



How DeNDRoN helped boost recruitment

The Dementias and Neurodegenerative Diseases Research Network (DeNDRoN) supported the delivery of a clinical trial involving care home residents from across the UK. This trial has resulted in an engaged network of care homes that can support the development and delivery of future studies.

Conducted by the Thames Valley DeNDRoN Local Research Network (LRN), the trial was the first time a multi-centre study had been carried out involving patients residing in care facilities. This case study discusses the methods employed by LRN staff and the challenges they faced.

Background

The study, titled MAIN-AD, was designed to evaluate the use of memantine as a potentially safer alternative to neuroleptics (sedative drugs) in patients with Alzheimer's disease (AD).

Some AD sufferers experience mood swings, anxiety and agitation, all of which present challenges for the individual, family and practitioners. Neuroleptics have often been used to manage these symptoms, however recent research suggests that this type of medication can be detrimental.

The MAIN-AD study took place over 24-weeks and involved 184 participants with AD in care homes. The LRN was involved in the set up of local sites, recruitment of participants and delivery of the study.

Challenges

- Recruiting participants: The number of eligible residents within the Thames Valley

region was significantly lower than had been originally anticipated as doctors were no longer prescribing sedative drugs due to the associated side effects. This resulted in the study's overall target of 300 participants being revised down to 184.

- Resource intensive: In order to get close to the target the LRN contacted almost 240 care homes to recruit residents.
- Red tape: Delays in getting the necessary approvals from the Clinical Trials Unit and NHS research and development (R&D) departments meant some time elapsed between researchers initiating the idea, writing the protocol and getting the study started.
- Local regulatory guidance: One Primary Care Trust R&D department had a different interpretation of local regulatory guidance in relation to the approval processes. This meant that access to residents was limited to those

under the care of secondary NHS clinical teams on one site, restricting the pool of potentially eligible participants.

- Denied access: Some care home groups denied access to their homes to conduct research.

Approach

A designated research team was set up to conduct the study. It included nurses, research assistants, psychologists, study doctors and the administrative team. The LRN then implemented the following recruitment strategies:

- 1. Establish a list of care homes using the local Care Homes Booklet** published by the county council social services department. To increase the success rate of care homes willing to support the study the LRN approached care homes via the Community Mental Health Team.
- 2. Identify potential participants via members of the Community Mental Health Team (CMHT).** The team drew on existing links with CMHTs, emailed clinicians, posted information on boards and intranet sites, provided training sessions for CMHT members on research-relevant topics and liaised with inpatient staff to alert the research team to people about to be discharged to care homes. The LRN assigned each CMHT a member of the network research team to act as named contact. These nominated individuals attended meetings and liaised closely with the CMHT to actively promote research, including the MAIN-AD study.
- 3. Identify potential participants** by looking at residents' notes and drug charts.
- 4. Encourage care home staff and GPs to make direct referrals to the study.** A GP (member of the network team) also liaised directly with other GPs to raise awareness of the study and increase recruitment.
- 5. Contact residents and seek consent.** The LRN either contacted the care home residents and carers directly or via a representative who makes decisions on behalf of the person such as care home staff or the CMHT. Once the resident and/or the consultee had consented to taking part they were sent copies of the patient information leaflets and given an opportunity to talk to a member of the LRN.
- 6. Open new sites to expand the pool of potentially eligible participants.** Initially recruitment activity took place in just one

county; recruitment was subsequently extended to all three counties within the region.

Outcomes

As a result of the study the Network now holds a list of care homes that are interested in being involved in future research, all of which can be easily identified through the Network database.

To maintain relationships the network invites care home managers to professional development events, keeps them up to date via a newsletter and follows up with residents taking part in other non-care home specific portfolio studies.

Lessons learned

The Thames Valley LRN has recommended a number of ways that could improve the design and delivery of future dementia-related studies within a care home:

At the study design phase:

- Ensure the recruitment strategy is as broad as possible.
- Scope out local populations to help set realistic targets.
- Target all organisations that support people with dementia and their carers. For example, residents can be recruited via GPs, CMHTs, Age UK and Dementia UK.

When carrying out the study:

- Provide education about clinical research to care home staff to help them understand why research is necessary and what the benefits are.
- Utilise existing links with DeNDRoN and CMHT and explore ways of maintaining them.
- Involve and inform a wide range of care home staff in the progress of the study.

For more information

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