

# DIAMOND-LEWY NEWSLETTER

*Patient & Public Involvement*

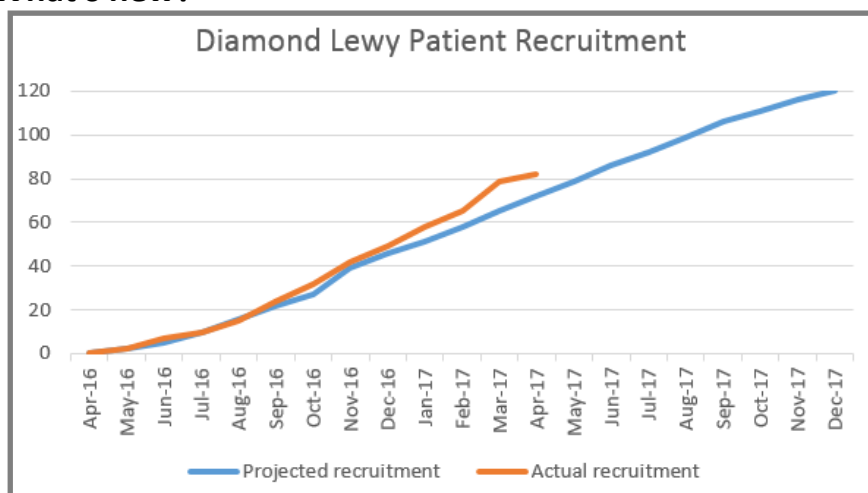


## Improving the diagnosis and management of neurodegenerative dementia of Lewy body type in the NHS (DIAMOND-Lewy)

### 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. We are currently undertaking a trial of a new management package to see if it improves outcomes for people with Lewy body dementia.

### What's new?



So far we have recruited 82 patients and 80 of their family carers.

Thank you to all those who have taken part and, though there is still some way to go, thus far helped recruitment to stay ahead of our projections.

### Other news

Professor John O'Brien, who leads the DIAMOND Lewy study, was awarded the Royal College of Psychiatrists 2017 Lifetime Achievement Award in Older People's Mental Health, with the award presented at the Faculty of Old Age Psychiatry annual meeting, Bristol, in March.



## Spreading the news

So far progress of the study has been published in three papers in academic journals and presented at nine conferences. Recently Dr Joe Kane, one of the research team, presented preliminary results on the diagnosis and management of dementia with Lewy bodies at the Royal College of Psychiatrists Faculty of Old Age meeting in Bristol during March 2017.

## Spotlight on patient experiences

We talked to 26 patients to explore the challenges of living with LBD. Many found it difficult to mix socially and to keep up interests and hobbies. One patient explained:

*“We used to have people to lunch or dinner, now it’s only tea or coffee.  
It’s scaling your life down to what you can cope with best.”*

Some patients found creative approaches to minimise these issues. It is important that professionals recognise the risk of isolation and work with each patient to find their individual ways of coping.



## Patient & public involvement (PPI)

Our PPI group has been involved from the start of the study. We volunteered because our lives have been touched by neurodegenerative diseases enabling us to provide a unique insight. Through regular meetings we have:

- Made recruitment leaflets more friendly
- Shared our experiences with a new researcher
- Refined the wording of patient & carer questionnaires
- Advised on acceptability of workload for patients and carers
- Contributed to programme management



If you would be interested in joining a PPI group, or for further information, please email [fms.engagement@newcastle.ac.uk](mailto:fms.engagement@newcastle.ac.uk) or call: Helen Atkinson on 0191 208 1287.

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