

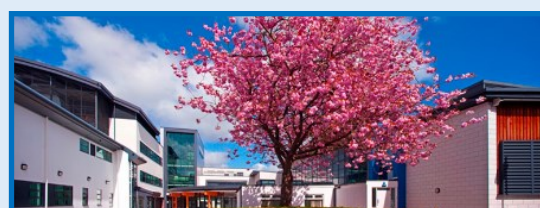
## Improving the diagnosis and management of neurodegenerative dementia of Lewy body type in the NHS (DIAMOND-Lewy)

### 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*

### Background

**Lewy body dementia** (LBD, comprising dementia with Lewy bodies and Parkinson's disease dementia) is the second most common cause of dementia in older people after Alzheimer's disease. However, diagnosing LBD can present challenges for clinicians working in dementia/memory assessment services and in movement disorder services. In addition, care pathways for LBD are often less well developed than for Alzheimer's disease. This study of research aims to facilitate detection and management of LBD within routine NHS secondary care services. The study will be delivered through a series of five interlinked work packages (WP). We are now half way through our five year DIAMOND-Lewy Study which is funded by the National Institute for Health Research (NIHR); our progress is detailed in this newsletter.

*DIAMOND-Lewy Patient & Public Involvement Team*

### 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*



## Patient and Public Involvement (PPI)

**PPI has been** an integral part of the DIAMOND Lewy programme from the start. The aim is to use the PPI group proactively throughout the programme to inform all phases of the study from patient and carer perspectives.

The PPI group consists of four members of the public, who have volunteered because their lives have been touched by neurodegenerative diseases. All have personal experience of PD, PDD or DLB, either as a patient or a carer. There are different levels of experience of PPI in the group. One member has been involved in PPI for over ten years; for another, this was their first experience of PPI. The group is convened by a research team member, who coordinates the response and communicates it to the research team. One member of the group is a co-applicant on the programme grant and also attends regular Programme Management Meetings; another member of the group is the PPI representative on the Programme Steering Group. These mechanisms ensure that the PPI group's comments and suggestions are speedily brought to the attention of the full programme management group and steering committee.

This five year study is complex, consisting of many interconnecting work packages. Continuity of involvement helps us (PPI representatives) to understand the study and its needs. Regular meetings give us a chance to discuss issues in depth and contribute meaningfully to the programme. We look at research processes and documents from the perspectives of patients and carers (we give them a voice) to make sure that participating in the study is a positive experience.

This has included:

- ◆ Rewording and formatting Participant Information Sheets
- ◆ Advising on the wording and ordering of questions in the Assessment Toolkit
- ◆ Discussing how best to explore patient & carer experiences of LBD through interviews

We have also contributed to the training of a new qualitative researcher by sharing our experiences of what it is like to live with PD or LBD.

As the study has progressed we sense that our input has been increasingly valued by the clinical team and that our involvement has become much more than a box-ticking exercise. We think that an effective model for integrated PPI representation, responsive to study needs, is emerging for use in future clinical research.

From a personal point of view, we get a lot of satisfaction out of PPI; we have gained insight into how research works and it keeps our brain cells ticking over!



*DIAMOND-Lewy Patient & Public Involvement Team*

## Work Package 1

Our team, Allison Bentley and Dr Ajentan Surendranathan in Cambridge, and Sally Barker and Dr Joe Kane in Newcastle, are now nearing completion of both Work Package (WP) 1A and WP1B. WP1A is looking at the frequency of dementia with Lewy bodies in both Cambridgeshire and the North East, and how this is currently being managed by clinical staff. 145 people living with dementia have agreed to have their notes analysed to see how, or if, clinical care differs between those with dementia with Lewy bodies and those with other subtypes of dementia.

In WP1B we have been looking at memory problems in Parkinson's disease by comparing current clinical management of people with and without memory problems in Parkinson's disease. With the kind help of Geriatricians, Neurologists, Parkinson's and Neurology specialist nurses, patients and families, we have recruited a combined 73 patients in both locations to WP1B. In total across the study we have recruited 221 people, well beyond our minimum target of 120 for WP1.

*Dr Ajentan Surendranathan, Clinical Research Fellow, & Allison Bentley, Research Nurse*



*Allison Bentley,  
Research Nurse*

## Work Package 2

This work package involved observing consultations, and interviewing clinicians, patients and carers. The findings highlight the potential value of the LBD Toolkit for improving the diagnosis and management of LBD. The interviews with patients and carers showed that most were unaware of the range of symptoms associated with LBD. As a result, they did not always raise issues and concerns in consultations, but relied instead on trial and error to find strategies that helped with symptom management. A more holistic approach to management could ensure that patients and carers have prompt access to effective treatment or strategies for symptoms associated with LBD. The interviews also suggested that patients often struggled with social situations, particularly those involving groups of people. This has important implications for the ways in which services are delivered, and also for how we can best engage people with LBD in PPI events. We are very grateful to all of the patients and carers who have given up their time to share their experiences of living with LBD.

*Dr Claire Bamford, WP2 Lead*



*Campus for  
Ageing &  
Vitality,  
Newcastle  
University*

## Work Package 3

The focus of Work package 3 was to develop clear and useful clinical guidelines for doctors, nurses and other health care professional to help them manage and treat people with Lewy body dementias better. We have done an in-depth review of all the medical literature to identify the best management strategies in Lewy body dementia as well as asked the opinions of a wide range of experts both nationally and internationally in developing the guidelines.

Our draft guidelines were then 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 guidelines to include visual flow-charts, so that healthcare professionals can more easily apply the guideline when seeing people with Lewy body dementia in their daily practice. The management toolkit and guidelines are now being taken forward for further testing in work package 5 of the DIAMOND-Lewy study.

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

## 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 5

**Our LBD Toolkit** is now complete. We think that it will really help healthcare staff recognise the problems that our patients and carers face, and give them advice on what to do about these issues.

Work Package 5 is all about introducing this toolkit to professionals, and determining how much of an improvement in patients' and carers' wellbeing it could bring. Over the next few months we'll be working closely with local services to identify patients that our toolkit might help, and we'll be inviting these 120 of these patients to take part in our new WP5 study. Our first patient was recruited to the study in May. We hope to have completed recruitment in late 2017 and start disseminating our findings in mid-2018.

We are extremely grateful to all the patients and carers who have helped us get to this important point of the programme.

*Dr Joe Kane, Clinical Research Fellow & Sally Barker, Research Nurse*

*Dr Joe Kane, Clinical Research Fellow*



## Useful Websites

Lewy Body Society:

<http://www.lewybody.org/>



DIAMOND-Lewy Study:

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



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