



# Royal College Recognition of Research

Memory Service National Accreditation  
Programme Supports Research

## Project Description

'We want more people into clinical trials; more people getting that chance to get the very latest drugs. Our ambition is this: at least 10 per cent of people with dementia should be able to take part in clinical trials – up around ten times from today'. This statement, from the 'Prime Minister's Challenge on Dementia: Delivering major improvements in dementia care and research by 2015' has given the work of the Dementias and Neurodegenerative Diseases Research Network (DeNDRoN) a significant boost. In order to ensure that this research message was implemented in a very tangible way, the organisation worked with the Royal College of Psychiatrists to obtain two new standards in the Memory Services National Accreditation Programme. These standards guarantee that services seeking accreditation service provide people with dementia and their carers with information about opportunities to participate in local, national and international research and that all people with dementia and their carers are offered the opportunity to register their interest in participating in research.



PARTNERSHIP



CASE STUDY

Successive governments in the UK have invested in scientific and medical research as well as in the National Health Service (NHS). The meeting point for many of these new initiatives is the clinical research networks which provides the infrastructure to allow high-quality clinical research to take place in the NHS. The benefit for patients is access to new and improved treatment and, of course, the tantalising promise of better health.

## Project Design and Implementation

Dementias are currently one of our biggest healthcare concerns. There are over 670,000 people with dementia in the UK and, with one in three of us over the age of 65 predicted to develop dementia, this number is set to double in the next 30 years.

The Prime Minister's Challenge on Dementia published in 2012 specified several ambitious aims to deliver major improvements in dementia care and research by 2015. The goals include a significant increase in the volume of research and to have at least 10 per cent of people with dementia being able to take part in clinical trials, a figure around ten times what it currently is. The document also set out a desire to increase the proportion of memory services accredited to the Royal College of Psychiatrists.

Over the past five years NHS mental health trusts have established Memory Assessment services. These specialist services particularly support patients with dementias. Their function is to provide quick and accurate diagnosis, and long term support to meet the needs of patients, coping with the increasing number of referrals and National Institute of Clinical Excellence (NICE) guidance. The Memory Services National Accreditation Programme (MSNAP) aims to provide those services that meet certain standards with accreditation from the Royal College of Psychiatrists. To do this, the programme provides support and encouragement so that services are constantly improving and striving towards higher standards and engages with staff in a comprehensive process of review, through which good practice and high quality care are recognised.

To ensure that research remained high on their agenda, the Dementias and Neurodegenerative Diseases Research Network (DeNDRoN) embarked upon a project to work closely with the Royal College of Psychiatrists to increase the opportunities for people with dementia and their carers to participate in high-quality research, and to deliver on the requirements laid out in the Prime Minister's Challenge on Dementia.

## Project Design and Implementation

The project kicked off with a direct approach from Adam Smith, programme manager with DeNDRoN, to the Royal College. 'There are around 200 specialist memory services across England. DeNDRoN has good working relationships with many, however often those sites are the ones that are research active. I wanted to ensure that more patients had a chance to be involved in research. MSNAP promotes providing the best possible service for patients, and it seemed logical to ask services working to those standards to work with the research communities and discuss research with patients. Thanks to the Prime Minister's Challenge on Dementia, there is now a push to ensure that as many memory services as possible are accredited. He continues 'We attended the College's annual conference which was specifically about adhering to the new standards and we made contact with a number of the key people who helped us to drive this forward'.

## Impact of the Project

The main outcome from this piece of work was that the network successfully managed to introduce two new standards to encourage research involvement into the MSNAP.

The first of these, MSNAP Standard 1, ensures that people are given the opportunity to participate in research including in studies and trials that are part of the National Institute for Health Research (NIHR) Clinical Research Network portfolio:

### Research in Memory Services – MSNAP Standard 1

The service provides people with dementia and their carers with information about opportunities to participate in local, national and international research, such as National Institute for Health Research (NIHR) portfolio studies

In practice, this means that there will now be a general promotion of NIHR research including the distribution of literature and the display of posters as well as active support of DeNDRoN to identify patients and carers who may be eligible to participate in studies. The standard also means that the network will be able to promote appropriate studies to suitable participants.

The second, MSNAP2, gives people the opportunity to register their interest in research by signing, for example, a 'consent for contact' form:

### Research in Memory Services – MSNAP Standard 2

The service ensures that all people with dementia and their carers are offered the opportunity to register their interest in participating in research

These standards are further supported by the introduction of a new quality indicator, which requires MSNAP participants to record the percentage of people with dementia who register an interest in participating in research.

'The process of working with the College also had a very positive effect on the number of contacts that we had' says Natasha Carrick, Communications Manager with the network. 'It opened up several new avenues for us. For example, we now have contact with new memory service clinics across the country where we really had no contact before, increasing the potential number of people having the choice to be offered research. Instead of research being a postcode lottery, more and more centres are now becoming accredited and being measured on research'.

## Challenges and Learning Points

This high-level project had several challenges but none that was insurmountable. The work took about a year to come to fruition and there is, of course, the realisation that this will not result in an immediate increase in recruitment. It could take some time before the beneficial effects of having these MSNAP standards will manifest in greater numbers of people being actively involved in research studies and clinical trials.

Going forward, however, there may be other challenges on the horizon. Many memory services have a long history of research involvement but, as new reforms in the NHS take a foothold and we move towards a commissioning-led system, it may be that new services are commissioned and set up in areas without this tradition. Moreover, some commissioners may not have research high on their agenda.

For staff, there is the additional challenge that many do not feel suitably skilled up to be involved in research and remain sceptical about the actual impact of research and wary about its effect on their patients.

'Having a policy compels organisations to act, however policies need to be successfully implemented if they are going to deliver the expected benefits. The next step for us was, and continues to be, to work with the accredited memory services to implement a register for interest in participating in research and help services engage with the local research communities. DeNDRoN is currently developing a portal which would allow NHS patients to register themselves into a national register. Once complete it should be much easier for Memory Services to signpost or to register patients directly into this register via a website' says Adam. 'We also need to recognise that the network can actively help healthcare teams by informing them about research and helping them to source the appropriate training like Good Clinical Practice and how to take informed consent. This will deliver long-term benefits for study recruitment and will improve patient access to research. I feel sure that there could be similar advantages in other disease areas' he concludes.

Recent top down drivers have given a major boost to dementia research. The new accreditation standards will help to raise its profile with services and, whilst there may not be a simple, 'one size fits all' solution that will meet the needs of each service, DeNDRoN appreciates the significance of this piece of work and will be working to ensure that it offers a significant resource for services aspiring to meet the challenge.



## PATIENTS IN RESEARCH

### Tips

- Actively seek out opportunities to work with relevant Medical Royal Colleges and other national bodies to promote research
- Recognise the early adopters of any new initiative and work with them to encourage take up by others and support people to implement policies and guidance
- Ensure that timely and relevant literature is made available to Trusts that are involved in research and work with them to promote NIHR research
- Encourage healthcare professionals working in the area to contact their nearest DeNDRoN local research network for support to become familiar with studies available to promote to patients
- Signpost healthcare professionals to available training like Good Clinical Practice that will allow them to be able to conduct high quality research



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