher) described the questions that his monitors ask, which challenge him to think about the practical applications of his work:

‘They often ask, “What are the practical applications of this? Where does this get us? Why is this worthwhile?” Those are the direct implications of the questions.’ – Sean (biomedical researcher)

Sean went on to suggest that these interactions have led him to change his focus from pure biology to therapeutic targets. Mario (biomedical researcher) also suggested that the changes he had made to his research, based on recommendations and questions from his monitors, had not only made his project more meaningful but had shaped his overall research focus.

‘That provides clear evidence of how not just using PPI as a means of improving or making my research more meaningful, but thinking from this perspective from the very beginning, has shaped my research.’ – Mario (biomedical researcher)

This particular impact is key to the volunteers we work with.

‘If research doesn’t have any practical implications, then it is research for research’s sake – is it going to help? Is it going to make more of a difference?’ – Kieran (volunteer)

Ensuring that research funded by Alzheimer’s Society makes a difference to people affected by dementia is an important aspect of the volunteer role.

94% said that lay reviews are either very important or essential to ensuring relevance.

93% said GAPs are either very important or essential to ensuring relevance.

78% said monitoring is very important or essential, even though this takes place after funding decisions are made.



4. Impact on Alzheimer's Society

**'There is an impact
from Research
Network volunteers
speaking at legacy
events... it brings
Alzheimer's Society
to life.'**

In interviews with Research Network volunteers, a recurring theme was that the Network provides a 'golden thread' to link different aspects of our research programme such as the boards, trustees and the RSC.

For example, Cathy (lay member for the RSC), described how she prepares for her role in representing the Network on the RSC. She regularly attends GAP and Area Coordinator meetings, to ensure that she can accurately represent volunteer discussions and ideas to the rest of the Council.

'If I don't go to boards, panels or coordinators meetings, how can I represent the views at the RSC?' – Cathy (volunteer)

As well as using these meetings to support her role on the RSC, Cathy provides a link between Area Coordinators and the GAP and RSC. In this way, she is able to provide Area Coordinators with updates and share her learning from volunteer meetings with the rest of the RSC.

Research Network volunteers are also involved throughout the grant funding process. All grant applications are reviewed by Network volunteers. These reviews are then discussed at GAP meetings where volunteers draw together the views of the wider Network on short-listed applications.

These were some GAP members' answers when asked about their role in representing the views of the wider Research Network:

'To speak for all the other Research Network volunteers who looked at the proposals, and reviewed at the panel, it is of course possible to state your personal opinion during the board, but... say that first and then you are presenting comments from other people. They need to be taken into account as well.' – Wendy (volunteer)

'Representing our own views, panel views and lay scores. There may be one application that the volunteers really liked, and it might not be so well scored by the panel or the academics, so if there is a discrepancy [between the academic and lay views] it is to voice the reason why – to justify to academics why scores were so low or high from the lay perspective.' – Frank (volunteer)

'It's good to see people really want to engage with the material, which is difficult to engage with.'

The lay review and GAP processes strengthen the impact of involvement at the board stage – giving volunteers the opportunity to hear and represent the views of a wider group. Having involvement at each stage of the funding process also helps scientific board members understand the Network's reviews and provides context to their comments. Additionally, GAB members have described the benefits of including involvement activities early on in the application process.

'Seeing how applicants write their lay proposal is instructive – a really good account for that purpose speaks volumes about the applicant's awareness of audience, which is a good thing all round to have.' – GAB member

This GAB member suggests that the lay review process adds to the depth of information available to inform final funding outcomes, by highlighting applicants' communication skills. This was also reflected in interviews with researchers, where the lay review process was described as providing valuable feedback to the applicant.

'It's good to see the comments as well. It's good to see people really want to engage with the material, which is difficult to engage with. It tells you how much people actually care.' – Sean (biomedical researcher)

Sean explained that some funders who ask for a lay abstract do not always provide feedback. Receiving volunteer comments helps the researcher understand how their work is perceived and understood by the lay audience.

Having this 'golden thread' of PPI throughout our programme strengthens the role of volunteers and the impact of PPI, providing links between the different stages of our process.

'I felt I put us on the map... it is so important that they understand what we're all up to.'

Partnership between lay and academic voices

Volunteers recognised the need for both lay and academic voices for the research programme to succeed.

