

Development of assessment toolkits for improving the diagnosis of the Lewy body dementias: feasibility study within the DIAMOND Lewy study

Alan J. Thomas¹, John Paul Taylor¹, Ian McKeith¹, Claire Bamford¹, David Burn¹, Louise Allan¹ and John O'Brien²

¹Institute of Neuroscience and Newcastle University Institute for Ageing Newcastle University, Newcastle upon Tyne, UK

²Department of Psychiatry, University of Cambridge, Cambridge, UK

Correspondence to: Alan J. Thomas, Professor of Old Age Psychiatry, E-mail: alan.thomas@ncl.ac.uk

Objective: The Lewy body dementias (LBD, dementia with Lewy bodies and Parkinson's disease dementia) are the second most common cause of neurodegenerative dementia but remain under-recognised, with long delays from initial assessment to diagnosis. Whilst validated instruments have been developed for key symptoms, there is no brief instrument for overall diagnostic assessment suitable for routine practice. We here report the development of such assessment toolkits.

Methods: We developed the LBD assessment toolkits in three stages. First, we conducted a systematic search for brief validated assessments for key symptoms and combined these into draft instruments. Second, we obtained feedback on acceptability and feasibility through two rounds of interviews with our patient and public involvement group. This led to modification of the toolkits. Finally, we piloted the toolkits in a feasibility study in routine dementia and Parkinson's disease services to produce final instruments suitable for routine clinical practice.

Results: Eleven clinicians, working in both dementia/memory assessment and Parkinson's disease/movement disorder services, consented to pilot the assessment toolkits and provide feedback on their feasibility. Clinicians worked in routine health service (not academic) settings and piloted the draft toolkits by integrating them into their regular clinical assessments. Feedback obtained informally, by written comments and through qualitative interviews led to modifications and production of final acceptable versions.

Conclusions: We were able to address an important need, the under-diagnosis of LBD, by developing toolkits for improving the recognition and diagnosis of the LBD, which were acceptable to clinicians working in routine dementia and Parkinson's disease services. © 2016 The Authors. International Journal of Geriatric Psychiatry Published by John Wiley & Sons, Ltd.

Key words: dementia with Lewy bodies; Parkinson's disease dementia; toolkits; assessment

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Introduction

The accurate recognition of dementia and the diagnosis of subtype of dementia ensure appropriate management and are central to improving patient care for those with dementia. Dementia with Lewy bodies (DLB) is the second most common cause of degenerative dementia in older people after Alzheimer's

disease (Stevens *et al.*, 2002). Dementia also develops in up to 80% of people with Parkinson's disease, (PDD) (Aarsland *et al.*, 2003)]. Prevalence estimates from both clinical and epidemiological samples of Parkinson's disease (PD) subjects indicate that at least 30% of those with PD have dementia (Riedel *et al.*, 2010), whilst longitudinal study shows that 80% of those with PD will eventually develop dementia

(Aarsland *et al.*, 2003). PDD and DLB together are known as Lewy body dementias (LBD) because they share common clinical features, have closely overlapping neurobiology and respond to similar management approaches (Aarsland *et al.*, 2004). Taken together, LBD accounts for 10–15% all cases of dementia (Stevens *et al.*, 2002), affecting around 100,000 people in the UK. Whilst both DLB and PDD share the problems of under-recognition and inappropriate management, the reason for these problems differs between DLB and PDD.

Despite the known prevalence of DLB, it has been estimated that only around one in three cases are currently detected in routine care in the UK (Alzheimer Society, 2007); for every DLB case properly diagnosed, another two are either not detected or misdiagnosed, usually as Alzheimer's disease. Furthermore, the route to diagnosis for patients with DLB is often protracted with one US study reporting that half of the patients had more than 10 clinic visits before the correct diagnosis was made (Galvin *et al.*, 2010). There are several reasons for these difficulties with recognition including lack of assessment of key clinical symptoms such as hallucinations, fluctuation and sleep disorder in dementia assessment services and the challenges in eliciting motor features of parkinsonism in those with dementia (Ballard *et al.*, 1997). Changing practices in dementia assessment services also mean that initial assessments are often carried out by non-medical staff who are not able to perform neurological examinations.

Improving the accuracy of detection and diagnosis of PDD raises related but also distinct issues. Although patients with PD are often under regular follow-up in neurology or geriatric medicine services only around one in three of those with PDD are currently recognised and diagnosed (Dujardin *et al.*, 2010), and usually late in their illness. Again, there are several reasons for missed and delayed diagnosis of PDD: (1) cognitive impairment develops insidiously and at a variable time after PD diagnosis; (2) initial symptoms such as fluctuation, attentional problems and hallucinations may be thought to be related to medication side effects; (3) there is a general lack of awareness of the benefits of diagnosing dementia and a reluctance of professionals to disclose the diagnosis; (4) cognition is often not routinely assessed in neurology and geriatric medicine clinics. As with DLB, the recognition of dementia in PD brings the clear management benefits recognised for all those with dementia, including allowing the prescription of anti-dementia medication, provision of support, education and advice, access to services, financial and other benefits and opportunities for future planning and attending to medico-legal issues (O'Brien *et al.*, 2011).

Considerable progress has been made in developing quick and validated tools for the assessment of key clinical symptoms of LBD, e.g. the Lewy Body Composite Risk Score (LBCRS) (Galvin, 2015). However, there is no single, simple to administer toolkit which incorporates the range of clinical symptoms and which can be used by clinicians broadly, e.g. the LBCRS assumes clinical expertise not necessarily present in the staff carrying out assessments in many clinics, and the LBCRS does not directly link to the diagnostic criteria for DLB. Hence, a brief assessment toolkit is needed, which is suitable for use in routine practice by all clinical staff. We report here the development of such toolkits as part of a feasibility study to improve the recognition and diagnosis of both DLB and PDD as part of the National Institute for Health Research (NIHR) 'Improving the diagnosis and management of neurodegenerative dementia of Lewy body type' study (DIAMOND Lewy study).

