Dementia Addendum
Consultation on draft guideline - Stakeholder comments table
8 February 2016 – 7 March 2016

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Stakeholder	Document	Page No	Line No	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
Primary Care Neurology Society	Addendum	General	General	Important to specify who qualifies as a Specialist for prescribing and follow-up. Many GPs have undertaking specific training in dementia such as MSc course or are supported by secondary care MH trust as a GPSI in their dementia work that includes diagnosing typical patients with dementia.	Thank you for your comment. The Guideline Committee considered how the term specialist should be interpreted and have made changes to the recommendations which now provide a clear description of a clinician with expertise in diagnosing and treating Alzheimer's disease.for the purposes of this guideline.
Primary Care Neurology Society	Addendum	general	General	Related to this cholinesterase and memantine prescribing to date in England has for the most part been initiated by secondary care and once the patient is stabilised the person's prescribing is moved to Primary Care as part of a Shared Care Protocol. There could still be the necessity for secondary care advice especially when changing between cholinesterase inhibitors or changing to / adding on memantine.	Thank you for your comment. The Guideline Committee considered the need for joint working between primary and secondary care and have made changes to the recommendations to ensure that they clearly address local arrangements for prescribing, supply and review of acetylcholinesterase inhibitors and mematine in people living with Alzheimer's disease through reference to the NICE guideline on medicines optimisation.
Primary Care Neurology Society	Addendum	general	General	Discontinuation or add-on cholinesterase to memantine: there are data to show that some patients thes have a marked decrease in function with discontinuation of, scholinesterase when changing	Thank you for your comment. The addendum chapter provides recommendations regarding the systems for prescribing and reviewing treatment with

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				to memantine. There is a case of combining cholinesterase and memantine as a person's dementia progresses to the severe stage.	donepezil, galantamine, rivastigmine and memantine in people living with Alzheimer's disease. The continuation or withdrawal of these drugs for people living with Alzheimer's disease will be considered as part of the full update of the NICE Clinical Guideline on Dementia which is scheduled for publication in 2017/18.
Primary Care Neurology Society	Addendum	general	general	Medicines Optimisation does not address evaluating the whole cholinergic burden (see attached slide).	Thank you for your comment. The NICE guidance on medicines optimisation addresses general principles including optimising the impact of medicines and minimising the number of medication-related problems. Applying the principles outlined in recommendation 1.4 during a structured medication review should identify any medicines related problems (such as the 'cholinergic burden'). In addition, recommendation 1.1.9 states: Consider using a screening tool – for example, the STOPP/START tool in older people – to identify potential medicines-related patient safety incidents in some groups. The slide provided by the stakeholder refers to the cholinergic burden as noted by Mahoney et al. 2014. The STOPP/START tool is recommended in the NICE guidance

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					on medicines optimisation and the original paper highlights the increased risk with anticholinergics in people with delirium or dementia (risk of exacerbation of cognitive impairment).
Primary Care Neurology Society	Addendum	general	general	Addendum only addresses Alz Disease - cholinesterases are also indicated for Parkinson's disease dementia but the guideline does not address this.	Thank you for your comment. The prescribing of acetylcholinesterase inhibitors and/or memantine for Parkinson's disease dementia will be considered as part of the full update of the NICE Clinical Guideline on Parkinson's disease, which is scheduled for publication in l 2017/18.
London Fire and Emergency Planning Authority	Addendum	General	general	LFB welcome the opportunity to comment on the Addendum to clinical guideline 42, Dementia: supporting people with dementia and their carers in health and social care. This is of interest to LFB due to the prevalence of people with dementia in the occurrence of fatal fires and fires where injuries were serious enough to require lengthy hospitalisation. Our published evidence[1] shows that people with dementia are significantly at risk from fire. As such, we	Thank you for your comment. The addendum chapter provides recommendations regarding the systems for prescribing and reviewing treatment with donepezil, galantamine, rivastigmine and memantine in people living with Alzheimer's disease. Evidence for assessing risks for people living with Dementia will be considered as part of the full update of the NICE Clinical Guideline on Dementia which

[1] Fire Safety of People in receipt of Domiciliary Care – FEP 1952
http://moderngov.london-fire.gov.uk/mgconvert2pdf.aspx?id=920

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				have worked with Skills for Care, the UK Home Care Association (UKHCA), the Care Quality Commission and the Prime Minister's Dementia Challenge Group to raise awareness of these fire risk factors and the means to reduce them. On a delivery front, a number of staff (both operational and non operational) have been trained as Dementia Friends and this is an area we hope to increase. Our work with Skills For Care lead to knowing how to identify and reduce fire risk for people receiving care and support, including those with dementia, being a requirement of the Care Certificate for care staff. However, our evidence[2] shows that opportunities to identify and reduce the risk of fire are sometimes still missed. We would therefore ask that the Addendum to clinical guideline 42, Dementia: supporting people with dementia and their carers in health and social care includes a requirement for an assessment of fire risk to be carried out as part of the process for prescribing and reviewing treatment with donepezil, galantamine, rivastigmine and memantine in people living with Alzheimer's disease, and contains a prompt to contact	is scheduled for publication in 2017/18.

