

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

Welcome to our first DIAMOND-Lewy newsletter, which I hope you find useful and interesting. As you may be aware, DIAMOND-Lewy is a 5 year study funded by the National Institute for Health Research (often abbreviated to NIHR) with a full title of “Improving the Diagnosis and Management of Neurodegenerative Dementia of Lewy body type” – hence DIAMOND-Lewy for short.

The study is broken down into a number of smaller studies, which we call work packages. These are described in more detail below. Our overall aim is to help clinicians recognise and diagnose Lewy body dementia, because there is evidence it is under-recognised, and to help develop a better, more consistent approach to its management. To do this we are developing an assessment and management toolkit for Lewy body dementia.

We thank you very much for your support with the study and plan to provide regular newsletters as the study progresses. If you have any comments about the newsletters, or indeed you 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 studying how often a diagnosis of Lewy body dementia is currently being made. We are doing this in two parts of the UK, in the North East Dr Joseph Kane and Research Nurse Sally Barker are working on this, and in East Anglia Dr Ajenthan Surendranathan and Research Nurse Allison Bentley are involved. We are looking at the rates of Lewy Body dementia in relation to the rates of other dementias being diagnosed among patients seen in services. We are then looking in more detail at individual's medical notes to gather



information about diagnosis and their care. We are very grateful for the help of so many patients and their families in giving us their time and consenting for us to look at medical notes.

Dr Joe Kane

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 develop best practice guidelines for health professionals treating people with Lewy body dementias. We have made significant progress with this: we have conducted a comprehensive search of all the research studies ever published on this topic and then have asked a panel of over thirty of the world's leading experts in the field for their input.

We have also been guided what patients and their families want and have held two very successful patient and public involvement (PPI) workshop events which have helped shape our guidelines. We will be ready for first testing of the management guidelines in the clinic as part of WP4 by mid-July 2015.

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

Tel: 0191 208 2420

Project Secretary:

Amanda Weston

Email: amanda.weston@ncl.ac.uk

Tel: 0191 208 1313

DIAMOND-Lewy Website:

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