

Research in Memory Services

Dr Chris Ball



Top Level - Political support

“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”

March 26 2012: Prime Minister’s Challenge on Dementia: Delivering major improvements in dementia care and research by 2015

Drive
improvements in
health and care

Create dementia
friendly
communities

Better research

Where we fit in...

Supports facilities for research
(e.g. Biomedical Research Units)

Commissions and funds NHS and social care research

National Institute for Health Research

Trains and develops researchers

The Clinical Research Network:

Provides practical support researchers need to run clinical studies in the NHS, allowing more studies to happen, and more patients to take part.

- Cancer
- **Dementia and Neurodegenerative Diseases**
- Diabetes
- Medicines for Children
- Mental Health
- Stroke
- Primary Care
- Comprehensive

The local DeNDRoN community

Locally we provide researchers with the practical support they need to make clinical studies happen in the NHS, so that more research takes place across England and more patients can take part.

- Dementia
- Parkinson's Disease
- Huntington's Disease
- Motor Neurone Disease



Increasing patient participation in research

How we are doing it

- Recruiting participants into our studies quickly
- Public involvement
- Embedding research in clinical practice
 - 100% coverage across England (CLRN / DeNDRoN partnership)
 - 18 improvement projects to evaluate and compare different ways to embed research.
- Developing a nationally consistent system for patients to register their interest in research – Patient Registers
- Developing a network of ‘research-ready’ care homes.

Benefits of becoming research ready

- Directly and indirectly enhances the quality of life for patients
- Can lead to professional development opportunities for staff.
- Can provide additional income to your service
- Provides your home with the latest in medical advances and clinical practice.
- Support from DeNDRoN local research network in the delivery of studies
- Demonstrates your commitment to the Prime Minister's ambition "10% of patients into clinical research"

New MSNAP Research Standards

Standard 1.2.6N

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

What does this mean in practice?

- generally promote NIHR research e.g. Literature distribution, display posters etc.
- actively support DeNDRoN to identify patients and carers that may be eligible to participate in studies e.g. receive study information and consider in terms of current patients and support recruitment
- allow DeNDRoN to appropriately promote studies to suitable participants
- join the DeNDRoN newsletter mailing list

How to meet this standard

- Contact your nearest DeNDRoN Local Research Network (LRN) for support.
- Become familiar with studies available and promote these to patients.
- Promote research through the literature and posters available
- Ask your patients if they would like to be involved in research and explain the benefits to them.

New MSNAP Research Standards

Standard 1.2.7N

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

How to meet the standard – 3 options

1. Contact with your nearest DeNDRoN LRN Office to be prioritised in local delivery plans. DeNDRoN will be able to provide an update on the approach being identified in your region.
2. DeNDRoN is currently developing a portal which would allow NHS patients to register themselves into a national register. Once complete it would be possible for Memory Services to sign-post / register patients directly into this register via a website. Details will become available through www.dendron.nihr.ac.uk
3. Memory Services could link with local researchers to develop local registers / lists, which suit their needs. DeNDRoN LRN Offices will be able to help you identify researchers, and options for delivery which meet national standards around Minimum Datasets and Information Governance.

Quality Indicators

Memory Services working with DeNDRoN can expect support to measure the number of patients coming on the register, allowing Memory Services to measure against this required indicator.

Indicator	Numerator	Denominator
The percentage of people with dementia who have registered their interest in participating in research over the past year	The number of people with dementia registering their interest in participating in research over the past year	All people with dementia who have had an appointment with the service in the past year

Further information

Please visit our website or contact us on:

T: (020) 3206 4960

E: info@dendron.org.uk

W: www.dendron.nihr.ac.uk

The screenshot shows the DeNDRoN website homepage. At the top left is the DeNDRoN logo with the tagline 'Dementias & Neurodegenerative Diseases Research Network'. To the right is the NHS logo and 'National Institute for Health Research' with a search bar. Below the logo is a navigation menu with tabs for 'Discover DeNDRoN', 'Researchers', 'Patients and Carers', 'Industry Partners', and 'Health Professionals'. The main content area features a large image of a woman looking at a petri dish with pink cells, with a red button below it that says 'Click to Stay up to Date on Research'. To the right of this image is a map of the UK with a red button 'About DeNDRoN' and a list of links: 'Find Your Local Network' and 'Search for Studies'. Further right is a 'Research Areas' section with a red button and a list of research areas: 'Dementia Research', 'Huntington's Disease Research', 'Motor Neurone Disease Research', 'Parkinson's Disease Research', and 'Other Neurodegenerative Diseases'. Below the main content area are three sections: 'FIND OUT MORE' with a list of links, 'NEWS' with a 'View All News' button and two news items, and a red circular 'FEATURE' badge that says 'NIHR/ESRC Funding call for social science research on dementia'. The news items include 'Clinical research starts from day 1: induction', 'DeNDRoN signs MND Charter', and 'Parkinson's disease research – getting involved'.