[2] Review Of Accidental Dwelling Fires and Fatalities – FEP 2484
http://moderngov.london-fire.gov.uk/mgconvert2pdf.aspx?id=4384

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				the local fire and rescue service for advice on reducing fire risk tailored to the person's individual need and circumstances.	
Royal College of Psychiatrists in Scotland	Addendum	General	General	Although the recommendations for comment are in relation to "donepezil, galantamine, rivastigmine and memenatine for the treatment of Alzheimer's disease", we wonder if extension of the remit to include other types of dementia such as "dementia in Parkinson's disease" (for which at least one of the drugs is licensed) should be considered.	Thank you for your comment. The prescribing of drugs for people living with Parkinson's disease dementia will be considered as part of the full update of the NICE Clinical Guideline on Parkinson's Disease, which is scheduled for publication in 2017/18.
Lundbeck	Addendum	General	General	Lundbeck supports the inclusion of TA217 into CG42 and therefore has no substantive comment on the additions in the addendum proposed. In addition, the company advocates the inclusion of the recommendations from TA217 into the main body of the guideline through the update process currently being undertaken.	Thank you for your comment.
British Psychological Society	Addendum	General	General	**References** Aupperle,P.M., MacPhee,E.R., Coyne,A.C., Blume,J., Sanchez,B. (2003) Health service utilization by Alzheimer's disease patients: a 2-year follow-up of primary versus subspecialty care, Journal of Geriatric Psychiatry & Neurology, **16**, 15-17, 20030716 Aminzadeh, F., Byszewski, A., Molnar, F. J., & Eisner, M. (2007). Emotional impact of dementia diagnosis: exploring persons with dementia and caregivers' perspectives. *Aging and Mental Health*, *11*(3), 281-290	Thank you for these references. The study by Aupperle et al (2003) was considered as part of this evidence review. Although the additional references did not meet our inclusion criteria for this evidence review, we will take these into consideration through the remainder of the guideline development process.

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				Bunn, F., Goodman, C., Sworn, K., Rait, G., Brayne, C., Robinson, L., & Iliffe, S. (2012). Psychosocial factors that shape patient and carer experiences of dementia diagnosis and treatment: a systematic review of qualitative studies. *PLoS Med*, *9*(10), e1001331 Bunn, F., Sworn, K., Brayne, C., Iliffe, S., Robinson, L., & Goodman, C. (2015). Contextualizing the findings of a systematic review on patient and carer experiences of dementia diagnosis and treatment: a qualitative study. *Health Expectations*, *18*(5), 740-753 Pravikoff, D. (2015). Dementia Assessment: Using the Clinical Dementia Rating Scale. *Nursing Practice & Skills*, available online https://www.ebscohost.com/assets-sample-content/Dementia_Assessment_-_Using_the_Clinical_Dementia_Rating_Scale.pdf).	
Parkinson's UK	Addendum	General	General	This clinical guideline is based upon the licence for the cholinesterase inhibitors and, therefore, focuses on Alzheimer's disease. However cholinesterase inhibitors are also prescribed for some people with a Lewy body dementia (also known as dementia with Lewy bodies [DLB] or Parkinson's dementia) or a mixed dementia. We would draw NICE's attention to two papers: • Boot BP. *Comprehensive treatment of dementia with Lewy bodies,* Alzheimer's	Thank you for your comment and for providing the references. The prescribing of acetylcholinesterase inhibitors and/or memantine for people living with Parkinson's disease dementia and dementia with Lewy bodies will be considered in the full update of the NICE Clinical Guideline on Dementia which is expected for publication in 2017/18.

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				Research & Therapy (2015) 7:45 • Stinton C et al. *Pharmacological Management of Lewy Body Dementia: A Systematic Review and Meta-Analysis,* Am J Psychiatry 2015 172:8 Meta-analyses within Stinton et al's systematic review of pharmacological strategies for Lewy body dementia indicated improvements with donepezil and rivastigmine for cognition, global psychiatric symptoms (in Parkinson's dementia only), hallucinations, delusions, and activities of daily living (without worsening motor symptoms of parkinsonism) but with adverse events. [Stinton et al, *Pharmacological Management of Lewy Body Dementia: A Systematic Review and Meta-Analysis,* Am J Psychiatry 2015 172:8] Lewy Body dementia associated deficits in attention, executive function, and visuospatial ability respond well to cholinesterase inhibitor treatment. In meta-analyses, the standardized mean treatment effects are 0.34 for cognition and 0.20 on behavioural and functional measures, although most of the source data are from Parkinson's dementia patients. These effects compare favourably with cholinesterase inhibitor treatment of Alzheimer's disease, because the targets of therapy are relatively preserved in DLB. Compared with Alzheimer's patients, DLB patients have	

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				relatively little neuronal loss but profound cholinergic dysfunction. The characteristic fluctuations in cognition in DLB are difficult to manage; they may have multiple contributing causes [17]. Cholinesterase inhibitor treatment is associated with reduced mortality; mortality odds ratios in treatment trials are 0.28 (P = 0.03) despite increases in adverse events on therapy (odds ratio 1.64, P = 0.0003). In addition, cholinesterase inhibitors can help to reduced pareidolias (visual misperceptions/hallucinations) and Rivastigmine has been shown to reduce depression in LBD patients. [Boot 2015] There are no head-to-head trials comparing efficacy of the cholinesterase inhibitors in Dementia with Lewy Bodies or Parkinson's Dementia, but rivastigmine has the widest evidence base. A Movement Disorder Society evidence-based review concluded that rivastigmine is effective in Parkinson's dementia, but that the data for other cholinesterase inhibitors and memantine are inconclusive. [Boot 2015] The underdiagnoses of Lewy body dementia, and the focus of research and guidelines on Alzheimer's, means that treatments have not been extensively studied in populations with a Lewy body dementia. We believe that NICE should broaden the scope of the guidance to managing Alzheimer's disease and Lewy body dementia. Or that separate, parallel guidance is	