Methods

We developed the LBD assessment toolkits in three stages. First, we identified brief validated assessments for different symptoms and signs that are key to making an LBD diagnosis and then combined these into a pilot instrument. Second, we obtained feedback on the acceptability and feasibility of the toolkit through interviews with patients, carers, clinicians and the programme patient and public involvement (PPI) group. This was used to modify the toolkits prior to piloting. Finally, we piloted the toolkits in a feasibility study in Dementia and PD services and modified the instrument to a final acceptable version suitable for use in routine clinical practice.

Development of pilot assessment tools

Clinical experts (AJT, JPT, IM, LA, DB and JOB) reviewed the published literature and supplemented this by their expert knowledge to identify available validated assessments instruments (Ballard *et al.*, 1997; Mosimann *et al.*, 2008; Boeve *et al.*, 2011; Lee *et al.*, 2014). Following funding, the DIAMOND Lewy programme management group (PMG) first discussed the basic approach to the problem and, building on this evidence, concluded two different instruments would be needed, one for DLB and one for PDD. These would be matched to the international diagnostic criteria for DLB (McKeith *et al.*, 2005) and PDD (Emre *et al.*, 2007). The PMG identified appropriate components

for each toolkit from the identified assessment instruments.

For the DLB toolkit, the aim was to improve identification of the core and suggestive diagnostic symptoms, because diagnosis of cognitive impairment and dementia in specialist dementia services is not a concern. There are six core and suggestive symptoms for diagnosing DLB. One is dopaminergic imaging, which would not form part of a clinical assessment tool, and another is neuroleptic sensitivity which can only be identified following exposure to antipsychotic drugs, which is now a rare event (Walker *et al.*, 2015). Hence, the focus was on assessment of the four remaining symptoms: persistent complex visual hallucinations, spontaneous cognitive fluctuations, spontaneous parkinsonism and Rapid eye movement sleep behaviour disorder (RBD). The following components of the instrument were identified:

- a) Cognitive fluctuation. Four questions to carers from the Dementia Cognitive Fluctuation Scale (Lee *et al.*, 2014).
- b) Rapid eye movement. A single screening question to carers from the Mayo Sleep Questionnaire (Boeve *et al.*, 2011).
- c) Visual hallucinations. Two core questions for patients and two for carers from the North East Visual Hallucinations Inventory (Mosimann *et al.*, 2008).
- d) Motor features of parkinsonism: five items from the Unified Parkinson's Disease Rating Scale (Ballard *et al.*, 1997).

For the PDD tool, the aim was to improve identification of cognitive impairment and to facilitate matching of symptoms to the PDD diagnostic criteria (Emre *et al.*, 2007). The Montreal cognitive assessment (MoCA) was identified as most appropriate for brief cognitive assessment in this context (Nasreddine *et al.*, 2005).

AT then put together the two instruments and after iteration with the rest of the PMG, a draft version was sent to the PPI panel. The PPI panel, including patients and carers, then contributed comments, and this feedback was incorporated into a revised version which was again commented on by the PPI members until a final agreed version and text was agreed for the pilot study. These two iterative rounds led to changes in wording of questions to try and improve clarity, and the major change suggested was to separate the PDD tool into one version for use with carers and one for use with patients, based on how patients present to PD services where they may or may not have a carer present. After final iterations between PMG and PPI

groups, three final assessment toolkits were produced for the pilot and feasibility study (Appendix 1)

Pilot and feasibility of assessment toolkits

A pilot and feasibility study of the assessment instruments was carried out within Gateshead Health NHSFT, a representative Trust which provides old age psychiatry (memory/dementia) services (OAP) and PD (movement disorder) services. Following ethical and research and development approvals from Gateshead Health NHSFT, medical and nursing staff were identified in the OAP and PD services and given brief information about the study and brief training in using the assessment tools. The aims of the pilot was to ensure that the diagnosis tools were acceptable to staff and could be integrated into current assessment procedures in busy clinical services. Piloting was to include all subjects having first assessments for memory impairments and/or dementia because of possible Alzheimer's disease or other causes in the OAP service, and in the PD Service, all those with PD where any cognitive impairment was suspected. The aim was to include at least four staff (doctors and nurses) in each service and at least 20 subjects per service. Completed assessment toolkits were kept by the research team with copies placed in the patient notes.

Results

Four OAP consultants and four Elderly Medicine PD clinicians (two specialist nurses and two consultants) agreed to take part initially. Three additional clinicians who were on leave or not initially working within the service were subsequently recruited (two specialist registrars within the OAP service and one consultant from the PD Service) to increase opportunities for accrual.

Patient recruitment

The number of patients consenting for the use of the tool(s) by individual clinicians ranged from zero to seven. Two PD clinicians did not use the assessment tool (one clinician moved from the service soon after the pilot study started, the other felt it was not appropriate for any of their patients) but a later PD clinician did. All OAP clinicians used the assessment tool at least once. Clinicians working in OAP recruited more patients (a total of 19) than their colleagues in the PD service (a total of seven).

The toolkits were used with patients with and without LBD (Table 1). One patient had diagnoses of both vascular dementia and PD, and therefore, the total number of diagnoses was 27. Patients with PD may be seen by the OAP service and the movement disorder service, and during the study period, one patient was seen by both services at different times and completed the appropriate assessment tool in each service.

Feedback and modification of the assessment toolkits

Feedback from clinicians was obtained in a number of ways:

- Informal feedback to the local chief investigator (AT) and the research nurse
- Written comments on completed assessment tools
- Qualitative interviews (CB).

For the patients, none of the questions from the assessment toolkits stood out as being inappropriate or unclear. For clinicians generally, the tools were found to be straightforward to use, with the constraints being on time available within current service structures. The PD service in particular found it difficult to integrate a cognitive assessment into their initial patient assessment. The toolkits were regarded as helpful in encouraging the assessment of the relevant symptoms for diagnosis and useful in providing structure and a specific approach.

