GETTING PEOPLE INVOLVED IN DEMENTIA RESEARCH POSITION STATEMENT

Background
Translating academic research into interventions that benefit people with dementia relies on the involvement of people in research. Potential diagnostic tools, preventions and treatments must be tested in clinical trials before they can be approved for public use. Within dementia research, finding sufficient people to join trials and other research projects can be very difficult and has been recognised as a major barrier in finding a new treatment or intervention. People with and without dementia, as well as carers for people with dementia, can also provide valuable input during the formative stages of research, improving the quality of studies and ensuring their needs are reflected. The recruitment of people with dementia and their carers for research and clinical trials is therefore vital in ensuring that promising research is focused on the people who will benefit from treatment.

Current recruitment targets
The Prime Minister’s Challenge on Dementia 2020 set a target for 10% of people diagnosed with dementia in England to be taking part in research [1]. In the 2015/16 period more than 24,000 people with dementia had been recruited to NIHR portfolio studies [2], representing 5.3% of the 451,561 people in England with a formal diagnosis [3]. This does not compare favourably to the around one in five cancer patients in the UK being recruited to cancer studies [4]. Taking into account current projections of dementia prevalence and assuming a constant rate of diagnosis, there will need to be an additional 43,275 people with dementia recruited for research by 2020 to achieve the NHS target[1].

Barriers to patient involvement
Two significant factors currently contribute to a lack of patient and public involvement. Firstly, there is a lack of awareness among both the general public and the medical community. Surveys show that 89% of the UK public would want to take part in clinical research if they were diagnosed with a medical condition or disease [5], but more than four in five people (81%) wouldn’t know how to volunteer [6]. Similarly, 86% of UK physicians surveyed were not aware of any clinical trials in their speciality that were recruiting patients, but 93% would recommend participation to patients [7].

The second barrier is the constraints inherent in the cognitive and physical impairments caused by dementia. The enrolment and trial processes can be confusing for people with dementia, and this may inadvertently deter individuals from continuing their involvement with research [8]. Many trials require a person with dementia to have a ‘study partner’ who can assist with transportation to trials, providing medication and monitoring an enrolled patient’s condition. This requirement may exclude some people with dementia from enrolling in trials, particularly in those cases where a carer or family member is not capable of committing such support due to other obligations.

Our position
Alzheimer’s Research UK believes that increasing dementia research capacity in the UK is a key component for more high-quality research to be conducted. Having a higher proportion of people with dementia and their carers involved in research increases the capacity for conducting clinical research and trials, which in turn increases the prospect of advancing diagnostics, shaping new prevention strategies, improving care approaches, and finding a disease-modifying treatment.
Alzheimer’s Research UK, alongside Alzheimer’s Society and Alzheimer Scotland, are partners in the National Institute for Health Research (NIHR)-led initiative called Join Dementia Research. This is a national service which enables people to register their interest in taking part in research.

We believe that a more direct recruitment strategy, that integrates recruitment services into diagnosis and care pathways, is required. This should include:

- Informing patients about research recruitment services as a standard requirement at the point of diagnosis. While the Dementia Core Skills Education and Training Framework [9] does outline expected skills for healthcare practitioners it is not explicit about the potential of Join Dementia Research. Health Education England should establish a national training programme for this purpose, which would help to embed a culture of research across the health service.
- Appropriate support for patients and carers during the enrolment process and clinical trial procedures. Carers and care staff in particular should have adequate support for facilitating involvement as a patient’s condition deteriorates.
- Increasing opportunities for volunteers to qualify for research participation through additional funding for dementia research studies.

1 2020 prevalence figure of 975,000 taking from OHE Trajectory. At current diagnosis rate of 69%, people diagnosed with dementia = 672,750. 10% recruitment = 67,275.

References

[2] Data obtained from NIHR. This figure does not include people recruited through private studies, non-NIHR portfolio research or those registered to peripheral recruitment services such as Brains for Dementia Research or Join Dementia Research.
[6] YouGov survey conducted on behalf of Alzheimer's Research UK (2015). Total sample size was 2,227 adults and fieldwork was undertaken between 29-30 January 2015. The survey was carried out online. The figures have been weighted and are representative of all UK adults (aged 18+).

Reviewed: January 2020
Review by: January 2021