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				produced for Lewy body dementia. By doing this, NICE can help to rectify this inequality and improvement treatment for people with this form of dementia.	
Parkinson's UK	Addendum	General	General	Parkinson's UK re-asserts the principles that treatment should be available early in the condition, to maximise the 'window of opportunity' to live well and organise one's affairs and that treatment should be continued where there is benefit.	Thank you for your comment. The guideline committee recognised that local arrangements may be in place for initiation of treatment and that the NICE guideline on medicines optimisation should be followed for treatment initiation, prescribing, supply and review. The Committee will be considering evidence associated with the continuation or withdrawal of acetylcholinesterase inhibitors and/or memantine as part of the full update of the NICE Clinical Guideline on Dementia which is expected for publication in 2017/18.
Parkinson's UK	Addendum	General	General	Dementia with Lewy bodies is an under-recognized condition. The diagnostic criteria have low sensitivity (12 to 32 %) and high specificity (>95 %) so many cases are not diagnosed. [Nelson PT, Jicha GA, Kryscio RJ, Abner EL, Schmitt FA, Cooper G, et al. *Low sensitivity in clinical diagnoses of dementia with Lewy bodies.* J Neurol.2010;257:359–66.] References include: • Vann Jones SA, O'Brien JT. The prevalence and incidence of dementia with Lewy bodies: a systematic review of population and clinical studies. Psychol Med. 2013;44:673–83.	Thank you for your comment and for providing the references. The guideline committee will consider the prescribing of acetylcholinesterase inhibitors and/or memantine for people living with Parkinson's disease dementia and dementia with Lewy bodies as part of the full update of the NICE Clinical Guideline on Dementia which is expected for publication in 2017/18.

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				• Boot B. The incidence and prevalence of dementia with Lewy bodies is underestimated. Psychol Med. 2013;43:2687–8. • McKeith IG, Dickson DW, Lowe J, Emre M, O'Brien JT, Feldman H, et al. Diagnosis and management of dementia with Lewy bodies: third report of the DLB Consortium. Neurology. 2005;65:1863–72. • Ballard C, Aarsland D, Francis P, Corbett A. Neuropsychiatric symptoms inpatients with dementias associated with cortical Lewy bodies: pathophysiology, clinical features, and pharmacological management. Drugs Aging. 2013;30:603–11. • Aarsland D, Zaccai J, Brayne C. A systematic review of prevalence studies of dementia in Parkinson's disease. Mov Disord. 2005;20:1255–63. Parkinson's disease dementia (PDD) accounts for a further 3 to 5% of dementia cases. [Ballard et al, 2013]. Therefore, meta-analytic studies suggesting that DLB accounts for 4% of dementia diagnoses underestimate the true prevalence which may be closer to 20% of people with dementia. It is therefore vital that any medications or treatments which could improve the condition of people with DLB or Parkinson's dementia are used at the earliest opportunity.	
Parkinson's	Addendum	General	General	Parkinson's UK's own research shows that the likely	Thank you for your comment. The guideline

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UK				prevalence of both Parkinson's dementia and DLB in the care home population with dementia could be around double of the general dementia population. Yet, residents with DLB are far less likely to have a formal diagnosis of their condition than residents with Parkinson's dementia [Jackson G et al. *Improving Care for People with Dementia with Lewy Bodies and Parkinson's Disease Dementia in Care Homes,* Parkinson's UK 2016 (internal report)]. There are additional barriers for the care home population to receive a formal dementia diagnosis, in comparison with general population, because of lack of in-reach services from clinicians who can diagnose or refer for diagnosis. It is imperative that this inequality is addressed, to give care home residents better access to those who can prescribe and manage medications for dementia – and we would ask NICE to include this in the scope of the next revision of the Dementia Clinical Guideline. In the context of the scope of the current addendum, we propose that no additional barriers to prescribing dementia medication should be imposed on the care home population i.e. any professional with the relevant experience and qualifications should be able to prescribe dementia medication.	committee will consider the prescribing of acetylcholinesterase inhibitors and/or memantine for people living with Parkinson's disease dementia and dementia with Lewy bodies as part of the full update of the NICE Clinical Guideline on Parkinson's Disease, scheduled for publication in 2017/18. The published scope for the guideline has identified 'people with specific housing and supported living needs, including the need for a living environment adapted for people with cognitive impairment' as a group requiring special consideration throughout the guideline and the guideline committee will consider evidence related to the care home population including diagnosis of dementia.
College of Mental Health	Addendum	7	21-23	It is essential that all medication is reviewed before treatment is started so it would be important to stress that treatment should only be started after a full	Thank you for your comment. The guideline addendum provides guidance in relation to an update of recommendation 1.3 from

