Partnership on 1st January 2012 to form the Norfolk and Suffolk NHS Foundation Trust. This means that DeNDRoN East Anglia is now hosted by one of the largest mental health trusts in the country.

Whilst we await the outcome regarding the funding of all the research proposals submitted to the NIHR Dementia Themed Call, it is anticipated that we will have a lull in the number of dementia studies actively recruiting over the next few months. We will be taking advantage of this in order to run a number of projects that have been set up under the Interact Project. In East Anglia we will be focussing on three areas:

- The development of consent lists (which will allow all patients receiving a new diagnosis of dementia to register their interest in participating in research)
- The involvement of Primary Care Dementia Services (such as the new Primary Care Dementia Practitioners who recently started in Norfolk) in increasing the awareness of dementia research in Primary Care
- Increased integration between DeNDRoN East Anglia and the Voluntary Sector

The autumn of 2011 was a very busy time for DeNDRoN East Anglia. On 26th September we held a very successful joint meeting with the NIHR CLAHRC (Collaborations for Leadership in Applied Health Research and Care) for Cambridge and Peterborough at the Trinity Centre, Norwich. The event was fully booked with over 80 people from many different backgrounds being able to attend.

The following month we were visited by a team from the DeNDRoN Coordinating Centre who spent the day listening to a variety of presentations in a meeting held at the University of East Anglia. We have received very positive feedback from the visit; the Coordinating Centre is very pleased with the progress that we have made in East Anglia over the past five years. Although East Anglia has the smallest population of all 7 DeNDRoN Local Research Networks (2.2 million), on a per capita basis our accrual rate into studies in 2010-2011 was second only to that achieved by North East DeNDRoN. We have a proven track record of developing new research sites and new principal investigators.

So what will 2012 hold for us?

We have already had a notable success in that all Acute NHS Trusts within DeNDRoN East Anglia are now actively involved in research into Parkinson’s Disease. Suitable patients across Norfolk, Suffolk and Cambridgeshire, wherever they live, will have the opportunity to participate in the PRoBaND Study (please see next page).

As many readers will already know, our host Trust (previously known as Norfolk & Waveney Mental Health Foundation Trust) formally merged with Suffolk Mental Health Partnership on 1st January 2012 to form the Norfolk and Suffolk NHS Foundation Trust. This means that DeNDRoN East Anglia is now hosted by one of the largest mental health trusts in the country.

The aim of all the projects is to assess the efficacy of these approaches in improving awareness of and access to research studies for patients and carers who wish to participate. Other projects are being run in all the DeNDRoN Networks and by this time next year we should have a much clearer idea of which approaches are most effective in allowing more patients and carers of patients with neurodegenerative conditions to participate in research studies.

Andrew Tarbuck
Director, DeNDRoN East Anglia
PRoBaND (Parkinson's Repository of Biosamples and Network Datasets) is a prospective multi-centre observational study and will be the largest long-term Parkinson’s study that the UK has ever seen.

A total of 3080 subjects will be recruited from 25-30 centres across the United Kingdom, which makes this a very exciting study with huge implications for Parkinson’s research in the future.

It will run at every acute trust in East Anglia which is an important step forward in Parkinson’s research for a number of reasons:

- A larger number of patients will have greater access to research, with consequential higher levels of awareness, involvement and expectations for PD research in the future.
- PRoBaND can build up effective partnerships with sites that have not had our involvement in the past in order to attract, facilitate and support future PD studies.
- The requirement for large sample sizes in PD research is now recognised as crucial, both nationally and internationally. The common theme in such studies is early and prospective detailed recording of the clinical phenotype, to capture variability.

The project will run for 5 years, and aims to identify genetic and biomarker factors which affect the expression of Parkinson’s Disease. It will be exploring the reasons for variability in the way PD affects different people, and the findings will in the future help the testing of treatments in those at risk, in the hope of delaying disease onset, or preventing the disease from developing.

The study involves interviews to measure the motor and non-motor features and the response to medication in people with Parkinson's disease. Blood tests will be taken and tested for known genes relating to Parkinson’s and for potential new markers of the disease.

First degree relatives will be invited to take part in order to determine whether Parkinson’s disease can be identified earlier than presently, allowing for the treatment of symptoms at an earlier stage and ultimately preventing the disease developing.

In order to join the study, patients need to be diagnosed within the past 3 years, or diagnosed under the age of 50. First degree relatives that are able to access one of the PRoBaND study centre are invited to join the study.

