

Examples of user involvement in commissioning research

User and carer review of research proposals sent to The Alzheimer's Society¹

Purpose: The Alzheimer's Society have created a Quality Research in Dementia (QRD) Network to be involved in all aspects of their research work - consulting about, commissioning, monitoring and reviewing research. Here we will concentrate on the commissioning research stage. The Alzheimer's Society has their own research grant fund and they use this to commission research that responds to the identified priorities for research about the cause, cure or care of dementia.

Society members have decided these priorities through the Quality Research in Dementia Network (QRD). It is an active partnership between carers, people with dementia and the research community. The QRD Network was launched in July 1999 with a commitment to making the values of people with dementia and their carers central to the Society's research programme.

Setting up the project: The Society maintains and supports this network so that they can spread the tasks involved in their research work across a wide number of people to avoid overloading them. The Society canvassed all of its members and invited them to be involved in the QRD Network. Members complete an application form to register their interest to be involved. They sign a 'volunteer agreement' to indicate they understand their role as a volunteer and what support they will receive.

There are ~ 150 current members of the QRD Network who are carers, former carers or patients with dementia. Their ages range from 23 to 92 years. Members are spread across 13 regions in England, Scotland, Wales and Northern Ireland. There are ~ 15 members per region and one coordinator.

Roles of the user consultants: There are two groups of user consultants involved. The group who review the proposals at the first stage create the priorities that are used to decide which proposals go on the short list. They do not have to come to meetings. This is what they do:

- are aware of The Society's research priorities
- agree to read and review research proposals - one member may be sent up to 10 proposals

- think about and decide how important the application is, how good the research strategies are and how it fits with The Society's research priorities
- provide written comment on the research proposals - this is used to short list the proposals according to consumer priorities before they go out to expert peer review

The other group sits on the Grant Review panel that makes the final decisions and they do have to come to meetings. They:

- receive and read the:
 - ω short-listed applications
 - ω consumer reviewer comments
 - ω expert reviewer comments
 - ω applicant's responses to the comments
- hear presentations by the applicants and have opportunities to question the research teams in detail
- discuss the proposal, feedback and interview outcomes with other panel members in depth - make final decisions on which research projects will be commissioned

Support provided to user consultants: Members of the QRD Network:

- receive induction training on their role and tasks
- receive written information and guidelines to carry out these tasks
- are supported by a contact person, often a staff member from the Society
- get personal development opportunities if they are available, such as attendance at a relevant conference
- are paid travel expenses when incurred and receipts are provided
- are sent a quarterly newsletter to keep them up to date with the activities of the network and the Society's research work

Level of influence or decision-making: User consultants who review proposals have the first opportunity to comment on the proposals and create the short list of proposals that go on to further review. The expert review stage happens after the consumer review and before the decisions are made - the expert comments inform the final decisions.

The Grant Review Panel is made up of half experts and half consumers - all members have equal say about the proposals and an equal vote in the decision making about which ones are commissioned. This is where final decisions are made.

Outcomes achieved: The Alzheimer's Society:

- has received national awards for its user involvement work
- achieves high loyalty and support from QRD Network members - in two years less than ten people dropped out of the network and more than 80 per cent of the network regularly respond to requests and return grant reviews
- ensure that all their research work is driven from a user and carer perspective, focusing on what they believe the priorities are - people will not get funded if they do not show that they understand how important this is
- influence priorities in dementia research across the UK even for people who do not seek funding from them, as they take The Society's research priorities as a start point

Strategies for success: They include:

- training user consultants for their role

- making sure user consultants meet and communicate with other users and carers
- following a strict process in the review of research proposals where consumers have the first say on them, and then the last say by making decisions with experts
- having a large enough pool of user consultants so that the work can be spread around and people do not get overloaded

Problems that occurred: Some user consultants find reading the technical language difficult. Research applicants are meant to write lay summaries and put things into easy to understand language, but sometimes this does not always happen. User consultants also feel that they cannot comment on some things. People who review the applications are encouraged to only comment on things they believe they can, or ask questions about the proposal to highlight that there may be some issues with the language and what the researchers mean. The researchers have to respond to these questions and also to the questions from user consultants on the grant review panel. Reviewers are told that it is fine to provide a gut reaction with reasons for their reaction.

Benefits achieved: User consultants believe that:

"An extremely valuable contribution from us is to make the scientists stop getting carried away with the complicated problems and ask the simple questions: 'Why are you doing this? What difference will it make to those suffering the disease and those having to watch others suffer?'"

Another benefit is making sure that The Society's research money is spent in a way that their members want and believe is beneficial to people living with dementia and their carers.

References

1. The Alzheimer's Society: Quality Research in Dementia Network:
http://www.qrd.alzheimers.org.uk/qrd_advisory_network.htm

Case example analysis

Use what you have learned so far about user involvement to decide if what happened in this example was:

Poor

OK

Good

Excellent

Rate the 7 areas below. For some areas you may wish you had more information. Just do the best you can with what you have. After you rate each area give brief reasons for your decision.

- If you liked something, say why.
 - If you think something was missing, then say what it was.
 - Someone must record your decision and reasons for each area. Another person must be your group representative when we return to the large group.
1. A good **range** of users, carers or the public were involved
 2. User consultants had meaningful **roles**
 3. There were realistic **expectations** of what they would do
 4. They received strong **support**
 5. They had strong **influence** in the decisions
 6. Their involvement had **benefits** for the organisation
 7. Their involvement had **benefits** for other users, carers, and/or members of the public