

Improving the diagnosis and management of Lewy body dementia: the DIAMOND-Lewy research programme including pilot cluster RCT

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Declared competing interests of authors: John T O'Brien reports grants from the National Institute for Health Research (NIHR) during the conduct of the study, personal fees from TauRx Therapeutics Ltd (Aberdeen, UK), grants and personal fees from Avid Radiopharmaceuticals/Eli Lilly and Company (Indianapolis, IN, USA) and personal fees from Eisai Co. Ltd (Tokyo, Japan), GE Healthcare (Chicago, IL, USA), and AXON Neuroscience (Bratislava, Slovakia) outside the submitted work. John-Paul Taylor reports grants from NIHR during the conduct of the study, non-financial support from Axovant Gene Therapies Ltd (Hamilton, Bermuda) and personal fees from GE Healthcare outside the submitted work. Alan Thomas reports grants from NIHR during the conduct of the study, and grants from GE Healthcare outside the submitted work. Luke Vale reports grants from NIHR during the conduct of the study, and membership of the Health Technology Assessment (HTA) Clinical Trial Committee (2014–18). Richard McNally reports grants from NIHR during the conduct of the study, and membership of the Health Services and Delivery Research (HSDR) Commissioned Panel (2015–19). James Mason reports grants from NIHR during the conduct of the study, and membership of the NIHR HSDR Funding Committee (2017–20), the NIHR HTA End of Life Care and Add-on Studies board (2015–2016) and the NIHR HTA Efficient Study Designs – 2 board (2015–16). David Burn reports grants from NIHR during the conduct of the study, and membership of the Efficacy and Mechanism Evaluation Prioritisation Group (2012–16). Ian McKeith reports grants from NIHR during the conduct of the study, personal fees from Eisai Co. Ltd, GE Healthcare, Axovant Gene Therapies Ltd, Sumitomo Dainippon Pharma (Osaka, Japan) and Sanofi SA (Paris, France), and grants and personal fees from La Fondation pour la Recherche sur Alzheimer (Paris, France) outside the submitted work.

Disclaimer: This report contains transcripts of interviews conducted in the course of the research and contains language that may offend some readers.

Published July 2021

DOI: 10.3310/pgfar09070

Plain English summary

The DIAMOND-Lewy research programme

Programme Grants for Applied Research 2021; Vol. 9: No. 7

DOI: 10.3310/pgfar09070

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Plain English summary

Lewy body dementia includes dementia with Lewy bodies and Parkinson's disease dementia. It is the second most common cause of neurodegenerative dementia in older people, but is underdiagnosed. There is no consistent approach to management.

We aimed to improve the diagnosis and management of Lewy body dementia by:

- understanding current practice
- identifying barriers to diagnosis and management
- developing evidence-based assessment toolkits
- producing and piloting a management toolkit.

We focused on hospital-based specialist services. Participants included people aged ≥ 50 years diagnosed with Lewy body dementia, carers and health-care professionals. Current diagnostic rates for dementia with Lewy bodies and Parkinson's disease dementia were lower than expected (4.6% and 9.7%, respectively). There was evidence of delays in diagnosis for both dementia with Lewy bodies and Parkinson's disease dementia. The use of services and the overall costs of care for patients with dementia with Lewy bodies and Parkinson's disease dementia were greater than for patients who had other dementias. We found many barriers to the diagnosis and management of Lewy body dementia and these indicated the need to upskill staff, challenge negative attitudes towards diagnosis and improve management pathways.

Using published evidence and clinical opinion, we produced assessment and management toolkits for dementia with Lewy bodies and Parkinson's disease dementia. We used these in a pilot clinical study and showed that we were able to recruit people with dementia with Lewy bodies and Parkinson's disease dementia to the study. The toolkits were well received, but their use by clinical staff was variable. Following introduction of the assessment toolkits, there was an increase in diagnostic rates for dementia with Lewy bodies, but not Parkinson's disease dementia. Our findings indicate that a further larger study of the management toolkit is both feasible and merited.

Programme Grants for Applied Research

ISSN 2050-4322 (Print)

ISSN 2050-4330 (Online)

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Editorial contact: journals.library@nihr.ac.uk

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This report

The research reported in this issue of the journal was funded by PGfAR as project number DTC-RP-PG-0311-12001. The contractual start date was in January 2014. The final report began editorial review in May 2019 and was accepted for publication in March 2021. As the funder, the PGfAR programme agreed the research questions and study designs in advance with the investigators. The authors have been wholly responsible for all data collection, analysis and interpretation, and for writing up their work. The PGfAR editors and production house have tried to ensure the accuracy of the authors' report and would like to thank the reviewers for their constructive comments on the final report document. However, they do not accept liability for damages or losses arising from material published in this report.

This report presents independent research funded by the National Institute for Health Research (NIHR). The views and opinions expressed by authors in this publication are those of the authors and do not necessarily reflect those of the NHS, the NIHR, CCF, NETSCC, PGfAR or the Department of Health and Social Care. If there are verbatim quotations included in this publication the views and opinions expressed by the interviewees are those of the interviewees and do not necessarily reflect those of the authors, those of the NHS, the NIHR, NETSCC, the PGfAR programme or the Department of Health and Social Care.

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