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Pharmacy				medication review, which could preferably be carried out on referral. This is essential to reduce the risk of interactions (sedatives and anticholinergics) and bradycardia (beta blockers) which affect safety and efficacy of treatment. This comment also implies that GPs may prescribe on the advice of the specialist prescribed (i.e. the specialist does not have to initiate treatment) which marks a significant step towards ensuring that medication is continued and can be part of the patients usual regimen. Follow up appointments in the memory service can be time consuming, wasteful where non attendance happens, and stressful for patients and carers so should be kept to a minimum. Post diagnostic support and explaining the benefits or treatment and ensuring the carer can supervise adherence are paramount to safe and effective treatment.	TA217 regarding prescribing and reviewing treatment with donepezil, galantamine, rivastigmine and memantine in people living with Alzheimer's disease only. However NICE is currently developing a full update of the NICE Clinical Guideline on Dementia and will be considering evidence associated with medical comorbidities (including medications interactions), diagnosis and post diagnostic support, including outcomes appropriate to both the person living with dementia and their carers. This guideline is scheduled for publication in 2017/18.
Alzheimer's Research UK	Addendum	7	21-23	It is essential there is a continued emphasis on getting an accurate and timely diagnosis of Alzheimer's disease when prescribing treatments. This is important at all stages of the disease, from the mild and moderate stages to the severe stages. Where it is more difficult to give an accurate diagnosis of Alzheimer's disease, for example in the mild stages of the disease, this should be undertaken by a clinician who is	Thank you for your comment. The guideline addendum provides an update to the recommendations for prescribing and reviewing treatment with donepezil, galantamine, rivastigmine and memantine in people living with Alzheimer's disease. However NICE is currently developing a full update of NICE Clinical Guideline on Dementia and will be considering evidence associated with both the diagnosis of dementia and the training and knowledge of healthcare staff. This guideline is scheduled for publication in 2017/18.

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				experienced in diagnosing Alzheimer's disease Getting an accurate diagnosis is not only important to ensure the right people are getting the right treatment at the right time, including the right post-diagnosis care. It is also important to ensure that people with a diagnosis of Alzheimer's disease can be signposted to opportunities to participate in research. We have heard anecdotal evidence that people with dementia are being discharged from secondary care back to the care of their GP, who then do not have appropriate knowledge or guidance on how to continue optimum treatment.	
College of Mental Health Pharmacy	Addendum	7	34-35	Local arrangements according to NG5 may not require a shared care protocol – Shared care implies that patients need a regular review by memory service as well as the annual review by GP. This duplicates care and our Health Board are working towards an arrangement whereby patients are risk stratified and the more needy/complex will be seen by memory clinic and the stable patients will have a review by the GP. This is in consultation but would be willing to submit the documents, including a tailored annual dementia review	Thank you for your comment. The Guideline Committee acknowledged that there may be variation in local practice with regard to shared care arrangements and have made changes to the recommendations so they more clearly address local arrangements and with reference to the NICE guideline on medicines optimisation.

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				proforma and MUR document for community pharmacists to the shared learning database. Contact Elizabeth.bond@wales.nhs.uk	
College of Mental Health Pharmacy	Addendum	7	34-35	Local shared care with dementia needs to be **holistic and include all patients with dementia**, not just those on memory drugs. Where people have reviews because they are on medication which does not need monitoring, this is inefficient and patients with dementia who are not on memory drugs are not seen because they are discharged to local shared care guidelines will vary from Trust to Trust. It is a moot point whether shared care is needed specifically for the memory drugs as once started; there is little need to review once stable unless the patient's condition deteriorates in which case they will be re-referred to the relevant person in the MH team. Treatment is only stopped at end stage or where the patient derives no benefit and has reached the point where other medication becomes more important to manage the condition. This could be managed by a protocol rather than shared care which in my experience has blocked up the service to a point where people with social and psychological needs are not getting seen as promptly as they should. The NG5 guidance is comprehensive and if this is followed then shared care should not be necessary for the drugs	Thank you for your comment. The Guideline Committee acknowledged that there may be variation in local practice with regard to shared care arrangements and have made changes to the recommendations so they more clearly address local arrangements and with reference to the NICE guidance on medicines optimisation.
Alzheimer's Research UK	Addendum	7	24-25	The guideline on medicines optimisation should be implemented for anti-dementia drugs. However, there is a need to better 'proactively share complete and accurate information	Thank you for your comments and for providing the link to the BAP guidelines. The Guideline Committee acknowledged that there may be variation in local practice with regard to shared care arrangements

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				about medicines' (1.2.2) and better share relevant information about the person and their medicines when a person transfers from one care setting to another (1.2.3). Through our contact with clinicians it is apparent that there is significant variation in the treatment pathway and that management of anti-dementia treatments could be vastly improved through better communication of expert clinical practice: • Too often treatments are discontinued or altered because of a lack of understanding about effect, impact and side-affects. • There is a need for clear, accessible guidelines for GPs that explains the impact and side effects of anti-dementia treatments and outlines common trajectories for individuals, with explanation and guidance about how to respond. • If and when patients are discharged back into primary	and have made changes to the recommendations so they more clearly address local arrangements. The problems highlighted can be addressed through effective implementation of NICE guidance on medicines optimisation. In addition, the NICE medicines practice guideline: Developing and updating local formularies provides good practice recommendations for the systems and processes needed to ensure NHS organisations develop and update local formularies effectively and in accordance with statutory requirements. It supports the development of decision outputs with respect to medicines such as shared care protocols and treatment pathways, which reflect local needs and reduce variation in prescribing.