Based on detailed feedback in these ways, the pilot toolkits were modified as follows (final DLB and PDD assessment toolkits are in Appendices 2 and 3, respectively). PD clinicians felt it would be helpful to have questions on core and suggestive symptoms of DLB in the PDD toolkit and did not feel that in practice, there was a need to have separate carer and patient versions of the PDD tool. Hence, the revised final version for PD services (Appendix 3) is titled 'Assessment toolkits for Lewy body dementia' and includes two toolkits, depending on whether the patient has longstanding PD and recent cognitive decline or whether the PD diagnosis/symptoms are recent, along with cognitive

symptoms. A specific issue raised for RBD was what to do if no bed-partner was available to answer the RBD question. AT contacted Dr Brad Boeve (Mayo Clinic, Minnesota) who had developed the RBD instrument and was advised that a similar question can be used with patients who are mildly cognitively impaired about any known history of 'acting out dreams'. This additional option was therefore included in the final versions. In the pilot version of the PD toolkits, the MoCA had been specified. However, PD nurses were not familiar with the MoCA, although they aimed to complete a Mini-Mental State Examination annually with each patient, and clinicians suggested that it be clarified that other cognitive instruments could be used if these were preferred, which has been performed in the final LBD toolkit. A third specific concern was that the wording, whilst clear, sometimes appeared prescriptive and seemed to not allow clinical judgement about the presence of symptoms, and so the wording has been changed at several points to make it clear that the questions in the toolkits are a guide, and ultimately, the presence of key symptoms, like final diagnoses, is a clinical judgement based on all available evidence. Several other more minor issues were raised about the layout and format which have been incorporated into the final versions of the toolkits, e.g. consistent use of tick boxes and an expanded list of diagnostic options for people with cognitive impairment.

Thus, following the pilot feedback led to changes in the assessment instruments. Specifically, a single PD assessment toolkit was produced which included the questions from the DLB toolkit for identifying visual hallucinations, cognitive fluctuations and RBD. Wording was also changed as was some of the layout in response to comments.

Discussion

We were able to combine elements from validated symptom assessment instruments into assessment toolkits for improving the diagnosis of DLB and PDD. These toolkits were developed to be aligned with the standard diagnostic criteria for these dementias (McKeith *et al.*, 2005; Emre *et al.*, 2007), and our

Table 1 Diagnoses of participating patients

	Possible/probable DLB	Non-DLB - other diagnoses including depression, vascular dementia and mild cognitive impairment	PDD or PD-MCI	Parkinson's disease
Use of tool(s)	5	12	2	8
Qualitative interview	3	2	0	1

DLB, dementia with Lewy bodies; PDD, Parkinson's disease dementia; PD-MCI, Parkinson's disease-mild cognitive impairment.

feasibility study proved to be broadly acceptable to clinicians in regular clinical services and easily integrated into routine care making them 'invisible' to patients during clinical assessments. The piloting of these toolkits identified a few key changes, such as the desire for a combined LBD toolkit for use with both patients and carers in PD services, and the addition of an RBD question for use when no bed-partner is available.

The study aimed to address the problem of inadequate recognition and diagnosis of both DLB (Galvin *et al.*, 2010; Alzheimer Society, 2007) and PDD (Dujardin *et al.*, 2010) and self-consciously sought to build on existing evidence by utilising previously researched and validated instruments (Ballard *et al.*, 1997; Mosimann *et al.*, 2008; Boeve *et al.*, 2011; Lee *et al.*, 2014). We did not therefore seek to assess the psychometric properties of the specific elements of the toolkits; rather we sought to address the need to combine these instruments into clinically useful and usable toolkits for clinicians working in dementia and PD services. Following this feasibility study, the toolkits will require further testing in other clinical populations to examine if they do indeed improve the diagnosis of LBD. Although the absence of validation may be regarded as a limitation, the fact the components have been tested and validated previously provides some reassurance. The piloting of these toolkits in a single organisation may also be regarded as a limitation of this study. Finally whilst we had an adequate number of OAP clinicians using the toolkits, we only had three PD clinicians. Whilst our study was deemed to have reached saturation, we acknowledge that future assessments of these toolkits will require more PD clinicians. However, the aim was to improve utility of the instruments in routine dementia, and PD services and the clinicians involved were not academics or researchers and are representative of clinicians in such services in the UK. Furthermore, it was clear from the feedback that we had reached saturation, making it unlikely that involvement of additional clinicians would have contributed usefully to the study. Although the instruments were not themselves regarded as burdensome, the intense pressure on clinicians' time sometimes made it difficult for them to use them, raising questions about how current service designs might be hindering high quality diagnostic assessments. One consequence of such pressures is that nursing staff are often conducting parts of the clinical assessments in many services and in order to assess Parkinsonism they require specialist training.

In conclusion, we sought to address an important need with this study, namely the under-recognition and under-diagnosis of LBD in routine services. We have performed this by developing brief and usable instruments

which can be integrated into routine clinical practice. The pilot versions proved acceptable to clinicians and patients, and we encourage the use of the final versions to improve the diagnostic rates of DLB and PDD.

Conflict of Interest

None declared.

