



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 the patients and their families 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

Work Package 1 aims 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 what extent and type of care patients with Lewy body dementia get from these services.



The teams in Newcastle and Cambridge have now completed the collection of information from the clinical notes of the patients that kindly consented to take part in our study. We are now in the process of trying to make sense of the extensive but valuable information that we've gathered.

The process is in its early stages but we think that we have found some interesting information on how long it takes for patients to receive a DLB or PDD diagnosis, and how much contact they require with services compared with other patients. Over the next few months the team will be showing our early findings with researchers and healthcare workers locally and internationally to determine the best way to communicate what we've found with as many people as possible.

We remain extremely grateful to everyone who took part in 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

Randomised controlled trials are used to find out whether an intervention, such as the introduction of new toolkits or guidelines, improves patient care. Process evaluations help us to understand the results of trials. New interventions may not appear to have made a difference to patients for a number of reasons. For example, the intervention may not work; health professionals might not have used the intervention in practice; or the way we measured the impacts of the intervention may not have picked up any changes. A process evaluation makes sure that we understand why trials have been successful or not. This makes sure that we get as much value for money as possible from research.

In the present study, the process evaluation will focus on the factors which influence whether and how clinicians make use of the assessment and management toolkits. We will collect information using questionnaires, semi-structured interviews, focus groups, informal discussions and observations. We hope to include as many clinicians as possible from participating services.

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