

Quality Research in Dementia Consumer Network

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Alzheimer's QRD Network

- Setup in 1999
- Patients/Carers/Ex-carers
 - Experience/Expertise
 - Tomorrow could be anyone, including you
- 170+ members
 - Scoring statistically valid
 - Website/Training/Manual

QRD Network

- Shaping the Society's strategy for research
- Providing ideas and suggestions for new research
- Providing comments on grant applications
- Selecting/scoring applications for funding
- Monitoring on-going projects being funded
- Developing follow-on bids
- Ambassadors for research

Patient/Carer Priorities

- Prevention
- Cause
- Cure
 - Interim care

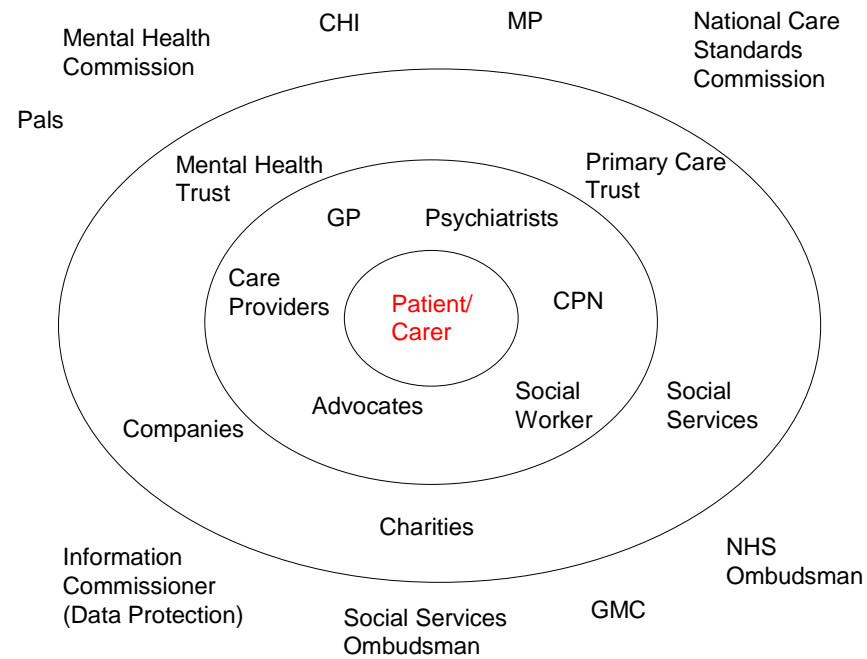
A scientist's experience of sitting on a research grants panel

- 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. However well intentioned, as a laboratory based scientist, it is sometimes rather easy to lose touch with the realities of dealing with the disease on a daily basis. 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 Alzheimer's disease 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 Alzheimer's disease 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 laboratory with a renewed sense of purpose.
- Dr Steve Gentleman, Imperial College London

Monitoring

- 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. We invited them to one of our early study management group meetings and 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 Rob Howard, Institute of Psychiatry, August 2005

Isolated Patient/Carer

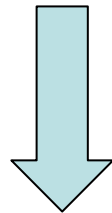


Benefits for Patients/Carers

- Not tokenism
- Geographical, wide range of ability
- Ability to use skills, isolation
- Flexibility
- Ex carers

Visual Spatial Disorders

- Dyslexia
- ADHD/ADD
- Asperges
- Dyspraxia
- Autism



- Treatment rather than coping mechanisms

Assessment

