

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

As you may be aware, DIAMOND-Lewy (Improving the Diagnosis and Management of Neurodegenerative Dementia of Lewy body type) is a 5 year programme funded by the National Institute for Health Research.

The study comprises of 5 work packages which are detailed below. Our overall aim is to help improve the diagnosis of Lewy body dementia, and to trial an evidence based approach to its management.

We would like to thank you very much for all your support with the study. We plan to provide regular newsletters as the study progresses. If you have any comments about the newsletters, or would prefer not to receive them, do please let us know.

*Prof John O'Brien (Chief Investigator)*



### Work Package 1

In Work Package 1 we are the baseline study for the DIAMOND-Lewy Study. Professor John O'Brien is leading the study and locally Dr John-Paul Taylor is the PI. Dr J Kane and Sally Barker are also working on WP1 in the North East and Dr A Surendranathan and Allison Bentley in East Anglia. It is a baseline study of current LBD diagnosis and management in NHS secondary care services. We are examining the proportion of LBD cases currently diagnosed and their management pathways, compared to non-LBD dementia.

The study team is very grateful for all the help we have

had, particularly many consultants in Northumberland Tyne and Wear NHS Foundation Trust (who are the study sponsor) and other Trusts in the North East and East Anglia including Northumbria, NUTH, CUHT and CPFT.

*Dr Joe Kane &  
Sally Barker*



### Work Package 2

This work package aims to ensure that the assessment and management toolkit are acceptable and feasible for routine practice. We have interviewed clinicians, patients and carers from four NHS Trusts (two in the North East and two in East Anglia) and also observed current practice. Barriers to the use of the assessment tool include the perceived value of diagnosing LBD; the practicalities of using the assessment tool; and clinician skills and knowledge about LBD. Patients and carers.

The interviews with patients and carers indicated the assessment tool was generally acceptable and highlighted some key principles for the management of LBD. These include access to information; practical strategies for managing the complex symptoms associated with LBD; and opportunities for carers to be seen separately.

The findings will be used to inform the content and structure of the assessment and management toolkit being developed in WP3.

*Claire Bamford*

### Work Package 3

The purpose of WP3 is to establish best practice guidelines for treating people with LBDs, and to present these in a way that clinicians working in the NHS can easily understand and use. We began by systematically reviewing all of the research studies that have ever been published on the topic. We discovered that the evidence base is limited and that more trials need to be done. Nevertheless we have been able to proceed to the second stage of writing a guideline which we have done with valuable help from two patient and public involvement (PPI) workshop events that were focussed upon identifying good and bad practice in LBD clinical management, based on their own experiences. We have also engaged an expert panel in excess of 30 individuals, selected nationally and internationally and representing NHS and academic clinicians, nursing, physiotherapy, OT and pharmacy. By means of what is called a Delphi process, they have helped us to refine our guideline which is now being assembled based upon the three streams of evidence (systematic review, PPI principles and Delphi statements) and have been delivered to WP4 in readiness for the first stage of testing in the clinic.

*Prof Ian McKeith & Dr John-Paul Taylor*

### Work Package 4

Work Package 4 is a pilot and feasibility study to try out our new Lewy Body Dementia assessment and management toolkits in Gateshead Health Trust. The toolkits will be piloted in both the old age psychiatry and Parkinson's disease services in Gateshead. This will involve local clinicians (consultants and specialist nurses) trying out the toolkits as part of their regular clinical practice when seeing people with dementia or Parkinson's disease related memory problems.

Later we will gather information about how we might improve the toolkits from these clinicians and also from the patients and carers. The aim is to prepare these toolkits for use in a cluster randomised trial (work package 5 of the DIAMOND Lewy programme) where they will be tested to see if they improve the care of people with Lewy body dementia.

*Prof Alan Thomas*

### Lewy Body Society's Polka Dot-ty Day Celebrated in Style!

The DIAMOND-Lewy team were asked by the Lewy-Body Society to help celebrate the Society's Polka Dot-ty Day in June by wearing something dark blue with white dots (which is the Society's symbol) and having their photo taken.

As you can see, the DIAMOND-Lewy team successfully rose to the challenge!

Further information about the Lewy Body Society can be found at: <http://lewybody.org/>



### Our Research News ...

Researchers from the DIAMOND-Lewy team have completed a review into the efficacy of current drug treatments for Lewy body dementia. This work has been recently published in the American Journal of psychiatry: <http://ajp.psychiatryonline.org/doi/full/10.1176/appi.ajp.2015.14121582>

Several members of the team will also be attending a major International Lewy Body Conference being held in Florida in December 2015, to share thoughts and findings from the Programme with other researchers around the world. This conference is also open for patients and caregivers to attend. Further details can be found at: <https://ce.mayo.edu/node/3844>

### Contact Details:



#### Project Manager:

Andrew West

Email: [andrew.west@ncl.ac.uk](mailto:andrew.west@ncl.ac.uk)

Tel: 0191 208 2420

#### Project Secretary:

Amanda Weston

Email: [amanda.weston@ncl.ac.uk](mailto:amanda.weston@ncl.ac.uk)

Tel: 0191 208 1313

#### DIAMOND-Lewy Website:

<http://research.ncl.ac.uk/>