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				care following diagnosis and treatment, there should be more appropriate monitoring of the progress and dosing regimen from secondary care. At the very least notes outlining the rationale for treatment, dose and key points at which changes may be required. Currently there is often little follow-up or information for GPs and no guidance on when to change dose, stop treatment or offer combination (e.g. combining memantine with donepezil as symptoms become more series versus a straight swap). The British Association of Psychopharmacology brings together an expert group to review the evidence on anti-dementia treatments. They are currently being updated, but the existing guidelines can be found here: http://bap.org.uk/pdfs/BAP_Guidelines-AntiDementia.pdf	
Alzheimer's	Addendum	7	34-35	See comments above.	Thank you for your comment.

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Research UK					
British Psychological Society	Addendum	7	20	The Society has concerns about the lack of clarity in the reference to 'a clinician experienced in diagnosing and treating Alzheimer's disease'. We welcome that cholinesterase inhibitors should only be started after a diagnosis or documented discussion with patient about diagnostic possibilities, and that only people experienced in dementia diagnosis should prescribe. However, the implication in this document is that the experienced clinician would not necessarily be a specialist physician or indeed a medical doctor. In addition, it is important to emphasise that diagnosis, especially in the early stages, requires input from a skilled clinical team. It might also be possible for a general indication as to what would constitute experience. This might need to cover a couple of points: • Much of the process of initiating and reviewing medication is covered in the earlier 2011 material, which is not subject for review. However, if an "*experienced clinician"* is to make decisions about initiating medication, then it is appropriate to point out that they should have competencies to conduct the assessment and make these decisions in the light of the guidance. • Best practice in memory clinics is that decisions, especially in complex cases, should	Thank you for your comment. The Guideline Committee considered how the term specialist should be interpreted and have made changes to the recommendations which now provide a clear definition of a clinician with expertise in diagnosing and treating Alzheimer's disease..for the purposes of this guideline**.** In addition, we are developing a full update of the NICE Clinical Guideline on Dementia and will consider the training of healthcare staff and the co-ordination of care for people living with dementia.

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				be made through discussion with a team, so perhaps a similar suggestion could be made here that the experienced clinician should have access to others in the clinical team who they can consult where relevant. • This access should include people within their specific team, but also to specialized services – thus while it might be OK for primary care to lead on some cases (although this is not proven), they also need to be able to refer to specialist memory clinics where necessary. We believe that some examples of what might constitute appropriate experience would be helpful, alongside a statement about the importance of team input, including the need for involvement of non-medical specialists such as clinical psychologists or clinical neuropsychologists. Without this information, there is a risk that people may be subject to false positive diagnoses. Given the number of false positive diagnoses that follow the use of simple, crude clinical assessment tools, large numbers of people could be prescribed these medications when they do not have dementia, and there is no evidence yet of their efficacy in MCI or subjective memory complaints. This is a problem, not because of the financial implications, but rather because of the potential labelling and adaptation issues that follow from receiving a medication package that	

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				clearly states its intended use for Alzheimer's, when the diagnosis is still uncertain. There are anecdotal reports that people have learned their diagnosis from reading the information leaflet in a box of donepezil when non-specialists have prescribed.	
Parkinson's UK	Addendum	7	21	In the light of need to broaden the scope of the guidance, section 1.3 should read: Prescribers should only start treatment….on the advice of a clinician experienced in diagnosing and treating Alzheimer's disease or Lewy body dementia.	Thank you for your comment. The guideline addendum provides an update of recommendation 1.3 from TA217 for prescribing and reviewing treatment with donepezil, galantamine, rivastigmine and memantine in people living with Alzheimer's disease. However, the Guideline Committee will consider prescribing of drugs for dementia with Lewy bodies in the full update of the NICE Clinical Guideline on Dementia, scheduled for publication in 2017/18.
Dementia UK	Addendum	7	21	Question 1: The widening of who can prescribe was considered to be positive due to changes in roles but there was some question about what constitutes sufficient "experience in diagnosing and treating Alzheimer's disease." A challenge of this recommendation is it that this may lead to a disparity in provision and service fragmentation. i.e. who has overall responsibility for overseeing and monitoring?	Thank you for your comment. The Guideline Committee considered how the term specialist should be interpreted and have made changes to the recommendations which now provide a clear description of a clinician with expertise in diagnosing and treating Alzheimer's disease. The Committee recognised that local arrangements may be in place for the overall responsibility of treatment and that the NICE guideline on medicines optimisation should be followed

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					for overseeing and monitoring of treatment.
Dementia UK	Addendum	7	21	Question 1: A challenge of this recommendation may be increased pressure on GPs to have more involvement and/ or more pressure on nurse prescribers. It may also result in an increased workload for Community Mental Health teams.	Thank you for your comment. The Guideline Committee considered the impact of the recommendations on primary care and have further amended the recommendations to address the need to consider local arrangements for prescribing, supply and review.
Dementia UK	Addendum	7	24	Question 1: We consider that adherence to medicines optimisation guidance may help encourage a more consistent approach to prescribing and reviewing medication. However a challenge to this recommendation is that independent prescribers will still vary in their practice as this is 'guidance' only.	Thank you for your comment. The Guideline Committee discussed the role of local arrangements and agreed that they should facilitate a more consistent approach to prescribing and reviewing medication. Locally agreed arrangements should also aim to reduce variation in prescribing practice. Commissioners have a statutory responsibility to make funding available for a drug recommended by a NICE technology appraisal (TA) within the timeframe recommended in that guidance. In practical terms, the effect of this legal obligation and the NHS constitution is that all NICE-approved treatments must be included in local formularies for use in line with the TA recommendations and with no additional funding or formulary restrictions. NICE guidance on developing and updating local formularies recommends that, where

