

Join Dementia Research (JDR)
The importance of embedding dementia research in care.



On 1st December 2017 26 people from across health, social care, research, commissioning, higher education, the 3rd sector organisations such as Carers First and Alzheimer’s Society and patient representatives came together at ULHT to collectively commit across the county to becoming JDR champion organisations and thereby a JDR Champion County. The launch event was to start planning this journey, to hear from experts in the field and to look into what we needed to do individually and jointly to make this happen. I welcomed everyone applauding this really exciting initiative with such a collaborative drive to contribute to what is perhaps one of the most under-researched conditions facing health and social care today. Dementia research gets 13 times less funding than cancer even though the cost to society is far greater (Oxford University) Treating and caring for cancer patients currently costs around £5 billion a year, but the bill for dementia is £11 billion, yet despite the huge burden of dementia just 8p is spent on researching new treatments for each £10 spent looking after people with the condition. In contrast, cancer research receives £1.08, more than 13 times more.....JDR can help to redress that balance and the aim for ULHT and Lincolnshire to become JDR champions is to see this begin to become a reality.

Derek Steward OBE (Associate Director for Patient & Public Involvement and Engagement at the National Institute for Health Research for the Clinical Research Network) had the audience enthralled with his opening address that looked at the importance of embedding dementia research in care. It was a great way to set the scene and to lay the footings for later discussion.

Tracy McCranor (Research & Development Coordinator) at our neighbouring Lincolnshire Partnership Foundation Trust then described her organisations journey; the ‘hows’ and the ‘whys’ and a generous open invitation to support all of us in taking our next steps with a message that ‘together we are better’.

Over a delicious (and diet wrecking) afternoon tea (very kindly funded by the NIHR) participants took part in a world café style workshop that looked to answer three key questions which have been summarised below.

What do we need to do as individual organisations to be ‘JDR’ ready?

- Brief our communication teams – be sure we can get the ‘messages’ out there.
- Work together – joint / connected working; better than in isolation.
- Take outside to the community, to carers & families.
- Signpost through dementia carers and carers organisations
- Include our volunteers; they can be champions
- Use CCG’s and GP’s information screens
- Communicate through our therapy services
- Advertise on Patient Line (bedside TV’s)
- Use social media
- Start the conversation.

What do we need to do collectively to be JDR ready?

- Communicate effectively across the partner agencies – be consistent in our message
- Education & awareness jointly
 - Events
 - Induction plans
 - Advertising
- Share best practice – get together
- Demonstrate how things have improved and steps made
- Patient (& service user) experiences & stories
- PALS when issuing Carers Badges
- Join the JDR Facebook page and twitter feeds

What help do we need?

- Leaflets & posters; our wards and departments need information and resources to hand
- ‘Care pathways’ across the organisation – so everyone knows the many opportunities and touchpoints
- Induction – add JDR information
- Show how can support revalidation
- Communications – get the info onto the intranet & internet, social media, case studies – let’s get the message out there!

To close the session participants made promises and pledges that included starting the conversation back in their teams and services and to come together with their local action plans and Eddie Alder, East Midlands Network Senate Senior Quality Improvement Manager summed up what he had seen and heard leaving us all buzzing and excited to truly make a difference to dementia care.

At ULHT with current winter operational pressures the plan is to pull a steering group together in early February to agree our action plan drawing from LPFT work and our research team having looked at this and considered how we can adapt this. It may be nice then in the Spring to come together across the county once more and share our progress, plans and experiences and to keep the collaborative aspirations flourishing.

Finally I would like to thank everyone who was involved in helping to get the launch event together; particularly to Goiz for securing such regional and national interest and support and to Tracy at LPFT for having the conversation with me in the first place!! Clearly too huge thanks to everyone for coming along and making the afternoon such a success.

Let’s make this happen – together.

JDR launch event participants	
Jo Walker	Lincolnshire Partnership Foundation Trust
Louise Higgins	Carers First
Katy Hoare	ULHT
Kate Truscott	Non-executive Director ULHT
Susie Butler	ULHT
Ali Raynor	CRN East Midlands
Zoe Leahy	ULHT
Debbie Jeffrey	CRN East Midlands
David Knight	ULHT
Tracey Pemberton	ULHT
Emma Wheatley	ULHT
Eddie Alder	NHS England
Richard Harding	SW Lincs CCG
Pauline Mountain	Patient Champion
Paul Herniman	Lincolnshire County Council
Sarah Haines	ULHT
Emma Clifton	ULHT
John Hudson	University of Lincoln
Dr. Tanweer Ahmed	ULHT
Clare Spendlove	ULHT
Rebecca Stanham	ULHT
Nicola Hine	ULHT
Deborah Birch	ULHT
Alison Strutt	ULHT
Karin Wistow	ULHT
Jenny Hinchliffe	ULHT
Jennie Negus	ULHT
Goizeder Aspe Juaristi	CRN East Midlands
Tracy McCranor	Lincolnshire Partnership Trust
Derek Steward OBE	NIHR