If you would like further details about the study, please visit: www.proband.org.uk
Or contact Kim Clipsham, Senior Research Nurse at k.clipsham@nhs.net or 01603 421736

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<tr>
<th>Location</th>
<th>Principal Investigator</th>
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<tbody>
<tr>
<td>1 Queen Elizabeth Hospital, King’s Lynn</td>
<td>Dr Pradip Sarda</td>
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<tr>
<td>2 Norfolk &amp; Norwich University Hospital, Norwich</td>
<td>Dr Paul Worth</td>
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<td>3 James Paget University Hospital, Gorleston</td>
<td>Dr Warren Woodward</td>
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<td>4 Ipswich Hospital, Ipswich</td>
<td>Dr Andrew Graham</td>
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<td>5 West Suffolk Hospital, Bury St Edmunds</td>
<td>Dr Graham Lennox</td>
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<td>6 Addenbrookes Hospital, Cambridge</td>
<td>Prof Roger Barker</td>
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<td>7 Hinchingbrooke Hospital, Huntingdon</td>
<td>Dr Colin Borland</td>
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<td>8 Peterborough City Hospital, Peterborough</td>
<td>Dr Sunku Gupta</td>
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Patients and carers discuss new ideas for research into dementia

A panel of patients and carers met in Cambridge in September 2011 to discuss new ideas for research into dementia. All the members of the panel had personal experience of dementia and were able to offer researchers the insights that come from daily contact with the disease.

The panel discussed anti-psychotic medications in care homes, hearing loss and dementia, how to estimate the number of people in England with dementia and ways to help patients and carers manage the condition.

Questions asked included: Would patients and carers be willing to take part? Do patients and carers think the research is worthwhile? What are the barriers to taking part?

By the end of the day the researchers had plenty of food for thought.
Positive recruitment to the SHIELD Carer Supporter Programme

With help from CMHT colleagues across the Norfolk localities in Norfolk and Suffolk NHS Foundation Trust, the Norwich DeNDRoN team have successfully recruited over 40 carers and people with dementia to the SHIELD study. Depending on the outcome of their randomisation, some family carers are now in regular contact with their Carer Supporter volunteer, this person being an experienced carer of someone with dementia. Facilitated by Doreen Harrison at Age UK Norfolk, this supportive relationship lasts for up to 10 months to see if this can go some way to improve the health and well-being of carers.

Some participants in the study have had the opportunity to take part in a reminiscence group held over 12 weeks at the Costessey Centre in Norwich, which the family carer and person with dementia attend together. The first group began meeting back in October 2011, and Pabulum coordinator Diane Collins reports that members of the group are having a very enjoyable time sharing memories and really getting to know each other. The second group begins on the 2nd February 2012.

Frequently Asked Questions to DeNDRoN Staff

Members of the DeNDRoN team frequently attend meetings throughout East Anglia, providing information about their research. These meetings provide opportunities for patients, carers, clinicians and prospective researchers to ask about research and about how DeNDRoN can help. We thought it might be helpful to regularly share some of their questions with you. You are welcome to contact us with your own questions.

My mother has dementia and might like to help with some research. What should she do to get involved?

The best source of information on present clinical research is the NIHR portfolio of clinical studies (http://public.ukcrn.org.uk/search/). You can also discuss this with your doctor or you can also telephone us at DeNDRoN (01603 421850). With your permission, we could let you know about future studies that you may be able to contribute to.

What is PPI? What can they do for me?

The acronym PPI refers to Patient and Public Involvement, an imperative for improving services throughout the NHS. Patients and carers can provide great insights into how clinical research studies can be designed or improved. Clinicians designing new studies are often keen for comment and advice from patients and carers on study design and DeNDRoN actively encourages this. Funding for research is often conditional on patient and public involvement. DeNDRoN, too, involves patient and carers at all levels including strategy and policy development for improving clinical research.

“It is time-consuming to travel and difficult to park at hospitals. Can the researchers come to me?”

Often, yes. DeNDRoN staff will always be as flexible as possible. Sometimes the research needs to happen in a hospital clinic or GP surgery though much of our work with patients or carers is within their own homes.

Will Hammerton Court be able to support research?

Hammerton Court is the recently commissioned Dementia Intensive Care Unit in Norwich at the Julian Hospital. It will provide high levels of expert care, training and academic research. DeNDRoN supports equally high-quality research throughout all areas of the region; in hospitals; in small clinics and GP surgeries; and in patients’ homes.