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					appropriate, local formularies should identify the place of a NICE-approved medicine in the care pathway, in line with NICE recommendations. It may be helpful for a local formulary to indicate arrangements for use of NICE-approved medicines (for example, recommending that a particular medicine or group of medicines should be started by a particular specialist team and individual responsibilities for ongoing monitoring and review). However, this is for local consideration and determination.
Dementia UK	Addendum	7	24	Question 1: A challenge of this recommendation is the risk of the use of 'local arrangements' being dictated by cost pressures rather than need.	Thank you for your comment. The Guideline Committee considered your comment and have made changes to the recommendations so they address the need to consider local arrangements for prescribing, supply and review and it is anticipated that clinicians will act in accordance with the NICE guideline on medicines optimisation.
Dementia UK	Addendum	7	24	Question 1: The separate and differing needs of younger people with dementia who often have more atypical diagnoses is considered to be a specialism in itself. This will be a challenge for those prescribing and reviewing who may not have sufficient knowledge in this area.	The guideline addendum provides guidance in relation to an update of recommendation 1.3 from TA217 for prescribing and reviewing treatment with donepezil, galantamine, rivastigmine and memantine in people living with Alzheimer's disease. However, the published scope for the full guideline has prioritised people

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					aged 40–64 years with early onset dementia, (which will include younger people with Alzheimers disease)as a group requiring special consideration during development of the NICE Clinical Guideline on Dementia and the Guideline Committee will consider evidence for the specific needs of younger people with dementia.
Parkinson's UK	Addendum	7	34	Shared care and medicines optimisation approaches are extremely important in managing Lewy body dementia. Prescribing and monitoring clinicians need to be particularly knowledgeable about under-recognised side effects of cholinesterase inhibitors. As cholinesterase inhibitor treatment can complicate cardiac and gastronintestinal dysautomnia…and the side effect proclivity applies to medications prescribed by other physicians…it is essential to rationalize treatment and to communicate with other care providers about the complexities of the disease [Boot, 2015] DLB patients frequently have disordered sleep and so may be more likely to experience the vivid dreams that are an under-recognised side effect of cholinesterase inhibitors. These dreams can be limited by avoiding night-time doses; for cholinesterase inhibitors that require twice-daily dosing, the second dose may be given in the afternoon. [Boot, 2015]	Thank you for your comment. The Guideline Committee will be considering the prescribing of acetylcholinesterase inhibitors and/ or memantine for people living with dementia with Lewy bodies as part of our full update of the NICE Clinical Guideline on Dementia.
Dementia UK	Addendum	7	34	Question 2: It was considered that users need to have	Thank you for your comment. The NICE

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				a clear pathway and having a 'one stop shop' i.e. a central place where services collaborate and coordinate care is important.	guideline on medicines optimisation (NICE guideline NG5) provides recommendations for communication systems when people move from one care setting to another. The Guideline Committee will also consider the coordination of care as part of the update of the NICE Clinical Guideline on Dementia which is scheduled for publication in 2017/18.
Dementia UK	Addendum	7	34	Question 2: Admiral Nurses attached to GP's may be a useful model i.e. specialists who can ensure that care is coordinated, supporting skilled, meaningful reviews with the engagement of families as well as offering post diagnostic support and ensuring that families are included in decision making.	Thank you for your comment. Evidence associated with the co-ordination of care for people living with dementia will be considered as part of our full update of the NICE Clinical Guideline on Dementia which is scheduled for publication in 2017/18.
Dementia UK	Addendum	7	34	Question 2: Further education of all staff including GP,s Practice nurses, community nurses/ OT's/ Physiotherapist and in particular Community Pharmacists about the symptoms and presentation of people with dementia, including an understanding of delirium and its impact.	Thank you for your comment. Evidence associated with education and training of healthcare professionals will be considered as part of our full update of the NICE Clinical Guideline on Dementia which is scheduled for publication in 2017/18.
British Psychological Society	Addendum	8	24	The Society believes that more emphasis should be placed on provision of person-centred care. There has clearly been discussion at the committee about best practice. However, the report does seem to feel more comfortable in looking at the mechanics of prescribing than in the human process around this. It seems in order to point out, from clinical experience, what	Thank you for your comment. The guideline addendum provides recommendations for prescribing and reviewing treatment with donepezil, galantamine, rivastigmine and memantine in people living with Alzheimer's disease. The Guideline Committee acknowledge that a person-centred

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				constitutes best practice in person-centred care – which might include at the minimum that in order for people to give informed consent to treatment with medication, they need to know what it is that they are consenting to – which means that they should be informed of the diagnosis, and given information about the medication and post-diagnostic sources of support. Many patients have written about their experience of being given a diagnosis and handed a prescription without any explanation or discussion. They are often in a state of shock and not in a position to discuss their 'values and preferences' (page 6, line 19). Some write about crying for weeks or describe symptoms similar to PTSD. There is no reference to the impact a diagnosis of dementia prior to implementation of prescribing. Qualitative studies highlight a common difficulty that prescribers face – a lack of awareness or denial of a problem in the person experiencing difficulties (Aminzadeh, F et al, 2007). In addition, this addendum does not acknowledge that people affected by dementia have mixed perceptions about medications for dementia (Bunn, F et al, 2012; Bunn, F et al, 2015). This section on person-centred care focuses largely on capacity issues and refers people to two links – patient	approach is central to supporting the needs of people living with dementia. NICE are currently developing a full update of the NICE Clinical Guideline on Dementia and the Guideline Committee will ensure that a person centred approach will be incorporated throughout the guideline. The Guideline Committee will also consider evidence associated with diagnosis and post diagnostic support as part of this update.

