

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

<https://www.neurodegenerationresearch.eu/survey/improving-the-diagnosis-and-management-of-neurodegenerative-dementia-of-lewy-body-type-in-the-nhs-diamond-lewy/>

## Principal Investigators

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## Institution

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## Contact information of lead PI

### Country

United Kingdom

## Title of project or programme

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

## Source of funding information

NIHR (PGfAR Theme: DTC Stage 2)

## Total sum awarded (Euro)

€ 2,628,795

## Start date of award

01/01/2014

## Total duration of award in years

5.0

## The project/programme is most relevant to:

Alzheimer's disease & other dementias|Parkinson's disease & PD-related disorders

## Keywords

Research Abstract

Aims and objectives

We aim to improve NHS care of people with dementia by increasing detection and optimising management of dementia with Lewy bodies and Parkinson's disease dementia (together termed Lewy body dementia (LBD)) within routine NHS secondary care services. We will introduce a brief assessment tool to detect key LBD symptoms (cognitive decline, fluctuation, hallucinations, sleep disturbances and parkinsonism) to facilitate earlier and more accurate diagnosis and develop, implement, and trial a LBD care pathway to improve patient management.

## **Background and rationale**

LBD is a common cause of dementia in older people, accounting for 15-20% of all cases. Although diagnostic criteria for LBD exist, recognition, even in secondary care settings, is still poor with less than one in three cases currently detected. Other cases are either missed or misdiagnosed with another dementia[1]. Accurate recognition has important implications for management. While some aspects of appropriate LBD management are recognised by clinicians, there is currently no unified evidence based management care pathway to optimise management.

## **Research environment**

Newcastle has a long track record of applied research in dementia, especially in LBD, and health services research. There is a strong interdisciplinary research culture, close links to NHS services, excellent infrastructure and substantial NIHR and other investment including a Clinical Trials Unit, a Biomedical Research Centre in Age-related diseases, a new Biomedical Research Unit in LBD and co-leadership (with UCL) of the national DeNDRoN network.

## **Research plan**

We will undertake a baseline study of current practice in the diagnosis and management of LBD. We will incorporate simple, quick and well validated tools for assessing fluctuation, visual hallucinations, parkinsonism and sleep disturbance into an assessment tool to allow core LBD symptoms to be elicited and a diagnosis to be made promptly and accurately. We will produce an evidence based toolkit for clinicians to improve management once diagnosis has been made, which can be incorporated into care pathways. Using embedded qualitative approaches we will identify and overcome barriers that may hinder implementation of the assessment and management toolkit in memory, neurology and geriatric medicine services. After piloting, we will introduce the assessment tool into routine NHS services and determine the extent to which it increases LBD diagnosis, and undertake a pilot randomised study of cases detected to investigate whether the new management toolkit improves outcomes for patients and carers.

## **Projected outputs and dissemination plans**

Main outputs will be a) demonstration that a brief assessment tool for the key symptoms of LBD can be implemented into routine NHS care and that use of this tool increases the identification of LBD cases; b) production of an evidence based management care pathway for LBD, with demonstration it can be successfully applied in routine NHS services and that it improves patient and carer outcomes. We expect this programme to result in a significant increase in the number of new diagnoses of LBD and to considerably improve patient care in terms of quicker, more accurate diagnosis and better management.

Findings will be disseminated to: i) NHS professionals; ii) NHS commissioners; iii) Social Care; iv) patient/public organisations. Participants will receive a newsletter on developments and progress. Scientific findings will be published in academic papers in high impact journals and presented at major conferences. The assessment and the management toolkit will be made available to others.

## **Relevant expertise and experience of the research team**

The programme combines researchers with an international reputation in dementia research, most especially the diagnosis and management of LBD, within the Institute for Ageing and Health with experts in applied health research from the Institute of Health and Society. The applicants have expertise in all the necessary areas for successful delivery of the programme and have a strong track record in PPI and NHS engagement.

## **Justification of costs**

We request funds for PI time, including time for qualitative and health economic studies. Core research staffing will be a research associate for 2 years to assist with the systematic review to inform the management pathway, 2 research nurses and 2 clinical research associates for 4 years who would undertake the baseline and follow-up data collection and assist with the development and training of the assessment and management toolkit. Other costs for statistical support and involvement of the Newcastle Clinical Trials Unit are included, as well as PPI, travel and dissemination costs.

## **Management and Governance**

Each work package has named PI leads(s) responsible for delivery. Overall study progress and work package co-ordination and monitoring delivery to pre-defined goals will be through a study steering committee which will meet 3 monthly, chaired by the Chief Investigator.

## **Patient and public involvement**

We include a lay co-applicant and PPI volunteers will be members of the study steering committee. A PPI panel will play a central role in the work packages relating to the development and piloting of the assessment and management tools.

### **Lay Summary**

**Further information available at:**

#### **Types:**

Investments > €500k

#### **Member States:**

United Kingdom

#### **Diseases:**

Alzheimer's disease & other dementias, Parkinson's disease & PD-related disorders

#### **Years:**

2016

#### **Database Categories:**

N/A

#### **Database Tags:**

N/A