Key points

- Lewy body dementias are under-recognised
- Validated key questions improve identification of LBD
- New toolkits facilitate recognition and diagnosis of LBD

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Appendix 1: Draft Toolkits for the Lewy Body Dementias

Assessment Toolkit for Dementia with Lewy Bodies

1. Clinician diagnosis of dementia (Cognitive decline sufficient to interfere with social/occupational function. Normally the cognition will score <24 on MMSE or <21 on MOCA if dementia present)
2. Using screening questions below to cover the four domains of: cognitive fluctuation, visual hallucinations, RBD and parkinsonism.
3. Using the responses and your clinical experience identify how many of below Core and suggestive features of DLB are present in subject with dementia:

Core features (at least one core + one suggestive or 2 core features must be present):

- Fluctuation
- Recurrent visual hallucinations
- Spontaneous parkinsonism

Suggestive features:

- REM sleep behaviour disorder
- Neuroleptic sensitivity (on antipsychotics and parkinsonism identified)
- Dopaminergic abnormalities in basal ganglia on SPECT/PET

Diagnose Probable DLB if either 2 core features are identified or 1 core and 1 suggestive feature

Diagnose Possible DLB if any one feature is present. In such circumstances consider referring subject for a DaTSCAN

Alzheimer’s Disease

Other Dementia

Patient Informed of Diagnosis? YES/NO

If the diagnosis is Dementia with Lewy bodies please refer to the Management Toolkit

Please respond to each of the questions below by circling 'yes' or 'no'.

Cognitive Fluctuation

- | | | |
|----|--|--------|
| 1. | Does the patient show moderate changes in their level of functioning during the day? | YES/NO |
| 2. | Between getting up in the morning and going to bed at night, does the patient spend more than one hour sleeping? | YES/NO |
| 3. | Is the patient drowsy and lethargic for more than one hour during the day, despite getting their usual amount of sleep the night before? | YES/NO |
| 4. | Is it moderately difficult to arouse the patient so they maintain attention through the day? | YES/NO |

REM Sleep Disorder Question (to informant = bed partner)

- | | | |
|----|--|--------|
| 1. | Have you ever seen the patient appear to "act out his/her dreams" while sleeping? (punched or flailed arms in the air, shouted or screamed). | YES/NO |
|----|--|--------|

If answered affirmatively, the sub-questions below may be asked:

- | | | |
|-----|--|--------|
| (a) | Has the patient ever been injured from these behaviours (bruises, cuts, broken bones)? | YES/NO |
| (b) | Has a bed partner ever been injured from these behaviours (bruises, blows, pulled hair)? | YES/NO |
| (c) | Has the patient told you about dreams of being chased, attacked or that involve defending himself/herself? | YES/NO |
| (d) | If the patient woke up and told you about a dream, did the details of the dream match the movements made while sleeping? | YES/NO |

Visual Hallucinations

For the participant: Some people see things that other people cannot see.

- | | | |
|----|---|--------|
| 1. | Do you feel like your eyes ever play tricks on you? | YES/NO |
| 2. | Have you ever seen something (or things) that other people could not see? | YES/NO |

For the Informant:

- | | | |
|----|--|--------|
| 1. | Does the patient have hallucinations such as seeing false visions? | YES/NO |
| 2. | Does he/she seem to see things that are not present? | YES/NO |

Assessment of Parkinsonism (5-item UPDRS)

Each item is scored 0-4. Please circle the appropriate score for each item

POSTURAL TREMOR OF THE HANDS

- 0: Normal: No tremor.
- 1: Slight: Tremor is present but less than 1 cm in amplitude.
- 2: Mild: Tremor is at least 1 but less than 3 cm in amplitude.
- 3: Moderate: Tremor is at least 3 but less than 10 cm in amplitude.
- 4: Severe: Tremor is at least 10 cm in amplitude.

KINETIC TREMOR OF THE HANDS

- 0: Normal: No tremor.
- 1: Slight: Tremor is present but less than 1 cm in amplitude.
- 2: Mild: Tremor is at least 1 but less than 3 cm in amplitude.
- 3: Moderate: Tremor is at least 3 but less than 10 cm in amplitude.
- 4: Severe: Tremor is at least 10 cm in amplitude.

FACIAL EXPRESSION

- 0: Normal: Normal facial expression.
- 1: Slight: Minimal masked facies manifested only by decreased frequency of blinking.
- 2: Mild: In addition to decreased eye-blink frequency, masked facies present in the lower face as well, namely fewer movements around the mouth, such as less spontaneous smiling, but lips not parted.
- 3: Moderate: Masked facies with lips parted some of the time when the mouth is at rest.
- 4: Severe: Masked facies with lips parted most of the time when the mouth is at rest.

GLOBAL SPONTANEITY OF MOVEMENT (BODY BRADYKINESIA)

- 0: Normal: No problems.
- 1: Slight: Slight global slowness and poverty of spontaneous movements.
- 2: Mild: Mild global slowness and poverty of spontaneous movements.
- 3: Moderate: Moderate global slowness and poverty of spontaneous movements.
- 4: Severe: Severe global slowness and poverty of spontaneous movements.

RIGIDITY

- 0: Normal: No rigidity.
- 1: Slight: Rigidity only detected with activation manoeuver.
- 2: Mild: Rigidity detected without the activation manoeuver, but full range of motion is easily achieved.
- 3: Moderate: Rigidity detected without the activation manoeuver; full range of motion is achieved with effort.
- 4: Severe: Rigidity detected without the activation manoeuver and full range of motion not achieved.

Total 5-item UPDRS Score =

The cut-off is 7/8 for significant parkinsonism

Is Parkinsonism present?

YES/NO

Instructions for Assessing Parkinsonism (from UPDRS)

POSTURAL TREMOR OF THE HANDS

Rate each hand separately. Rate the highest amplitude seen. Instruct the patient to stretch the arms out in front of the body with palms down. The wrist should be straight and the fingers comfortably separated so that they do not touch each other. Observe this posture for 10 seconds.

KINETIC TREMOR OF THE HANDS

This is tested by the finger-to-nose maneuver. With the arm starting from the outstretched position, have the patient perform at least three finger-to-nose maneuvers with each hand reaching as far as possible to touch the examiner's finger. The finger-to-nose maneuver should be performed slowly enough not to hide any tremor that could occur with very fast arm movements. Repeat with the other hand, rating each hand separately. The tremor can be present throughout the movement or as the tremor reaches either target (nose or finger). Rate the highest amplitude seen.

