

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

Welcome ...

to the Winter 2016 Newsletter. We have now passed the half-way point of our five year DIAMOND-Lewy study, funded by the National Institute for Health Research (NIHR).

Analysis of the data is ongoing for Work Package 1, and they are busy disseminating their results. They were recently awarded Best Poster at the Joint Conference of the College of Psychiatrists of Ireland and the Royal College of Psychiatrists in Northern Ireland, and the abstract will shortly be published in the Irish Journal of Psychological Medicine. Well done to Joe, Sally, and colleagues!

Work packages 2, 3 and 4 are also at the writing up stage. Initial results have been presented at conferences, and the first papers to feature outputs from the project will be published soon.

Activity on Work package 5 has been split into three discrete but interconnected work streams (5A-C), and recruitment is on target. The Assessment toolkit (produced by Work Package 4), and the Management toolkit (produced by Work Package 3) form an integral part of this new activity.

We wish you all a very happy festive season, and would like to thank everyone for their ongoing support and participation in our project, we look forward to gaining further insights into the diagnosis and ongoing treatment and care of patients and their families affected by Lewy Body Dementia. Should you have any questions or feedback, we would love to hear from you!

Sarah Greenhalgh, Project Manager

We are extremely grateful for the help of all our participants who have given their time to us over the past year.

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**Festive Greetings from
The DIAMOND-Lewy
Team**



Work Package 1



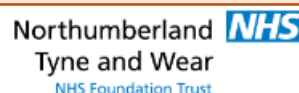
DIAMOND-Lewy Work Package 1 aims to determine the prevalence of DLB and PDD in NHS clinical services, and to establish a baseline measurement of the extent and nature of clinical input received by patients with Lewy body disease. The process of extensive retrospective data extraction from the clinical notes of our 166 consented patients has now concluded in both Newcastle and Cambridge, and data analysis of this information has begun.

Our initial findings have identified some interesting findings that have been recognised by many clinicians but perhaps not necessarily represented in the literature to date; topics such time to DLB diagnosis, symptom prevalence and the differences between clinical service input for DLB patients when compared to that for patients with other dementia subtypes have all emerged as topics for discussion.

Over the next few months we'll be discussing our preliminary findings at local, national and international conferences before pursuing publication and other means of dissemination.

We remain extremely grateful to everyone who facilitated the study and we look forward to sharing our findings with you in the near future.

Dr Joe Kane (pictured) and Sally Barker, Research Nurse





Work Package 2

This WP is now closed to recruitment and is at the data analysis and output stages. The WP lead, Claire Bamford, during November 2016, presented the initial findings at the Alzheimer Europe Conference in Copenhagen and the Lewy-Body Conference in Newcastle. Additionally, three papers are planned for this WP. *Amanda Weston, Project Secretary*

Work Package 4

The assessment and management toolkits have now been piloted in the Gateshead Health NHS Foundation Trust and feedback has been collated. Subsequently, the assessment toolkit was improved and is now being used in WP5. Additionally, the first paper from WP4 will be published in the near future. *Amanda Weston, Project Secretary*

Work Package 3

We carried out a comprehensive systematic review of pharmacological and non-pharmacological treatments in Lewy body dementia last year and outputs have included one high impact, international publication for doctors and health care professionals involved in treating people with Lewy body dementia and we are currently writing another.

Using our systematic review and input from a panel of international experts in the field we have also completed our management toolkit for people with Lewy body dementia which is now currently being trialled in WP5.

Prof Ian McKeith & Dr John-Paul Taylor (pictured)



Work Package 5A&B

We are very pleased that work package 5, the clinical trial of the management toolkit developed earlier in the programme started in April this year. We have more than 20 different services (sites) involved in this study, half in the North East of England and half in East Anglia, and so far recruitment is going well and we are meeting our targets of recruiting around 6 subjects each month. The plan is for recruitment to continue at least until the end of 2017, with the follow-up of subjects continuing until mid 2018.

We are extremely grateful to all the staff involved in the sites for their help and assistance in preparing for the study and helping get things started. Most of all, of course, we are grateful to the many people with Lewy body dementia, supported by their families and friends/ carers, who have volunteered to take part. For each person with dementia or memory problems we are asking for a close friend or relative who know them well to also take part in the study, and we have had an excellent response to this as well.

By collecting information from people involved at the start of the study, and 3 and 6 months in, we hope to be able to determine whether the management toolkit does indeed improve the management of people with Lewy body dementia, and if so how. We will continue to provide updates as this aspect of the study continues.

Prof John O'Brien (pictured)
Chief Investigator



WP5C

The purpose of the process evaluation is to understand the factors which influence whether and how clinicians make use of the assessment and management toolkits. We will be seeking feedback on: the initial briefing and any training provided; strategies used by clinicians to facilitate use of these resources; and the acceptability and perceived value of the toolkits in diagnosing and managing LBD.

We will use a range of methods including questionnaires, semi-structured interviews, focus groups, informal discussions and observations. For this part of the study, all participating clinicians will be sent two questionnaires; one towards the beginning of WP5 and the second towards the end. These will be administered via Survey Monkey; we would be very grateful for your participation as a good response rate will increase our confidence in the results. If you would like to provide any informal feedback on the toolkits, please email claire.bamford@ncl.ac.uk. Your support for this aspect of the study would be much appreciated as it will help us to understand the results of the pilot trial.

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