

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

Welcome ...

to the winter 2017 issue of the bi-annual DIAMOND-Lewy study newsletter for professionals. The study has again 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), will close to recruitment at the end of December 2017 and has, throughout, successfully recruited above target. Additionally, a further sub-work package, aligned to work package one, (WP1R) will soon be introduced.

Amanda Weston, Project Secretary



Work Package 1 Review (WP1R)

We are planning to start the next part of the DIAMOND-Lewy Study Programme at the beginning of 2018. DIAMOND-Lewy Work Package 1 Review (WP1R) A and B aims to determine the prevalence of DLB and PDD in NHS clinical services, and compare with the prevalence and incidence data from Work Package 1 A and B. We want to establish whether the implementation of the assessment toolkit to NHS clinical services has influenced diagnostic rates. We plan to review medical notes of patients seen in selected services over an 18 month period. We remain extremely grateful to everyone who has facilitated the study and we are looking forward to working with you again on the new study WP 1R in the DIAMOND-Lewy Programme.

Sally Barker, Research Nurse

Process Evaluation of Management Toolkit (WP5C)

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

The process evaluation (WP5C) aims to understand whether and how the toolkits are used in routine practice. We are very grateful to those clinicians who have already given their feedback or allowed Claire to observe their clinics. This has been invaluable in helping us to understand different perspectives on the toolkits and how they fit with usual practice.

We are hoping to complete data collection in the next few months. If you are approached, we would appreciate your participation – the more clinicians who take part, the more confident we can be of capturing the full range of opinions. To ensure that all clinicians have an opportunity to provide feedback, we will be sending a final questionnaire early next year. Achieving a good response rate is crucial, so we hope that you will spare a few minutes to share your experiences.

Claire Bamford, Research Nurse

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International DLB Consortium

As you will probably be aware, since the last Newsletter the fourth report from the International DLB Consortium has been published (McKeith, I.G., et al. 2017. *Neurology*. Diagnosis and management of dementia with Lewy bodies: Fourth consensus report of the DLB Consortium. 89:88–100) which revises the DLB diagnostic criteria. Many member of the DIAMOND-Lewy study team made key contributions to the revision of the criteria and are co-authors on the paper, which was of course ably co-ordinated by Ian McKeith who has led the International DLB consortium since its inception. The key changes are that, in addition to the previous 3 core clinical features (spontaneous parkinsonism, fluctuation and recurrent visual hallucinations), a 4th, REM sleep behaviour disorder, has been added. There are also changes in “indicative biomarkers”, “supportive biomarkers” and “supportive clinical features”. As a result of this change, we will be slightly revising the DLB and PDD Assessment Toolkits to make them consistent with the new criteria, and once this work is complete we will circulate to all sites.

Prof John O'Brien, Chief Investigator

International Psychogeriatric Association Conference

Professor John O'Brien (*pictured*), Chief Investigator, recently attended the International Psychogeriatric Association (IPA) conference in Queenstown New Zealand (November 2017) and, as well as presenting at the conference, was invited to lecture to consultant medical staff from Hammond Care. Hammond Care is a not-for-profit organisation which has recently been awarded the Australian Governmental contract for the management of BPSD in community settings and residential/nursing homes throughout the whole of Australia. His topic was Lewy body dementia, and he presented work from the DIAMOND-Lewy programme, in which there was considerable interest, especially in relation to the Assessment and Management toolkits.

Prof John O'Brien



Spreading the News

In July a number of DIAMOND-Lewy researchers presented at the Alzheimer's Association International Conference 2017 in London, including Dr Ajenthalan Surendranathan who presented a poster that summarised the rates of dementia diagnosed in Parkinson's disease within clinical services in East Anglia and the North East (Work Package 1B), which was well received.

Additionally, findings from the study are being presented in various national forums, such as The British Association for Psychopharmacology.

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

Congratulations!



We would like to say a big thank you to the Ipswich team (*pictured*) who have been one of our overall top recruiters for the trial. Recruitment was steady over the Summer period and we are now well on our way to reach our recruitment target, which has recently been increased, by December 2017.

Additionally, we would like to say thank you and congratulations to everyone who has contributed to, or participated in, the study.

Prof John O'Brien

Selected Publications

Thomas, A.J., et al. 2016. *International Journal of Geriatric Psychiatry*. Development of assessment toolkits for improving the diagnosis of the Lewy body dementias: feasibility study within the DIAMOND Lewy study.

Connors, M.H. et al. 2017. *Psychological Medicine*. Non-pharmacological interventions for Lewy body dementia: a systematic review.