FACIAL EXPRESSION

Observe the patient sitting at rest for 10 seconds, without talking and also while talking. Observe eye-blink frequency, masked facies or loss of facial expression, spontaneous smiling and parting of lips.

GLOBAL SPONTANEITY OF MOVEMENT (BODY BRADYKINESIA)

This global rating combines all observations on slowness, hesitancy, and small amplitude and poverty of movement in general, including a reduction of gesturing and of crossing the legs. This assessment is based on the examiner's global impression after observing for spontaneous gestures while sitting, and the nature of arising and walking.

RIGIDITY

Instructions to examiner: Rigidity is judged on slow passive movement of major joints with the patient in a relaxed position and the examiner manipulating the limbs and neck. First, test without an activation maneuver. Test and rate neck and each limb separately. For arms, test the wrist and elbow joints simultaneously. For legs, test the hip and knee joints simultaneously. If no rigidity is detected, use an activation maneuver such as tapping fingers, fist opening/closing, or heel tapping in a limb not being tested. Explain to the patient to go as limp as possible as you test for rigidity.

Assessment Toolkit for Parkinson's Disease Dementia (Patient Version)

Step 1: Please ask the following questions to the patient:

(NOTE: If you already know memory problems are significant you may pass straight to the Executive Impairment/Function questions)

Memory

Please ask the patient the following questions about their memory.

Do you have problems remembering things, e.g. what happened yesterday or what you were doing earlier? YES/NO

Do you have difficulty remembering names of people you know well? YES/NO

When talking to people do you often forget what had been said? YES/NO

Executive Impairment/Function

Please try to determine whether any difficulty is due to memory decline or physical impairment:

Do you have problems handling money or cards when paying for things? YES/NO

Do you have difficulty looking after your own tablets? YES/NO

Are you able to use household appliances on your own that you have used for a long-time, e.g. the TV or washing machine? YES/NO

Step 2: If Yes to 1 or more question on memory and 1 or more question on executive impairment/function in step 1 then please administer the MOCA (or other cognitive assessment instrument)

Step 3: If MOCA<26 (or below cut-off for other instrument) and problems with everyday activities are due to memory decline and not due to physical impairment then please discuss with carer/relative

1. Seek confirmation of memory decline and related impairments in daily living activity YES/NO
2. Ask how long have these memory problems been present? (Determine if >1 year before Parkinson's disease) YES(>1 YR)/NO
3. Did these changes or difficulties develop gradually or did they come on suddenly? YES/NO
4. Do you think there was anything specific that caused these memory problems? YES/NO

Step 4: Now determine if the patient meets each of the 8 criteria below:

- 1. Clinician diagnosis of Parkinson’s Disease (Queen Square Brain Bank Criteria)
- 2. Onset of cognitive decline >1 year after onset of Parkinson’s disease
- 3. Represents a decline from premorbid level
- 4. Deficits are severe enough to impair daily life (social, occupational, or personal care), independent of the impairment due to motor or autonomic symptoms
- 5. MOCA <21 (if MOCA <26, diagnose PD-MCI if impairments in daily living mild)
- 6. A dementia syndrome with insidious onset and slow progression, developing within the context of established Parkinson’s disease and diagnosed by history, clinical, and mental examination, defined as:
 - Impairment in **more than one** cognitive domain from the MOCA:
 - Attention: Serial 7s
 - Executive functions: Lexical fluency, trails
 - Visuo-spatial functions: Clock drawing, wire cube, abstraction
 - Memory: Recall of 5 objects
- 7. Absence of delirium, depression, systemic illness or drug intoxication sufficient to the cause cognitive impairment
- 8. Absence of other plausible cause of dementia, especially severe cerebrovascular disease

What is your clinical diagnosis?

- Parkinson’s Disease Dementia
- Parkinson’s Disease MCI
- Parkinson’s Disease
- Other Diagnosis

Patient Informed of Diagnosis?

If the diagnosis is Parkinson’s Disease Dementia please refer to the Management Toolkit

Assessment Toolkit for Parkinson's Disease Dementia (Carer with Patient Version)

Step 1: Please ask the following questions to the patient and his/her informant/carer:

(NOTE: If you already know memory problems are significant you may pass straight to the Executive Impairment/Function questions)

Memory

Please ask the patient the following questions about memory.

Do you/does your relative have problems remembering things, e.g. what happened yesterday or what you were doing earlier? YES/NO

Do you/does your relative have difficulty remembering names of people you know well? YES/NO

When talking to people you/does your relative often forget what had been said? YES/NO

Executive Impairment/Function

Please try to determine whether any difficulty is due to memory decline or physical impairment:

Do you/does your relative have problems handling money or cards when paying for things? YES/NO

Do you/does your relative have difficulty looking after your own tablets? YES/NO

Are you/is your relative able to use household appliances on your own that you have used for a long-time, e.g. the TV or washing machine? YES/NO

Step 2: If Yes to 1 or more question on memory and 1 or more question on executive impairment/function in step 1 then please administer the MOCA (or other cognitive assessment instrument)

Step 3: If MOCA<26 (or below cut-off for other instrument) and problems with everyday activities are due to memory decline and not due to physical impairment then please discuss with carer/relative

5. Seek confirmation of memory decline and related impairments in daily living activity YES/NO
6. Ask how long have these memory problems been present? (Determine if >1 year before Parkinson's disease) YES(>1 YR)/NO
7. Did these changes or difficulties develop gradually or did they come on suddenly? YES/NO
8. Do you think there was anything specific that caused these memory problems? YES/NO

Step 4: Now determine if the patient meets each of the 8 criteria below:

1. Clinician diagnosis of Parkinson's Disease (Queen Square Brain Bank Criteria)
2. Onset of cognitive decline >1 year after onset of Parkinson's disease
3. Represents a decline from premorbid level
4. Deficits are severe enough to impair daily life (social, occupational, or personal care), independent of the impairment due to motor or autonomic symptoms
5. MOCA <21 (if MOCA <26, diagnose PD-MCI if impairments in daily living mild)
6. A dementia syndrome with insidious onset and slow progression, developing within the context of established Parkinson's disease and diagnosed by history, clinical, and mental examination, defined as:
 - Impairment in **more than one** cognitive domain from the MOCA:
 - Attention: Serial 7s
 - Executive functions: Lexical fluency, trails
 - Visuo-spatial functions: Clock drawing, wire cube, abstraction
 - Memory: Recall of 5 objects
7. Absence of delirium, depression, systemic illness or drug intoxication sufficient to the cause cognitive impairment
8. Absence of other plausible cause of dementia, especially severe cerebrovascular disease

What is your clinical diagnosis?

