

## LINCOLNSHIRE COUNTY FLIES THE FLAG FOR DEMENTIA RESEARCH

The county of Lincolnshire have come together to support people with dementia and their families in getting involved in research. All three of Lincolnshire's NHS Trusts and Lincolnshire County Council have joined forces and pledged to be a Join Dementia Research champion county.

### How Did This Initiative Start?

Join Dementia Research is a service where people with dementia or memory problems, their carers, and anyone 18 or over can register their interest in participating in dementia research. Signing up is the first step in becoming involved in supporting vital research studies.

Goizeder Aspe Juaristi, Dementia Project Manager at the NIHR Clinical Research Network East Midlands, initially started discussions with Tracy McCranor, Research and Development Coordinator, at Lincolnshire Partnership NHS Foundation Trust, about how Trust staff could champion Join Dementia Research. Having Join Dementia Research champions within the Trust led to patients being encouraged to express any interest in research by signing up to the service. The Trust's Chief Executive, Dr John Brewin, were among those who signed up as a Join Dementia Research Champion during Dementia Action Week in 2017.

*"The Lincolnshire Partnership NHS Foundation Trust (LPFT) research delivery team have been the driving force to raise awareness of Join Dementia Research in the Trust and across the wider county health and social care environment. We have led this work with great enthusiasm and many county residents are now taking part in research as a result of Join Dementia Research. I could not be prouder of our achievements."*

**Tracy McCranor**  
Research and Development  
Coordinator, LPFT



Goizeder Aspe Juaristi, Dementia Challenge Project Manager,  
NIHR Clinical Research Network East Midlands

Discussions around truly embedding the concept of people expressing interest in taking part in research led to the idea of the organisation becoming a Join Dementia Research champion. Proactively led by the NIHR research delivery team, Lincolnshire Partnership NHS Foundation Trust registered as a whole organisation Join Dementia Research Champion – the first NHS Trust in the country to take this innovative approach.

Being the first to become a whole organisation Join Dementia Research champion, however, meant that there was no precedent to follow. Thus, a delivery group was formed of key people (including clinicians, communications colleagues, researchers) within the Trust and an ambitious action plan developed to integrate Join Dementia Research into the core work of the Trust. The executive lead for this work was Dr Sue Elcock, Medical Director, Lincolnshire Partnership NHS Foundation Trust.

The aim of the action plan was to ensure that all staff were aware of Join Dementia Research, for the service to be promoted within individual teams and buildings, and most importantly, for staff to signpost Join Dementia Research to patients with dementia and their carers. Activities from the action plan included improving visibility of Join Dementia Research in all Trust communications and disseminating information about the service to Trust staff during dementia training.

### Collaboration

The success of this initiative depended on county-wide collaborations. Dr Sue Elcock got in touch with the Board of Lincolnshire's acute hospitals Trust, i.e., the United Lincolnshire Hospitals NHS Trust, to explain the plan of action and highlight how the Trusts could work together on their Mental Health strategy.

Working together, the two Trusts then explored the possibility of a county approach to advocating Join Dementia Research - where the county council, local Alzheimer's Society, Clinical Senate, and Clinical Commissioning Groups were approached to get involved. An event was then held to launch their combined work in highlighting the importance of embedding dementia research in care. The event saw people from across health and social care, research, commissioning, higher education and third sector organisations collectively committing across Lincolnshire to becoming Join Dementia Research champion organisations, and thereby, becoming a county-wide champion.

Commitment from Lincolnshire County Council (LCC) included details of the Join Dementia Research service being added in the council's Dementia Strategy – which looks to improve the experiences of individuals with dementia and their families in Lincolnshire.

Paul Herniman, Commissioning Officer at LCC, stated that "LCC endorses the priority given to dementia research by national and local dementia policy. Supporting Join Dementia Research is vital to developing the best treatment and support for affected individuals and their families."

*"Initially the plan was for United Lincolnshire Hospitals NHS Trust to follow Lincolnshire Partnership NHS Foundation Trust's lead and sign up for Join Dementia Research. Then we heard Lincolnshire Community Health Services NHS Trust were interested and with the county council's refresh of the Lincolnshire joint dementia strategy, it was agreed that we would all just embrace this for our patients and their families across the county."*

**Jennie Negus**  
Deputy Chief Nurse, United Lincolnshire Hospitals NHS Trust

### Long-Term Planning

Gozeder has emphasised that this is a long-term plan. With so many partners, Gozeder is aware that the project relies on the commitment from all the organisations. She highlighted the need of county-wide engagement to remain a priority for the initiative to become successful and sustainable.

Recently, Lincolnshire Community Health Services NHS Trust also committed to becoming a whole organisation Join Dementia Research champion.

Ensuring that Join Dementia Research becomes a part of the culture of each organisation can be challenging. United Lincolnshire Hospitals NHS Trust has made a significant step of adopting change by adding the 'Provide a Join Dementia Research leaflet' to their Trust's Dementia Care Bundle - a set of interventions used for patients with dementia; with the intention to significantly improve patient outcomes.



