

# 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 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 trial of the new management package to see if it improves outcomes for people with Lewy body dementia will continue until the end of this year. We have almost reached our recruitment targets; so far we have recruited 125 patients and 122 family members. Thank you to all those who have taken part – your ongoing help is vital to the success of the study.

### What's new?

Feedback from the clinicians using the assessment toolkit indicates that it has increased awareness of LBD. Clinicians have also told us that the management toolkit:

- Is easy to use
- Provides up to date information, and
- Increases their confidence in managing LBD.

### Other news

Dr Joe Kane, the clinical researcher in Newcastle, has returned to Ireland to continue training as an old age psychiatrist; we thank Joe and wish him every success for the future. Joe has been replaced by Dr Sarah Lawley.

We currently seeking approval to screen patient notes in selected services to see whether the introduction of the assessment toolkit has increased the diagnosis of LBD.



## Spreading the news



Claire Bamford and Dr Joe Kane presented preliminary results from the study at the Alzheimer's Association International Conference in London in July. A research paper summarising non-drug interventions for LBD has been accepted for publication. This paper highlights the need for research to specifically look at how interventions which have been successful in other types of dementia could be used to help people with LBD.

## Spotlight on the assessment toolkit

The aim of the assessment toolkit is to speed the early diagnosis of LBD. It was developed by experts in the field and then tested by 11 clinicians. Their feedback was used to produce the final versions which are currently being used in the trial and are freely available to clinicians. We anticipate that the use of the assessment toolkit will address the under-diagnosis of LBD.



## Patient & public involvement (PPI)

We are beginning to plan two PPI events to thank patients and carers who have taken part in the study and to feedback key findings.

These free events will be held at Ravenwood Hall, Bury-St-Edmunds, on 13 June 2018, and the Centre for Life (pictured) in Newcastle-Upon-Tyne, on 24 September 2018, and will include afternoon tea. More information will be provided in the next newsletters and we hope to see many of you at one of these



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