

Report from Focus Groups in North East on Barriers to Participation in Dementia Research and How to Overcome Them

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DeNDRoN North East recently held two focus groups for patients and carers in the Newcastle and Sunderland areas. DeNDRoN research staff and Alzheimer's Society personnel very kindly assisted with the events and discussions were led by DeNDRoN's Patient and Public Involvement (PPI) Coordinator. Together we looked at why people do – or don't – choose to take part in dementia research. We suggested solutions to help increase interest in taking part in research. The Newcastle one took place as snow was piling outside, but people were keen to stay and discuss barriers to research.

Here are some of the ideas which people raised about barriers to participation in dementia research – and some suggestions how to overcome them.

Information and decisions about research

It's sometimes difficult find out finding out about research opportunities in the first place. People felt that GP advice would be useful if they had enough knowledge of dementia. It was suggested that financial incentives for being more involved with dementia patients might help. GPs should be informed about DeNDRoN research case registers. Dementia specialists should routinely discuss research opportunities, ideally the doctor, but it could be someone else as long as it is mentioned. People felt that the internet is now used by a surprising proportion of dementia patients and carers, with the Alzheimer's Society website being a favourite.

The patients and carers acknowledged that patients would be wrong to expect major personal benefits from being in research themselves, as no cure is in sight, and would be participating to help others. Therefore, to help patients decide about participation, they said researchers must explain very frankly the likelihood that the research will or will not benefit patients in the future. Another concern raised was that any new drug treatments developed might end up being limited in use by NICE decisions.

Cynicism about NHS and the need to learn from where research works well

An enormous issue raised in the Newcastle group was widespread anger and cynicism about dementia care in the NHS. Carers gave powerful examples showing lack of care, dignity or respect for patients with dementia. The group felt that it would make people feel less willing to consider participation in research.

By contrast, some sites were “rare examples of good practice” around research with:

- welcoming environments and excellent relationships,
- good communications with patients and with carers,
- multidisciplinary team approaches (clinical staff, admin staff, CPN, social worker, occupational therapist),
- clinicians who don't use desk as “barriers”.

The Newcastle group urged that less welcoming research sites should learn from what works well. Frequent changes in hospital set-ups and management should not disrupt the continuity needed to build up good research teams.

Practicalities of research appointments

People said from experience that research always adds more time to appointments than is predicted. Across the North East, travelling long distances to centres put people off, and it's difficult sorting out wheelchair access taxis. Parking problems included not wanting to leave people with dementia in a car whilst walking off to buy a parking ticket, and one suggestion was reserved parking places for research participants and carers.

It was said that patients might not want to take part in research if they will be identified as having dementia due to some stigma about dementia in the North East. However, the North East was felt to have a strong research tradition in dementia and this was felt to be true across the whole of the North East.

Stages of illness and when to start research

People in the Sunderland group said that, whilst some patients with dementia are quite well and not highly interested in research, on the other hand many other patients find themselves too ill to be interested or involved in research.

It was considered important to identify cases early and design research for early stages of dementias – and this was felt to be important across all types of dementia, including fronto-temporal dementia which needed more devoted research. Carers gave examples where earlier diagnoses could have been made, but instead phrases were used like “She's just an old lady” and “It's just a slight shrinkage of the brain” without a diagnosis.

Once patients unfortunately become more ill, both the focus groups felt that those patients would usually want to stick to current approved treatments. Even if patients and carers were interested in research in the latter stage, they would have too many health problems, and stress and depression would be big barriers.

Two specific research ideas were raised. As mentioned above, there was a call for more specific fronto-temporal dementia research. Another person suggested research into the issue of fits in dementia and how to deal with them.

Carers' involvement

Some carers in the focus groups talked about their own experiences of helping relatives and others in research. Carers were often left “out of the loop” with little information. One solution was to have written information produced specifically for the carer, to explain how they can be involved in decision-making and what role they might offer to the patient. For

example, carers shouldn't need to ask when they can and cannot accompany a patient during tests. Also, on the subject of advanced directives, reliable advice on its impact on research might help.

Appendix: Quotes from the Two Focus Groups

Case register

- *"I think it's a very good thing - the case register. I think if GPs were more aware that actually they could go onto this register, maybe people would be caught earlier for research."*

Failures in general NHS care for patients with dementias puts people off research
A carer described how once her husband was left for a very long time in badly soiled clothes and important tests were not done...

- *"Sometimes Alzheimer's patients are treated worse than animals."*
- *"It's awful how carers are treated sometimes by the professionals, and not involved in discussions. It was [nurse's] attitude – saying stupid things. It makes me feel as small as a spider, and after that I thought, 'What's the point of coming to something like this'."*
- *"And then you wonder why, possibly, if someone had approached me then about research, I would have said no."*
- *"What is so appalling is that one still can come at this time and hear stories that we've just heard about what happens on the ground."*

Dissemination and implementation

'Newcastle has been ahead of the game on dementia research for 30 years, but...'

- *"Research on its own is useless without good practice being managed and funded. It can only be spread if it is properly funded. All the change, not just in practice, but in the reorganisation of hospital services and social services over and over again, does nothing to help that, and has probably broken up instances of good practice that were being spread and then had to close up their shop."*
- *"It's not just research its good practice that was known about, it's the implementation of these good practices and what do we hear about that happening? There's no point in the research happening if you then feel that it doesn't matter. Someone's made a name for it and has maybe moved up the career ladder, fine for them, but it's what happening on the ground, it's the stone and the ripples - we want to see that dispersed and that good practice. Who is doing that, who is ensuring that good practice is spread?"*