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				experience in adult NHS services, and service user experience in adult mental health. We have concerns that this is too general and may fail to provide much more than an outline of principles of care in general. Although worthy, many people (and especially those without much experience of dementia care) may well struggle to translate these principles into a working context.	
British Psychological Society	Addendum	8	27	We believe that consideration of rights could be strengthened. People with dementia also have rights under the UN Conventions on the Rights of Persons with Disabilities (CRPD) (under Article 1). The 'I Statements' in the Global Dementia Charter reflect specific points from the CRPD. These set more stringent requirements regarding professional conduct and maintenance of human rights in health care settings.	Thank you for your comment. The guideline addendum provides recommendations in relation to an update of recommendation 1.3 from TA217 for prescribing and reviewing treatment with donepezil, galantamine, rivastigmine and memantine in people living with Alzheimer's disease. A full update of the NICE Clinical Guideline on Dementia is also in progress and the Guideline Committee will consider evidence to ensure people living with dementia maintain independence.
Parkinson's UK	Addendum	8	29	The patch formulation of Rivastigmine has the advantage of being easier for patients with swallowing difficulties (a common problem in dementia with Lewy bodies and Parkinson's dementia) and it also has fewer gastrointestinal side effects. Parkinson's UK receives reports through its members about the difficulty patients have in consistently	The guideline addendum provides recommendations in relation to an update of recommendation 1.3 from TA217 for prescribing and reviewing treatment with donepezil, galantamine, rivastigmine and memantine in people living with Alzheimer's disease. The prescribing of these drugs for dementia with Lewy bodies will be

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				receiving medication in the most suitable formulation (e.g. patches or liquid rather than tablets for patients with swallowing problems). NICE guidelines should strongly emphasise the importance of clinicians prescribing the formulation of the medication that is most suitable for patient and not the lowest unit cost.	considered in the full update of the NICE Clinical Guideline on Dementia, scheduled for publication in 2017/18.
Parkinson's UK	Addendum	9	1	Stinton articulates a concern of Parkinson's UK's that guidelines need to reflect clinical significance and the reality of patient and carer experience, rather than solely statistical evidence from study conditions that do not reflect the diversity of clinical practice. A notable outcome from our review is a potential disconnect between research trials and the reality of clinical practice and the preferences of patients or caregivers. For example, patient-related outcomes and symptom-specific measures were rarely used, and apparent benefits of strategies were typically determined on the basis of statistical rather than clinical significance. Furthermore, no studies were identified on the views that patients with Lewy body dementia or their caregivers have of pharmacological management strategies. Research that focuses on areas of need reported by patients with Lewy body dementia and their families may provide useful information about which strategies to employ. [Stinton, 2015] Research on pharmacological management strategies	Thank you for your comment. The guideline addendum provides recommendations in relation to an update of recommendation 1.3 from TA217 regarding the systems for prescribing and reviewing treatment with donepezil, galantamine, rivastigmine and memantine in people living with Alzheimer's disease. Patient-reported outcomes were included within the review protocol for this evidence review and all relevant outcomes that met the inclusion criteria were reported. The Guideline Committee will be considering the prescribing of these drugs for dementia with Lewy bodies in the full update of the NICE Clinical Guideline on Dementia which is currently in development and scheduled for publication in r 2017/18.

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				for Lewy body dementia has usually taken the form of efficacy studies. While these are important in establishing therapeutic effects under highly controlled circumstances, the results are not necessarily generalizable to clinical practice. For example, in research trials, samples are often homogeneous, interventions are standardized without scope for flexibility, concurrent treatments or comorbid conditions are not allowed, and patients with more severe difficulties may be less likely to be recruited or to participate. Effectiveness studies provide a way to address some of these concerns. Therefore it is crucial that the guideline is amended to ensure that the experience of the patient and carer is included along with the reality of the diverse range of clinical practice.	
British Psychological Society	Addendum	14	general	The Society believes the statement, "*Interpretation of evidence",* requires clarification: "Although, in Aupperle et al. 2003, the authors did not report standard deviation at 2 year follow up the Committee noted that, participants who were seen by a geriatric psychiatrist experienced an **overall decline** in Clinical Dementia Rating (CDR) over 2 years (suggesting that the average participant's dementia improved over this period). The committee thought this would be very unusual, as Alzheimer's disease is a degenerative condition." The reference to a decline in Clinical Dementia Rating	Thank you for your comment. The reference to a decline in Clinical Dementia Rating (CDR) has been amended to ensure that the change reported is clearly described. The sentence now reads "Although, in Aupperle et al. 2003, the authors did not report standard deviation at 2 year follow up the Committee noted that, participants who were seen by a geriatric psychiatrist experienced an overall slight improvement in Clinical Dementia Rating (CDR) over 2 years. The Committee thought this would be very unusual, as