Parkinson's Disease Dementia

Parkinson's Disease MCI

Parkinson's Disease

Other Diagnosis

Patient Informed of Diagnosis?

If the diagnosis is Parkinson's Disease Dementia please refer to the Management Toolkit

Appendix 2: Assessment Toolkit for Dementia with Lewy Bodies

Study No: _____

Assessment Toolkit for Dementia with Lewy Bodies

Name:	Date of testing:
Date of birth:	Tester's name:
NHS No:	Informant:

Please use this Assessment toolkit in all people with cognitive decline. Below are the diagnostic features of dementia with Lewy bodies (DLB) at two levels of confidence (probable DLB and possible DLB) and on the following pages are specific questions to assist in the identification of the core and suggestive features of DLB.

DLB Diagnostic Criteria		Tick
1	Clinician diagnosis of dementia (cognitive decline sufficient to interfere with social/occupational function).	<input type="checkbox"/>
2	Use screening questions below to cover the four domains of: cognitive fluctuation, visual hallucinations, RBD and parkinsonism.	
3	Using your clinical experience identify how many core and suggestive features of DLB are present (see below):	
Core features		
	• Fluctuation	<input type="checkbox"/>
	• Recurrent visual hallucinations	<input type="checkbox"/>
	• Spontaneous parkinsonism	<input type="checkbox"/>
Suggestive features		
	• REM sleep behaviour disorder	<input type="checkbox"/>
	• Neuroleptic sensitivity	<input type="checkbox"/>
	• Dopaminergic abnormalities in basal ganglia on SPECT/PET	<input type="checkbox"/>
Diagnose Probable DLB if either 2 core features are identified or 1 core and 1 suggestive feature.		<input type="checkbox"/>
Diagnose Possible DLB if any one feature is present. In such circumstances consider whether to refer subject for a dopaminergic SPECT scan (DaTSCAN).		<input type="checkbox"/>

Other Diagnoses	
Parkinson's Disease Dementia (PDD) (PD >1 yr before cognitive symptoms)	<input type="checkbox"/>
Alzheimer's Disease	<input type="checkbox"/>
Other Dementia	<input type="checkbox"/>
MCI	<input type="checkbox"/>
Patient informed of diagnosis.	Yes <input type="checkbox"/> No <input type="checkbox"/>

Questions to Identify Symptoms of DLB

Please respond to each of the questions below, asking carer or patient as appropriate.

Cognitive Fluctuation (to carer)

If two or more of these are answered 'Yes' the subject is highly likely to have cognitive fluctuation

1	Does the patient show moderate changes in their level of functioning during the day?	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
2	Between getting up in the morning and going to bed at night, does the patient spend more than one hour sleeping?	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
3	Is the patient drowsy and lethargic for more than one hour during the day, despite getting their usual amount of sleep the night before?	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
4	Is it moderately difficult to arouse the patient so they maintain attention through the day?	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>

REM Sleep Disorder

(to carer = bed partner)

Have you ever seen the patient appear to "act out his/her dreams" while sleeping (punched or flailed arms in the air, shouted or screamed)?

Yes

No

If answered affirmatively, then RBD is highly likely to be present.

REM Sleep Disorder

(to patient only if no bed partner and they have sufficient cognitive ability to be confident their answer is reliable)

Have you ever been told that you seem to "act out your dreams" while sleeping (punched or flailed arms in the air, shouted or screamed)?

Yes

No

Visual Hallucinations

For the participant: Some people see things that other people cannot see.

1	Do you feel like your eyes ever play tricks on you?	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
2	Have you ever seen something (or things) that other people could not see?	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>

For the carer:

1	Does the patient have hallucinations such as seeing false visions?	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
2	Does he / she seem to see things that are not present?	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>

If, according to clinical judgement, visual hallucinations are present, determine as far as possible their frequency and recurrence. As a guide, visual hallucinations associated with DLB should not only occur during delirium, and are often recurrent over a period of months.

