

DIAMOND-LEWY NEWSLETTER

Patient & Public Involvement



Improving the diagnosis and management of neurodegenerative dementia of Lewy body type in the NHS (DIAMOND-Lewy)

The story so far

Lewy body dementia (LBD) is the second most common neurodegenerative dementia, after Alzheimer's disease, yet it is poorly understood and challenging for doctors to diagnose and manage. This study is using information from patients, carers and experts to produce and test ways of improving practice. The assessment tools are now freely available to clinicians. We have now started collecting data to see whether diagnostic rates have improved. We have successfully completed the initial trial of the new management package for clinicians to use with people with Lewy body dementia. We have exceeded our recruitment targets – thank you to everyone who has taken part – we could not have done it without you!

Other news

As a thank you to our patient and carer participants in the North East and East Anglia regions of England the DIAMOND-Lewy study will be hosting two celebratory research dissemination events.



The first, in June, will take place at Ravenwood Hall, near Bury St Edmunds, and the second will be held at the Centre for Life in Newcastle during September. The DIAMOND-Lewy Patient and Public Involvement Group look forward to welcoming you to the Newcastle event.



Spreading the news

In May a number of DIAMOND-Lewy researchers presented at the annual Northumberland Tyne and Wear NHS Foundation Trust Research and Development conference in Newcastle. Dr John-Paul Taylor provided an update on the DIAMOND-Lewy study and a poster on the development of the management package. Claire Bamford presented a poster on the role of people with LBD and their carers in the development of the management package. Two papers about the study have recently been accepted for publication; further details are available on the DIAMOND-Lewy website.

Spotlight on variations in diagnostic rates

We investigated the frequency of diagnosis of LBD in nine services within two regions of the UK. Of people diagnosed with dementia, 4.6% had dementia with Lewy bodies. However, this proportion varied significantly both geographically and across different hospital services. Of people with Parkinson's disease, 9.7% had a diagnosis of Parkinson's disease dementia, with no significant variation between regions or services. These figures are much lower than would be expected, suggesting considerable under-diagnosis. This suggests that the systematic introduction of a more standardised approach to diagnosis would improve the rates of diagnosis of both conditions.

Patient & public involvement (PPI)

Our PPI group has been involved throughout the study. We volunteered because our lives have been touched by neurodegenerative diseases enabling us to provide a unique insight. Through regular meetings we aimed to help scientists and participants to communicate by:

- Making recruitment leaflets more friendly;
- Sharing our experiences with a new researcher;
- Contributing to programme management;
- Writing lay summaries of scientific papers.



If you would be interested in finding out more about PPI, please talk to us at the Newcastle afternoon tea event.

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