

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

### Welcome ...

to the summer 2017 issue of the bi-annual DIAMOND-Lewy study newsletter for professionals. The study has been very productive over the last six months with our wide-ranging work packages being at a differing stages of delivery and completion. Work packages one and two are closed to recruitment and at the data analysis and publication stages. The Management Toolkit has been developed in work package three and, correspondingly, the Assessment Toolkits have been developed and tested, with the Management Toolkit, in work package four. Work package five, comprising a clinical trial of the toolkits (WP5A&B) and process evaluation (WP5C), commenced in April 2016 and has, to date, consistently recruited above target.



*Amanda Weston, Project Secretary*

### Current practice in the diagnosis and management of LBD (Work Package 1)



Work Package 1 aimed to determine how common Lewy body dementia is within a range of NHS services in the North East and in East Anglia. We also aimed to establish the degree of the contact patients with Lewy body dementia receive from these services.

The WP1 team are in the process of disseminating our preliminary findings to both researchers and clinicians. We recently presented data at the Alzheimer's Society Annual Conference and the Royal College of Psychiatrists Faculty of Old Age Meeting, where Professor O'Brien was also presented with a Lifetime Achievement Award.

*Dr Joe Kane, Clinical Research Fellow*

*Prof John O'Brien & Dr Amanda Thompsell, Royal Society of Psychiatrists*

### Publications

Stinton, C., et al, 2014, A systematic review of management strategies for Lewy body dementia (dementia with Lewy bodies and Parkinson's disease dementia), *PROSPERO*, 2014.

Stinton, C., et al, 2015, Pharmacological management of Lewy body dementia: A systematic review and meta-analysis, *American Journal of Psychiatry*, 172 (8).

Thomas, A., et al, 2016, Development of Assessment Toolkits for Improving the Diagnosis of the Lewy Body Dementias: the DIAMOND Lewy Study, *International Journal of Geriatric Psychiatry*, 10 (1002).

Connors, M.H., et al, 2016, Non-Pharmacological Interventions for Lewy Body Dementia: A Systematic Review, *PROSPERO*, 2016.

### Conference Presentations

Presentations have been made at a number of international conferences, and, going forward, there will be three presentations at the Alzheimer's Association International Conference 2017 in London.



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## Clinical trial of the LBD management toolkit (Work Package 5A&B)

The clinical trial of the management toolkit for Lewy body dementia has been running since May 2016, with over 20 clinical services across North East of England and East Anglia now taking part. We are extremely grateful to all the clinical staff involved in recruiting and making the study run so smoothly.

We have recruited over 85 participants so far and have until the end of December 2017 to recruit a further 35 participants. Please do keep sending the referrals!

Our research nurses in East Anglia - Catherine and Marina (pictured), and Mike, Anita and Lucia at Dendron Northumberland, Tyne and Wear, have also been working hard visiting the participants in their own home to complete the assessments at baseline and then at three and six months.

We are particularly grateful to our many participants with Lewy body dementia and their families who have taken part so far. More than 20 have now completed the three visits. Below are some of their comments about taking part in DIAMOND-Lewy:

Participants with PDD:

*'I thought it would be beneficial to me and other people diagnosed with Parkinson's Disease'  
'absolutely go for it-take part'*



Carers (spouses) of patients with PDD:

*'I strongly believe in research. How are we ever going to find a cure if there is no research? It may not benefit ourselves at this moment but hopefully generations to come'*

*'the researchers were delightful and made the whole experience easy and straightforward'*

Carer (spouse) of a patient with DLB:

*'I feel being involved in the study has really helped me.'*

*Marina and Catherine from Windsor Research Unit – research team in East Anglia*

*Dr AJ Surendranathan and Allison Bentley (study team East Anglia)*

## Process evaluation of management toolkit (WP5C)

The importance of understanding the factors influencing the success (or otherwise) of new interventions is now widely recognised. The objectives of the process evaluation are to explore and understand:

- the acceptability and perceived value of any training provided;
- the extent to which clinicians integrate the assessment tool and management toolkit into their routine consultations
- the range and success of strategies used by clinicians to facilitate use of these resources
- the acceptability and perceived value of these resources in diagnosing and managing LBD.

We will be inviting clinicians to participate in interviews and/or focus groups over the next year. We would also like to observe clinics.

The data collected so far has given us some really valuable insights and we would be very grateful if participating clinicians would continue share their views and experiences.

*Claire Bamford, Research Associate*

### Lewy Body Society

Congratulations to the Lewy Body Society, which celebrated its 11th Anniversary on 6 June 2017.



**The Lewy Body Society**

*The more people who know, the fewer people who suffer.*

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