Assessment of Parkinsonism (5-item UPDRS)							
Each item is scored 0–4. Please tick the appropriate score for each item (see next page for further details)							
POSTURAL TREMOR OF THE HANDS							
Normal	No tremor.	0	<input type="checkbox"/>				
Slight	Tremor is present but less than 1 cm in amplitude.	1	<input type="checkbox"/>				
Mild	Tremor is at least 1 but less than 3 cm in amplitude.	2	<input type="checkbox"/>				
Moderate	Tremor is at least 3 but less than 10 cm in amplitude.	3	<input type="checkbox"/>				
Severe	Tremor is at least 10 cm in amplitude.	4	<input type="checkbox"/>				
KINETIC TREMOR OF THE HANDS							
Normal	No tremor.	0	<input type="checkbox"/>				
Slight	Tremor is present but less than 1 cm in amplitude.	1	<input type="checkbox"/>				
Mild	Tremor is at least 1 but less than 3 cm in amplitude.	2	<input type="checkbox"/>				
Moderate	Tremor is at least 3 but less than 10 cm in amplitude.	3	<input type="checkbox"/>				
Severe	Tremor is at least 10 cm in amplitude.	4	<input type="checkbox"/>				
FACIAL EXPRESSION							
Normal	Normal facial expression.	0	<input type="checkbox"/>				
Slight	Minimal masked facies manifested only by decreased frequency of blinking.	1	<input type="checkbox"/>				
Mild	In addition to decreased eye-blink frequency, masked facies present in the lower face as well, namely fewer movements around the mouth, such as less spontaneous smiling, but lips not parted.	2	<input type="checkbox"/>				
Moderate	Masked facies with lips parted some of the time when the mouth is at rest.	3	<input type="checkbox"/>				
Severe	Masked facies with lips parted most of the time when the mouth is at rest.	4	<input type="checkbox"/>				
GLOBAL SPONTANEITY OF MOVEMENT (BODY BRADYKINESIA)							
Normal	No problems.	0	<input type="checkbox"/>				
Slight	Slight global slowness and poverty of spontaneous movements.	1	<input type="checkbox"/>				
Mild	Mild global slowness and poverty of spontaneous movements.	2	<input type="checkbox"/>				
Moderate	Moderate global slowness and poverty of spontaneous movements.	3	<input type="checkbox"/>				
Severe	Severe global slowness and poverty of spontaneous movements.	4	<input type="checkbox"/>				
RIGIDITY							
Normal	No rigidity.	0	<input type="checkbox"/>				
Slight	Rigidity only detected with activation manoeuvre.	1	<input type="checkbox"/>				
Mild	Rigidity detected without the activation manoeuvre, but full range of motion is easily achieved.	2	<input type="checkbox"/>				
Moderate	Rigidity detected without the activation manoeuvre; full range of motion is achieved with effort.	3	<input type="checkbox"/>				
Severe	Rigidity detected without the activation manoeuvre and full range of motion not achieved.	4	<input type="checkbox"/>				
Total 5-item UPDRS Score =			<input type="text"/>				
Is Parkinsonism present? (Use clinical judgement but for guidance a score >7 usually suggests significant parkinsonism is present)			<table border="1"> <tr> <td>Yes</td> <td><input type="checkbox"/></td> <td>No</td> <td><input type="checkbox"/></td> </tr> </table>	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
Yes	<input type="checkbox"/>	No	<input type="checkbox"/>				

Instructions for Assessing Parkinsonism (from UPDRS)

POSTURAL TREMOR OF THE HANDS

Rate each hand separately. Rate the highest amplitude seen. Instruct the patient to stretch the arms out in front of the body with palms down. The wrist should be straight and the fingers comfortably separated so that they do not touch each other. Observe this posture for 10 seconds.

KINETIC TREMOR OF THE HANDS

This is tested by the finger-to-nose maneuver. With the arm starting from the outstretched position, have the patient perform at least three finger-to-nose maneuvers with each hand reaching as far as possible to touch the examiner's finger. The finger-to-nose maneuver should be performed slowly enough not to hide any tremor that could occur with very fast arm movements. Repeat with the other hand, rating each hand separately. The tremor can be present throughout the movement or as the tremor reaches either target (nose or finger). Rate the highest amplitude seen.

FACIAL EXPRESSION

Observe the patient sitting at rest for 10 seconds, without talking and also while talking. Observe eye-blink frequency, masked facies or loss of facial expression, spontaneous smiling and parting of lips.

GLOBAL SPONTANEITY OF MOVEMENT (BODY BRADYKINESIA)

This global rating combines all observations on slowness, hesitancy, and small amplitude and poverty of movement in general, including a reduction of gesturing and of crossing the legs. This assessment is based on the examiner's global impression after observing for spontaneous gestures while sitting, and the nature of arising and walking.

RIGIDITY

Instructions to examiner: Rigidity is judged on slow passive movement of major joints with the patient in a relaxed position and the examiner manipulating the limbs and neck. First, test without an activation maneuver. Test and rate neck and each limb separately. For arms, test the wrist and elbow joints simultaneously. For legs, test the hip and knee joints simultaneously. If no rigidity is detected, use an activation maneuver such as tapping fingers, fist opening/closing, or heel tapping in a limb not being tested. Explain to the patient to go as limp as possible as you test for rigidity.

Appendix 3: Assessment Toolkits for Lewy Body Dementia

Study No: _____

Assessment Toolkits for Lewy Body Dementia

There are two toolkits, depending on whether the patient is presenting with a primary cognitive problem or with cognitive decline in the context of established Parkinson's disease.

One toolkit is for assisting in the diagnosis of Parkinson's Disease Dementia

This is therefore recommended for people with cognitive decline who have established Parkinson's disease (diagnosis for more than one year before the cognitive problems began).

The other toolkit is for assisting in the diagnosis of Dementia with Lewy Bodies

This toolkit is designed for use with people whose primary presenting problem is cognitive decline and who may or may not have evidence of recent Parkinson's disease (parkinsonian symptoms beginning at the same time or within a year of the cognitive symptoms).

Assessment Toolkit for Parkinson's Disease Dementia

Name:	Date of testing:
Date of birth:	Tester's name:
NHS No:	Informant:

Step 1: Please ask the following questions to the patient and/or his/her informant/carer:

Memory		Tick	
Please ask the following questions about memory.			
1	Do you/does your relative have problems remembering things, e.g. what happened yesterday or what you were doing earlier?	Yes	No
2	Do you/does your relative have difficulty remembering names of people you know well?	Yes	No
3	When talking to people do you/does your relative often forget what had been said?	Yes	No

Executive Impairment/Function		Tick	
Please try to determine whether any difficulty is due to memory decline or physical impairment:			
1	Do you/does your relative have problems handling money or bank cards when paying for things?	Yes	No
2	Do you/does your relative have difficulty looking after your/their own tablets?	Yes	No
3	Are you/is your relative able to use household appliances on your own that you have used for a long-time, e.g. the TV or washing machine?	Yes	No

Step 2: If Yes to 1 or more questions on memory AND 1 or more questions on executive impairment/function in step 1 then please administer the MOCA (or any other preferred cognitive assessment instrument to more fully assess for cognitive impairment).