The team who enabled Lincolnshire to be the first Join Dementia Research champion county

### Starting Conversations About Research

This project has also explored how clinicians can start a conversation about research with their patients.

Join Dementia Research is a great solution for clinicians, since it does not take long to tell patients about it. The clinicians also do not need to know anything about research studies that are currently taking place, since people who register for the service will automatically match to studies they may be eligible for and find out more about each study. They can then decide if they are interested in participating.

Derek Stewart OBE, Associate Director for Patient & Public Involvement and Engagement at the NIHR Clinical Research Network, also recommended having more engaging conversations about research.

Rather than simply saying, "Have you considered taking part in research?" he recommends using the following phrase to create more impact:

"We are doing so much to try and find the answers to your questions. This campaign, Join Dementia Research, is at the forefront of asking questions about treatment, diagnosis, and care. Have a look at [this short YouTube clip](#) while I finish your notes."

Tracy McCranor and Carol Duff, Consultant Occupational Therapist and Senior Lecturer at the School of Health and Social Care at the University of Lincoln, are also collaborating to introduce Join Dementia Research into training curriculums. The vision is for every nurse and allied health professional qualifying in Lincoln to be prepared and ready to talk to their patients and spread the research message.

*"The work going on in Lincolnshire is a great example of the statutory and voluntary organisations across health and social care working together with the community. It is that real understanding that dementia is a condition that demands a joined up approach, which includes finding some of the answers through high quality research. Lincolnshire and Lincoln City have grasped this opportunity to help patients and their carers whilst providing information about Join Dementia Research. The strong hope is that this will lead to good multidisciplinary research, which invites the public to comment on study developments as well as taking part."*

**Derek Stewart OBE**

Associate Director for Patient & Public Involvement and Engagement, NIHR Clinical Research Network

### Coming Together as a County

Lincolnshire county is well underway to ensuring Join Dementia Research is introduced in the clinical pathway, with the formulation of the Mental Health Trust's action plan, initiation of the Hospitals Trust activities, County Council engaging through their Dementia Strategy, and the County's Community Health Services NHS Trust also coming onboard. The county was able to successfully establish themselves as the first county to be a champion of Join Dementia Research.

Rachel Redgrave, Mental Health Lead at Lincolnshire Sustainability and Transformation Partnership, stated that "The Lincolnshire Dementia Strategy acknowledges that it is paramount that the people of Lincolnshire have access to and contribute to dementia research; all health and social care providers are committed to this vision."



### Hopes for Replication

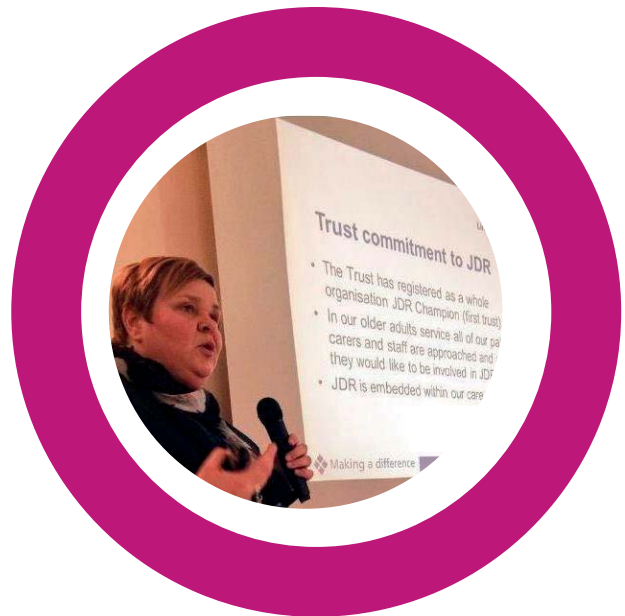
As the Government's Dementia 2020 Challenge policy includes targets of 25% of people with dementia being registered on Join Dementia Research and 10% of people with research taking part in research, it is significant these activities are recognised as important steps towards these objectives.

With Lincolnshire having such success working together, it is hoped that other counties around the nation will follow suit and work collaboratively to see Join Dementia Research offered to patients with dementia, and their carers and families, as part of the regular care pathway.

As Derek Stewart added: "If we can get this to work in Lincolnshire with all its rural complexities then it is possible anywhere in the country. Wouldn't that be fantastic!"

### Top Tips

- Ensure you have a strong team leading the initiative
- Look to engage all NHS Trusts and the County Council in the region – drawing on Dementia Strategies
- Make sure organisations are aware of the Government's Dementia 2020 Challenge policy
- Look to keep all organisations engaged by having regular meetings to review progress
- Invite third sector organisations, such as the local Alzheimer's Society and other charities, to be involved in collaborations to champion Join Dementia Research
- Join Dementia Research can be integrated into existing care pathways, and training and induction programs



Carol Duff, Consultant Occupational Therapist at Lincolnshire Partnership Foundation Trust and Senior Lecturer at University of Lincoln

For more information visit:  
[nhs.joindementiaresearch.nihr.ac.uk](https://nhs.joindementiaresearch.nihr.ac.uk)