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				scores is confusing, as readers may be unaware that lower scores are better on the CDR. What the study reports is that the CDR score reduced (slightly) on average, suggesting an improvement – hence the word 'decline' is misleading here and should be amended, for example to 'experienced an overall slight improvement in Clinical Dementia Rating (CDR) score over 2 years. The degree of improvement could also be qualified to indicate that it was a slight improvement. As an improvement in scores over this period would be very unusual indeed, one might question whether the geriatric psychiatrist understood how to rate the CDR correctly, or whether other factors have influenced the reported outcome of this study (Pravikoff, D, 2015).	Alzheimer's disease is a degenerative condition.
British Psychological Society	Addendum	15	general	The Society has concerns that insufficient emphasis is placed on the importance of considering the views of carers. Under 'other considerations' the paper suggests that consideration of carers' views can be dealt with through cross-reference to the NICE Medicines Optimisation guideline (NG5). However, we have been unable to identify in NG5 any detailed guidance on the need to involve carers. The introduction and section on person-centred care relates largely to safeguarding children and young people. The recommendations section relate to the following: Systems for identifying, reporting and learning from medicines‑related patient safety incidents; Medicines-related communication	Thank you for your comment. The NICE medicines optimisation guideline recommendation 1.4.3 relating to medication review, recommends taking into account the person's, and their family members or carers where appropriate, views and understanding about their medicines and concerns, questions or problems with the medicines. Recommendation 1.5 relating to self-management plans refer to the importance of including family / and carers when appropriate in the background information:

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				systems when patients move from one care setting to another; Medicines reconciliation; Medication review; Self-management plans; Patient decision aids used in consultations involving medicines; Clinical decision support; Medicines-related models of organisational and cross-sector working. Therefore we believe that it would be important to reiterate in the current document at least the basics of what communication with carers involves in this context. Carers' perceptions of the impact of medication on the care-couple should be a core concern of post-diagnostic support services, and it is important to emphasise the involvement of carers throughout.	"Self-management plans can be patient-led or professional-led and they aim to support people to be empowered and involved in managing their condition. Self-management plans are structured, documented plans that are developed to support a person's self-management of their condition using medicines. People using self-management plans can be supported to use them by their family members or carers who can also be involved when appropriate during discussions – for example, a child and their parent(s) using a self-management plan." The recommendations relating to patient decision aids also refer to the involvement of patient decision aids: "Many people wish to be active participants in their own healthcare, and to be involved in making decisions about their medicines. Patient decision aids can support health professionals to adopt a shared decision-making approach in a consultation, to ensure that patients, and their family members or carers where appropriate, are able to make well-informed choices that are consistent with the person's values and

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					preferences." In particular, recommendation 1.6.4 states: "In a consultation about medicines, offer the person, and their family members or carers where appropriate, the opportunity to use a patient decision aid (when one is available) to help them make a preference-sensitive decision that involves trade-offs between benefits and harms. Ensure the patient decision aid is appropriate in the context of the consultation as a whole."
Department of Health	General	General	General	No comments	
Royal College of Nursing	General	General	general	No comments	
Royal College of Psychiatrists in Scotland	Short	7	First bullet point under 1.3	The Faculty of OAP in Scotland agrees with the recommendation that "prescribers should only start treatment with donepezil, galantamine, rivastigmine or memantine on the advice of a clinician experienced in the diagnosing and treating of Alzheimer's disease", however we would like to provide further comments to aid clarity: • The term "experienced clinician" should include those with the appropriate knowledge and skills and in practice it would include not only "secondary care" medical specialists (psychiatrists, geriatricians, neurologists) but also general practitioners and other health	Thank you for your comment. The Guideline Committee considered your comment and have amended the recommendations to provide a clear description of the definition of a clinician with expertise in diagnosing and treating Alzheimer's disease..within the context of this guideline.

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				professionals (for example, nurse consultants, advanced nurse practitioners, independent prescribers) with specialist experience.	
Royal College of Psychiatrists in Scotland	Short	7	Secon2nd bullet point under 1.3	The Faculty of OAP in Scotland agrees that the implementation of local arrangements for prescribing and supply follow the NICE guideline on medicine optimisation and in particular we would like to emphasise the importance of prescribing to be carried out from initiation of these drugs by Primary Care for the following reasons: • The main reason being patient safety. We have conducted surveys in some parts of Scotland which have shown that when prescription is carried out by "secondary care", up to 50% of patients do not have those drugs recorded in the electronic system populated by Primary Care which is the source of information for hospitals when patients are admitted. Therefore, such patients' records are incomplete and this leads to clear safety issues regarding these medications. This is in contrast with those areas where prescribing occurs in Primary Care from initiation of the therapy with these drugs. • The safe prescribing system linked to local pharmacies that GP Practices have is lacking in secondary care where prescriptions are mostly handwritten (this is time-consuming in a potentially unsafe system). • The treatment of such a common condition, in	Thank you for your comment.

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				line with other long-term conditions management, should be mainstreamed, and therefore normalised, in Primary Care. • The local arrangements should focus on safe and effective communication systems between clinician advising the commencement of the treatment and the prescriber (when these are two different professionals, for example when it is not the GP who both diagnoses and treats the condition.)	
Royal College of Psychiatrists in Scotland	Short	7	Third bullet point under 1.3	The Faculty of OAP in Scotland agrees that reviews of treatment should be in line with local shared-care arrangements and the NICE guideline on medicine optimisation. We further believe that the review of these treatments for such a long-term condition as Alzheimer's disease should be carried out in a person-centred and holistic approach and favours this being part of an annual dementia review as opposed to a purely routine medication review.	Thank you for your comment