'We come from totally opposite ends of the spectrum. They come from the high up academic side and we just come at it from the basic side... "Do we actually want it, need it?"... and provide that broader spectrum at a practical level.' – Wendy (volunteer)

During a discussion about their role at GAB meetings, GAP members talked about these different perspectives in terms of passion: a passion for research, and the passion that comes with a personal experience. Similarly, Cathy described the RSC as a combination of perspectives and 'voices', bringing together the academic and personal view:

'In that conversation you have lots of different voices, of which mine is one. But I think it's a carer/dementia point of view, it's not an academic interest point of view.' – Cathy (volunteer)

Throughout these discussions, there was a strong sense that one voice was not more important than the other – that it is the combination of the academic and the personal experience that gave strength to the process.

Likewise, in the GAB and RSC survey comments, several participants expressed that there should be no distinction between people affected by dementia and the scientific community.

'What is relevant to people with dementia has to be relevant to the research community and vice versa.' – GAB member

Consensus and accountability

Several volunteers thought that one of the benefits of this partnership was that it ensured consensus and accountability. Cathy has had the opportunity to give a presentation to the Alzheimer's Society Board of Trustees on the Research Network and what volunteers do. As a result of Cathy's role on the RSC, the Research Network has been represented at Trustee meetings, ensuring that their role in the research programme is recognised and understood.

'I felt I put us on the map... it is so important that they understand what we're all up to.' – Cathy (volunteer)

Cathy also described a sense of 'collective responsibility' on the RSC, whilst Kieran described the benefit of our approach including both lay review and the panel stages. He described the way that this ensures a consensus that takes a broad range of views into account:

'You could just send the applications out to lay reviewers and peer reviewers and you could come to a consensus based just on the paper exercise, but I think that would defeat the object. For example, from the peer reviewers you can see three very varied scores – that's why I think you need the research panel with experts. So I think there is a place for both, you have to have both, if you are missing one or the other it's like having toast without butter.' – Kieran (GAP member)

Involvement at the panel and board stages therefore allows us to reach a consensus that is representative of the diverse views of our Research Network, and takes into account diverse peer reviewer opinions. Part of our grant funding process is to interview all fellowship applicants. GAP members join the interview panels, and ask questions on behalf of the rest of the GAP. Volunteers described this process as giving them the opportunity to contribute to the consensus reached on Fellowship candidates.

'At the end of each interview, the lay and academic interviewers reach a consensus of opinion after a discussion. Through this you are essentially influencing the agenda for the board for fellowships.' – Frank (volunteer)

'What is relevant to people with dementia has to be relevant to the research community and vice versa.'

One GAP member related this back to their relationship with other board members, saying that having a say in this consensus meeting helped GAB members see them as equals.

'I have found when you go to a board meeting having been at the interviews, your opinion is respected by other board members as you are lay people and scientists talking about that applicant's research approach together.' – Kieran (volunteer)

Raising the profile of Alzheimer's Society

Both volunteers and researchers described the Network as raising the profile of the Society. Volunteers discussed the impact that Research Network volunteers could have when representing the Society to the public.

'There is an impact from Research Network volunteers speaking at legacy events. Not just from a fundraising perspective, but also it brings Alzheimer's Society to life and can bring research home to people... making it local.' – Kieran (volunteer)

'It is the same for me when I have done talks... you notice while you are speaking that you have people's attention.' – Frank (GAP member)

Wendy (GAB member) connected this to a respect for the Society research programme in general. She described her approach to encouraging other people affected by dementia to get involved in research, saying that mentioning the Network's role was a source of comfort for those outside of the Society.

'The knowledge that there is lay involvement makes research more appealing to other people, rather than it just being academics somewhere.' – Wendy (volunteer)

This suggests that the Research Network boosts the Society's reputation for funding research that is relevant to, and supported by, people affected by dementia.

Mario (biomedical researcher) suggested that the Society's track record in PPI makes us an attractive research funder. Mario described 'having PPI at the top of the list as an activity through which we expect to draw benefit so that we can make our research meaningful.' He saw this as a unique benefit of working with the Society. Having had experience in PPI in other contexts, he also considers the Research Network a uniquely valuable group.

'Not all PPI environments are equally productive.'
– Mario (biomedical researcher)

'Alzheimer's Society's exemplary involvement of people with dementia brims over with genuine ethos, effort and results.'

This suggests that having a strong reputation for involvement not only helps raise our public profile as a research charity, but also helps to make our funding offer attractive to researchers in the field.