Step 3: If MOCA<26 (or below cut-off for other instrument) and problems with everyday activities are due to memory decline and not due to physical impairment then please discuss with patient and/or carer/relative.

1	Seek confirmation of memory decline and related impairments in daily living activity.	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
2	Ask how long have these memory problems been present: Have they been present for >1 year before Parkinson's disease	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
3	Did these changes or difficulties develop gradually or rather than coming on suddenly?	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
4	Do you think there was anything specific that caused these memory problems?	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>

Step 4: Now determine if the patient meets each of the 8 criteria below:

1	Clinician diagnosis of Parkinson's Disease.	<input type="checkbox"/>
2	Onset of cognitive decline >1 year after onset of Parkinson's disease.	<input type="checkbox"/>
3	Represents a decline from premorbid level.	<input type="checkbox"/>
4	Deficits are severe enough to impair daily life (social, occupational, or personal care), independent of the impairment due to motor or autonomic symptoms.	<input type="checkbox"/>
5	MOCA <21 or impaired on other cognitive test (if MOCA <26, diagnose PD-MCI if impairments in daily living are mild).	<input type="checkbox"/>
6	A dementia syndrome with insidious onset and slow progression, developing within the context of established Parkinson's disease and diagnosed by history, clinical, and mental examination, defined as: <ul style="list-style-type: none"> • Impairment in more than one cognitive domain from the MOCA: <ul style="list-style-type: none"> • Attention: Serial 7s • Executive functions: Lexical fluency, trails • Visuo-spatial functions: Clock drawing, wire cube, abstraction • Memory: Recall of 5 objects. 	<input type="checkbox"/>
7	Absence of delirium, depression, systemic illness or drug intoxication sufficient to the cause cognitive impairment.	<input type="checkbox"/>
8	Absence of other plausible cause of dementia, especially severe cerebrovascular disease.	<input type="checkbox"/>

Please go to page 6 to confirm your clinical diagnosis.

Assessment Toolkit for Dementia with Lewy Bodies

Name:	Date of testing:
Date of birth:	Tester's name:
NHS No:	Informant:

Please use this Assessment toolkit in all people with cognitive decline. Below are the diagnostic features of dementia with Lewy bodies (DLB) at two levels of confidence (probable DLB and possible DLB) and on the following pages are specific questions to assist in the identification of core and suggestive features of DLB.

DLB Diagnostic Criteria		Tick
1	Clinician diagnosis of dementia (cognitive decline sufficient to interfere with social/occupational function).	<input type="checkbox"/>
2	Use screening questions below to cover the four domains of: cognitive fluctuation, visual hallucinations, RBD and parkinsonism.	
3	Using your clinical experience identify how many core and suggestive features of DLB are present (see below and next page):	
	<p>Core features</p> <ul style="list-style-type: none"> • Fluctuation • Recurrent visual hallucinations • Spontaneous parkinsonism 	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
	<p>Suggestive features</p> <ul style="list-style-type: none"> • REM sleep behaviour disorder • Neuroleptic sensitivity • Dopaminergic abnormalities in basal ganglia on SPECT/PET 	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>

Diagnose **Probable DLB** if either 2 core features are identified or 1 core and 1 suggestive feature.

Diagnose **Possible DLB** if any one feature is present. In such circumstances consider whether to refer subject for a dopaminergic SPECT scan (DaTSCAN).

Please go to page 6 to confirm your clinical diagnosis.

Questions to Identify Symptoms of DLB	Tick
Please respond to each of the questions below, asking carer or patient as appropriate.	

Cognitive Fluctuation (to carer)					
If two or more of these are answered 'Yes' the subject is highly likely to have cognitive fluctuation					
1	Does the patient show moderate changes in their level of functioning during the day?	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
2	Between getting up in the morning and going to bed at night, does the patient spend more than one hour sleeping?	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
3	Is the patient drowsy and lethargic for more than one hour during the day, despite getting their usual amount of sleep the night before?	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
4	Is it moderately difficult to arouse the patient so they maintain attention through the day?	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>

REM Sleep Disorder (to carer = bed partner)					
Have you ever seen the patient appear to "act out his/her dreams" while sleeping (punched or flailed arms in the air, shouted or screamed)?		Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
If answered affirmatively, then RBD is highly likely to be present.					

REM Sleep Disorder (to patient <u>only</u> if no bed partner and they have sufficient cognitive ability to be confident their answer is reliable)					
Have you ever been told that you seem to "act out your dreams" while sleeping (punched or flailed arms in the air, shouted or screamed)?		Yes	<input type="checkbox"/>	No	<input type="checkbox"/>

Visual Hallucinations					
For the participant: Some people see things that other people cannot see.					
1	Do you feel like your eyes ever play tricks on you?	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
2	Have you ever seen something (or things) that other people could not see?	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
For the carer:					
1	Does the patient have hallucinations such as seeing false visions?	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
2	Does he / she seem to see things that are not present?	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>

If, according to clinical judgement, visual hallucinations are present, determine as far as possible their frequency and recurrence. As a guide, visual hallucinations associated with DLB should not only occur during delirium, and are often recurrent over a period of months.
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What is your clinical diagnosis?	Tick
Parkinson's Disease Dementia	<input type="checkbox"/>
Parkinson's Disease MCI	<input type="checkbox"/>
Parkinson's Disease	<input type="checkbox"/>
Probable DLB	<input type="checkbox"/>
Possible DLB	<input type="checkbox"/>
Alzheimer's Disease	<input type="checkbox"/>
Other Dementia	<input type="checkbox"/>
	Tick
Patient Informed of Diagnosis?	<input type="checkbox"/>