Andrew Cornwall, Family Carer and Research Network Volunteer, Alzheimer's Society

- 3. How can health professionals effectively utilise linguistically and Culturally appropriate diagnostic tools to increase diagnostic rates for BAME and other hard to reach groups?
- There are a large number of PPI (Patient & Public Involvement) Groups/Service User Groups/Friends Groups for care homes etc. Many of these groups have been carefully recruited to include representation of local BAME groups. These PPI Groups are often only used for advice on research and possibly for service audits. As a member of several such groups, I can safely say that many would welcome approaches to discuss appropriate tools & language.
- 4. What impact has the introduction of named GPs had on personalising care for people with dementia, and what more needs to be done to improve post-diagnosis support?
- We all know that GP's are overloaded. What's needed is a Dementia Support Worker for each & everyone diagnosed with dementia. It's not just health issues that need support, but even more essentially all the social & bureaucratic issues, e.g. council tax, employment issues, probable loss of driving licence and other issues that often cause isolation.
- We need more joined up initiatives with assistive technology. There are a lot of good ideas out there, but often the different systems don't communicate with each other and aren't linked to the healthcare professionals responsible for supporting the person with dementia.
- 5. With the UK Government and other G8 nations committing to developing a cure or treatment for dementia by 2025, how is this likely to be affected by the outcome of the EU referendum, and what are the next steps for increasing participation in research?
- Funding for research and access to databases & international partnerships are threatened by the decision to leave the EU. What would have been automatic as a member of the EU will be greatly complicated by having to buy our way into any consortium, paying for access to data and new complications in gaining ethic approval. Many international research collaborations that would previously have been centred around UK universities, will now be centred around EU universities on the continent. We are already seeing this in grant applications.
- Many PhD students that I have regular contact with as part of monitoring their projects for Alzheimer's Society, are not UK passport holders. The majority come from other EU countries, but there are a significant number from other parts of the world as well. They all report that the atmosphere has changed since the referendum. Many of them have faced abuse personally, even in places such as Brighton with a very diverse population. Many of the students have told me that they are keen to finish their studies here asap and to move elsewhere to start their research careers.

- There is a post-doc bottle neck. We are training more doctoral students in the neurosciences than before, but the opportunities to progress to a career in dementia research are very limited. The option of going to the USA for their first post-doc experience, which a large percentage did in the past, has now gone. The dementia research community cannot be successfully built up, when we lose so many post-doc's.
- Participation in research has to be continually tackled. At the moment it seems spasmodic and highly postcode dependent. It must be raised by the consultants at diagnosis and then repeatedly afterwards by specialist nurses, GP's, Dementia Support Workers etc.
- Join Dementia Research has had a very successful launch and initial growth period. It needs to be adequately resourced to promote itself better.

I have not been able to cover in my responses above, the issue that a considerable number of people with dementia have no carer; often guesstimated at 40% of people with dementia.