

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

**Welcome** to the Summer 2018 edition of our newsletter for professionals. It is hard to believe that we are now in the final year of the Programme. We look forward to the completion of data collection for work package 5 in July, having exceeded our original recruitment target of 120 (we recruited 131 subjects, a fantastic effort from all our participants and everyone associated with the study).

We are now repeating work package 1 (looking at diagnostic rates for DLB and PDD) in some services this year, to see if the Programme has achieved one of its aims to increase diagnostic rates for DLB and PDD over a 3 year period. We are extremely grateful to everyone for their tremendous support of the Programme thus far, and look forward to sharing some exciting results from these work packages next year.

We continue to disseminate results from the earlier work packages. The paper on differences in diagnostic rates for DLB and PDD between services has now been published (<https://alzres.biomedcentral.com/track/pdf/10.1186/s13195-018-0350-6>), as have our revised Assessment Toolkits that are updated to reflect changes to the DLB diagnostic criteria published last year (<https://research.ncl.ac.uk/diamondlewy/toolkits/>). We are producing a video to accompany the Toolkits, which will be available soon on our website (<https://research.ncl.ac.uk/diamondlewy/>), and we are also holding two major PPI events, one in June in East Anglia (Bury St Edmunds) and one in September in the North East (Newcastle).

*Prof John O'Brien, Chief Investigator*



### Work Package 1 Review (WP1R)

DIAMOND-Lewy Work Package 1 Review (WP1R) aims to determine the prevalence of DLB and PDD, and compare with data from Work Package 1 A and B. We plan to explore whether the implementation of the assessment toolkit to NHS clinical services has influenced diagnostic rates. We are very grateful to all the clinicians allowing us to screen their services for the DIAMOND-Lewy WP1R.

We have successfully completed the application processes REC and CAG. A condition of the CAG approval is we will need to ask to display small (A4 size) poster in services. The five trusts involved in WP1R are Northumberland, Tyne and Wear NHS Foundation Trust (the sponsoring trust), Cambridgeshire and Peterborough NHS Foundation Trust, Newcastle upon Tyne Hospitals NHS Foundation Trust, Northumbria Healthcare NHS Foundation Trust and Cambridgeshire and Peterborough NHS Foundation Trust. We are looking to starting screening in all the trusts.

*Sally Barker, Research Nurse*

### Process Evaluation of Management Toolkit (WP5C)

#### How are clinicians using the assessment and management toolkits in practice?

We are very grateful to all of the clinicians who have contributed to the process evaluation. Data collection is now nearly complete. A total of 57 clinicians have taken part in either interviews or focus groups. We have achieved a good balance of clinicians working in memory and movement disorder services, and have included doctors, nurses, trainee doctors and professionals allied to medicine. We have also observed 22 clinics or home visits involving a total of 53 patients and 46 family members. These data will provide a detailed picture of whether and how the toolkits have been used in practice.

The final questionnaire for the process evaluation will go out next month. This will be your last chance to share your views and experiences of the toolkits and we do hope you will complete and return the questionnaire.

Achieving a good response rate is crucial to give us confidence in the findings. We do hope that you will spare a few minutes to share your views.

*Claire Bamford, Senior Research Associate*



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## Clinical Trial of the LBD Management Toolkit (WP5A&B)

We would like to say a huge thank you to all the clinical teams across East Anglia and Newcastle who have taken part in the clinical trial of the Lewy body dementia management toolkit, and also used the assessment toolkits (WP5A&B). We finished recruiting patients and carers at the end of December 2017 and are delighted to say that 131 participants and 129 carers took part over the period of the trial. Staff from the local networks (Catherine & Marina, East Anglia) and Mike Kelly from Newcastle are due to finish their final visits this July. In order to say thank you to all the participants, and keep them informed of the progress we have made, we are organising a research event, with afternoon tea, in each area.

Allison Bentley, Research Nurse

### DIAMOND-Lewy Patient and Public Involvement Group

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 aim 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
- Refining the wording of patient & carer questionnaires
- Advising on acceptability of workload for patients and carers



DIAMOND-Lewy PPI Group

### Revision of Assessment Toolkits for Improving the Diagnosis of Lewy Body Dementia

As a consequence of new 2017 diagnostic criteria for DLB, the assessment toolkits have been revised and updated by Prof Alan Thomas, with these changes being reflected in a forthcoming editorial publication in the *International Journal of Geriatric Psychiatry*.

Further details can be found at: <https://research.ncl.ac.uk/diamondlewy/toolkits/>

### 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, including Dr John-Paul Taylor, whose presentation provided an update on the DIAMOND-Lewy study, and Claire Bamford who presented posters on *Principles for managing Lewy body dementia: patient and carer perspectives from the DIAMOND-Lewy study* (Bamford, C., Boyles, M., Killen, A., Finch, T., Taylor, JP, McKeith, I. & O'Brien, J.) and *The development of an evidence-based Lewy Body Dementia practical management toolkit: results from the DIAMOND-Lewy study* (Taylor, JP., Elder, G., Thomas, A., Allan, L., Stinton, C., Bamford, C., Burn, D., O'Brien J. & McKeith, I.).

### DIAMOND-Lewy Patient and Carer Events

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 have provided excellent advice regards the events, which is valued by the study team.



Amanda Weston, Project Secretary

### Selected Publications

Kane, J.P.M., et al. 2018. Clinical prevalence of Lewy body dementia. *Alzheimer's Research & Therapy*, 10:19.

Thomas, A.J., et al. 2018. Revision of Assessment Toolkits for Improving the Diagnosis of Lewy Body Dementia: the DIAMOND Lewy Study. *International Journal of Geriatric Psychiatry*, forthcoming.

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