

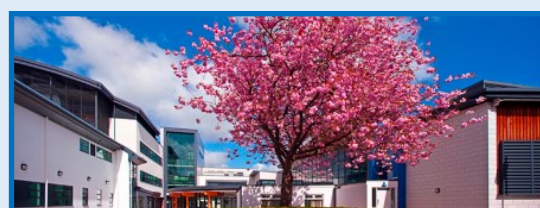
Improving the diagnosis and management of neurodegenerative dementia
of Lewy body type in the NHS (DIAMOND-Lewy)

Welcome ...

to the summer 2016 newsletter. I am pleased to report that we are now half way through our five year DIAMOND-Lewy Study which is funded by the National Institute for Health Research (NIHR). Work packages 1 and 2 are drawing to a close and we have collected some valuable data which will be analysed over the next few months. Work packages 3 and 4 have been successfully completed and with this our assessment and management toolkits have been created and piloted. We are about to embark on work package 5, a trial to measure the effect of the management toolkit in clinical practice.

More detail on the status of all the Diamond Lewy work packages can be found in individual sections below. If you have any comments about the newsletter please do let us know.

Emma Burton, Project Manager



Biomedical Research Unit, Newcastle University

Work Package 1

Work package (WP) 1 is a baseline study looking at the current diagnosis and management of Lewy body dementia, with the team consisting of Allison Bentley and Dr Ajenthan Surendranathan in Cambridge and Sally Barker and Dr Joe Kane in Newcastle, led by Professor John O'Brien.

Analysis of the medical notes of the 75 DLB patients and 70 controls who have been recruited is nearly complete. We have also recruited 37 PDD patients to the study with 23 controls, with analysis of these patients also under way.

Our team is very grateful for the help we have had from Consultants and Specialist Nurses throughout the North East and East Anglia who have given up their valuable time to help us recruit patients.

Dr Ajenthan Surendranathan, Clinical Research Fellow, & Allison Bentley, Research Nurse

Our Research News

Several members of the Diamond-Lewy study team were able to be present at a major International Conference on Lewy Body Dementia which was held in Florida in December 2015. While the location sounds exotic, the weather was certainly not so we were all able to pay full attention to the excellent scientific programme that the UK made a great contribution to. Many of the Diamond-Lewy investigators gave oral presentations about their work, and some very early provisional results of the study, suggesting large geographical variations within the UK in how often Lewy body dementia is diagnosed, were also presented.

Prof John O'Brien, DIAMOND-Lewy Chief Investigator



Work Package 2

We are grateful to the clinicians, patients and carers who contributed to the success of this part of the study. We used a clinician questionnaire to explore confidence in diagnosing and managing LBD (38% response rate). This showed that clinicians were less confident in diagnosing and managing DLB and PDD than other types of dementia (with the exception of FTD). Confidence in managing many of the characteristic symptoms of LBD (e.g. REM sleep disorder, somnolence, parkinsonism) was also relatively low. These findings confirm the potential value of the assessment tool and management toolkit.

Interviews and focus groups with clinicians (including those in the pilot study) suggested that the assessment tool would facilitate a more consistent and comprehensive approach to the assessment of LBD symptoms. The management toolkit was similarly thought to encourage a holistic approach to the management of the complex constellation of symptoms associated with LBD. This could improve outcomes for patients and carers who may not raise issues and problems in consultations since they are often unaware that symptoms are related to LBD.

Dr Claire Bamford, WP2 Lead

Work Package 4

In February 2016 we formally completed and closed the WP4 trial of the Assessment and Management Toolkits in Gateshead Health NHS Foundation Trust. The staff within both Old Age Psychiatry and Parkinson's Disease services were able to use and comment on both toolkits and from this evidence changes have been made by the teams that will enable the implementation of Work package 5.

The interviewing and analysis of the data has proven successful and the hard work of those involved, appreciated; thank you to everyone - patients and staff - who helped to make this a success.

Bryony Storey, Research Nurse

Work Package 3

The guidelines developed in work package 3 were delivered to work package 4 for feasibility assessment (to see whether they were ready to be applied in practice). On the basis of feedback received we have subsequently developed the management toolkit to include visual flow-charts, so that clinicians can more easily apply the guideline when seeing people with LBD in their daily practice. The management toolkit and guidelines are now being taken forward for testing in work package 5 of the DIAMOND-Lewy study.

*Prof Ian McKeith &
Dr John-Paul Taylor, WP3 Leads*

*Campus for
Ageing &
Vitality,
Newcastle
University*



Work Package 5

Having created and piloted our two LBD toolkits in Work Packages 3 and 4, we now aim to measure the effect of our management toolkit in clinical practice. We are employing a randomised cluster trial design to compare a range of patient outcomes in services with and without access to our toolkit. We will also be providing all participating services with access to our assessment toolkit. We will be recruiting patients with LBD management issues from participating clinics over the next 18 months.

We are currently working with a number of representatives of services to determine how our WP5 study teams can best complement clinical teams in accessing the toolkits. We are extremely grateful to staff working in participating services for their help this far. *Dr Joe Kane, Clinical Research Fellow, & Sally Barker, Research Nurse*

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