This was reflected in responses to our RSC and GAB survey. The vast majority (94%) of participants agreed that Alzheimer's Society works in partnership with people affected by dementia.

'Alzheimer's Society's exemplary involvement of people with dementia brims over with genuine ethos, effort and results.' – RSC and GAB member

'Alzheimer's Society led the way in terms of engaging with the lay individuals who are affected by dementia when making funding decisions. Other charities are now adopting similar inclusive approaches.' – RSC and GAB member



Other key findings

People with dementia have a unique voice

GAP and GAB members described the importance of including the views of both people with dementia and carers in discussions about research. For example, when talking about the challenges of finding balance in a board meeting:

‘The only problem could be that family carers and supporters might see issues very differently to those living with dementia.’ – GAB member

There was a strong feeling amongst those interviewed that people with dementia have a unique contribution to make. Keith (GAB member) spoke about his role in not just sharing his experience with researchers, but also helping other volunteers to understand the experiences of someone living with dementia.

‘I have challenged some people, but I hope I can illustrate to those people that dementia is more than just the late stages, and is more than just affecting people over 80 years of age. So I see that as part of my role.’ – Keith (volunteer)

This illustrates another impact of the Network, which is to challenge the stigma associated with a diagnosis of dementia.

Wendy spoke about her role as a person with dementia sitting on a board, bringing her experience to the discussion. But she also stressed that the strength of the board process is the partnership between people with dementia and carers. She said that the combination of her and a carer on the board increased their impact on the discussions because they brought different skills to the table.

‘I think it is important to acknowledge the fact that [he] was able to instantly push the point over, whereas I might not have... it is nice to have the balance of the supporter and people with dementia – he complimented me where I fell behind.’ – Wendy (volunteer)

This illustrates the importance of balance between the different views and experiences, suggesting that the strength in our process lies in the partnership between people with dementia and those with experience as carers or supporters.

Attitude shifts

Another interesting theme that came through was that we have seen a certain attitude shift amongst the researchers towards the importance of involvement, and the ability of people affected by dementia to be involved. We saw this in discussions about improved lay communications skills, but volunteers also talked about experiencing a change in the interactions they have with researchers. Several volunteers suggested that they now felt more accepted and listened to, and that their relationship with researchers had become more equal.

‘I think people have recognised... that I’m not in conflict with them. I’m not trying to change them, I’m just trying to add a different viewpoint.’ – Cathy (volunteer)

‘The only problem could be that family carers and supporters might see issues very differently to those living with dementia.’

This suggests that any anxieties over potential conflicts between academic and lay member opinions have lessened throughout Cathy’s time on the RSC. She has become a part of the team, contributing to the discussion.



**Looking to
the future**

Involving people with dementia

In compiling these case studies, we were also able to evaluate our involvement programme and identify areas of development.

Interviews with people with dementia highlighted the importance of championing their involvement at every level of the research programme. Discussions about the partnerships we create focused on the uniqueness of the input that people with dementia can give. We also heard that for our volunteers, a key part of their role is educating others on the skills and experiences that people with dementia bring. To expand on this, we plan to increase the number of people with dementia volunteering with the Network, and are reviewing the accessibility of all Research Network volunteer roles.

Sharing our impact

It is important to acknowledge that some of our data also highlighted a persistent belief that certain volunteer roles have little impact on research. For example, the GAB and RSC survey highlighted that some responders believe lay review and research monitors were less effective in biomedical/laboratory research than in care research in ensuring relevance to people affected by dementia. This suggests that there is more work to be done to share our impact case studies, and to build an evidence base for the benefits of involvement for different types of research.

‘... we plan to increase the number of people with dementia volunteering with the Network, and are reviewing the accessibility of all Research Network volunteer roles’.

The impact that the Research Network has had in care research (for example volunteers as co-researchers) is different to the impacts we have observed in biomedical research (such as communication and accessibility). We also cannot expect that all these benefits will be realised in every project we support. However, this report has shown the varying impacts that involving people affected by dementia can have in reviewing, monitoring and developing research. The next step is to continue assessing these impacts, and making our evidence base publicly available. This will continue to support shared learning and a greater understanding of best practice in PPI.



Alzheimer's Society is the UK's leading dementia charity. We provide information and support, improve care, fund research, and create lasting change for people affected by dementia.

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