Monitoring our Research: The Research Network

Alzheimer's Society believes that patient and public involvement has a positive impact on research, and that people affected by dementia can make a unique and valuable contribution to our work. Our Research Network includes approximately 260 carers, former carers and people with dementia. They are involved in:

- setting our research priorities
- supporting researchers to develop improved grant applications
- prioritising and commenting on grant applications
- sitting on grant selection panels
- monitoring on-going projects funded by Alzheimer’s Society
- informing others about the results of research.

How Your Monitors Can Help You

A unique part of your Alzheimer’s Society award is that you will have three members of the Research Network allocated to your project as Monitors. Research Network Monitors visit all our funded researchers to receive updates on the project and to give advice from their experience of dementia.

Meeting people affected by dementia

Your monitors will be people with dementia, carers or former carers. Discussing your research with them will give you and your team the opportunity to hear about their personal experience of dementia, and what your research means to people affected by dementia. Many researchers tell us that they find the process extremely rewarding.

“They …enabled me to take a step back from the laboratory atmosphere, think about the wider picture and provide perspective on the issues concerning people with Alzheimer’s and their carers.” A funded researcher

Gain advice and feedback

Discussing your research with monitors, you can ask for their input throughout your project (as appropriate) on:

- Project plans
- Methods
- Data analysis
- Dissemination plans
- Communication to a lay audience
- Patient literature in advance of ethics submission
- Writing your next grant application

As volunteers with direct experience of dementia, your monitors can give you advice on how to involve people affected by dementia in your research and how to communicate your research to the public. By holding regular meetings, you can access this advice throughout your research.

Monitors are not expected to participate in the research itself (e.g. interviewed as part of a qualitative study or enrol in a clinical trial).

Strengthen PPI input in your grant

Monitors can support Patient & Public Involvement (PPI) beyond your annual monitoring meetings. You can request additional support from them or from other members of the Research Network. Where the research is clinical and involves a scientific steering group, monitors could become lay representatives on the steering group, if appropriate. If you already have a PPI group at your University or Institution, you may also consider including your monitors in this group and holding both meetings on the same day. Please contact the Research Office for advice or support on this.
Meeting Your Monitors

Organising your meeting
You should organise a first meeting with your allocated monitors shortly before the project is due to start or within 3 months of your start date. Once you have received the monitors’ contact details, please make contact with them to introduce yourself. If you are a PhD grant-holder, it may be appropriate to ask your PhD student to manage monitoring meetings. Please share this guidance with the student or other appropriate members of your team.

Meetings should be arranged at least once a year, although some researchers benefit from meeting their monitors every 6 months. Monitors will claim their expenses directly from the Society.

Data Protection
You will receive the name and email address of each of your monitors. Please keep this information strictly confidential. We share these contact details with you so that you (or your student, if appropriate) can correspond with your monitors and organise your meetings. Please do not share the monitor’s details more widely, unless you have agreed to do so with your monitoring team.

Who should attend?
Monitoring meetings can be open to any member of your team, including students, co-applicants and staff employed on the grant. In some circumstances a member of Alzheimer’s Society Research staff might also attend a monitoring meeting. You will be asked for permission in advance.

Location
Where possible, meetings should take place at your University, so that monitors can be shown the lab/research facility. Some monitors may have access requirements – please check whether this is the case and take these into account.

Agenda
There is no set formula for what should happen during a monitoring meeting. Typically they last between 2-3 hours, ideally with coffee or lunch along the way. You might consider including the following on your agenda:

- A presentation of the progress made and future experiments planned.
- A discussion about the implications of the research for people with dementia
- A tour of the research facilities and demonstration of techniques.
- A discussion about how the findings of the research could be disseminated more widely, or made more accessible to the general community.
- Discussion about goals and aims for the next 6-12 months.
- Handouts the monitor can use to discuss the research with friends and family.
- Planning the date for the next meeting

Feedback Reports
After each monitoring meeting, the monitors are asked to provide a brief report on the monitoring meeting and their impressions of the research. This is stored on your grant file. If you would like to receive feedback from them, Monitors may be able to share their reports with you.
Alzheimer’s Society staff responsibilities

Society staff (usually the Research Engagement Officer) will contact you to give you contact details for your monitoring team. Society staff are not generally involved in organising meetings with your Research Network monitors – these should be coordinated by you and the monitoring team.

If there is a change in circumstances (e.g. a volunteer has had to resign as monitor), these will be communicated to you via the Research Office. If there is a change within your monitoring team, Society Staff will recruit a new volunteer and inform you of their contact details.

If you are unable, for any reason, to reach your monitors or for any further advice please contact

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