Parkinson's disease stakeholder workshop notes

Discussion on the scope relates to version 5.3 which was circulated at the stakeholder workshop.

Group 1

- **What aspects of the previous guideline would you like to see changed, e.g., what has not worked? Were there any 'unintended consequences' of the previous guideline**

The stakeholder workshop highlighted the following aspects of the current Parkinson's disease (PD) guideline that the stakeholder community may like to see changed but did not highlight any 'unintended consequences'.

- Falls are different in PD and should be covered
- Dementia is integral to PD and should be included within the update of the guideline
- Nutrition was highlighted as a very important area that was not covered by the last guideline, including delayed gastric emptying because the gastrointestinal tract can be affected by PD, protein intake and also constipation
- The group highlighted that the last guideline focussed on the motor features of PD and focusing on non-motor features in the update may add the greatest value to the guideline and benefit to people with PD
- Stakeholders felt there was new evidence in the area of speech and language therapy, occupational therapy and physiotherapy, including more on physiotherapy conducted at an earlier stage in PD
- There is new evidence around intermittent use of apomorphine and the drug is now used to help the on time rather than the off time in PD
- The group highlighted safety issues and the importance of people with PD receiving medication in a timely fashion. Aspects such as self-administration may help to shorten length of stay. Admissions of people with PD into hospital in the UK are very high
- Impulse control disorders affect many people with PD and it is important the new guideline considers these. Predictors for the development of impulse

control disorder may be less important than management of withdrawal of dopaminergic therapy. Parkinson's Disease UK are now advocating written consent for dopaminergic therapy

- Stakeholders were pleased to see pregnant women would not be excluded from the scope of the guideline
- One stakeholder also suggested restless leg syndrome as an area which affects many people with PD
- One stakeholder expressed the importance of a multidisciplinary care team and the need for coordinated integrated service delivery
- Some stakeholders expressed the importance of updating palliative care in the guideline and the need for palliation to be introduced to patients from diagnosis and revisited throughout the course of the disease
- Some stakeholders highlighted the lack of detail in the non-pharmacological therapy recommendations. They felt this lack of detail may have led to barriers in implementation. This particularly applied to occupational therapy (published audit data has shown a lack of consistency in approach), speech and language therapy and dietetics. Stakeholders suggested the guideline update should consider signposting to existing resources such as "quick reference cards" produced by the Royal Colleges

Section 4.1: Population

The population stipulated within the scope was fine. No specific subgroups were highlighted to be considered.

Exclusion of juvenile onset PD from within this guideline was agreed to be proportionate as the population of patients with this condition is very small and would receive highly specialised treatment, and this guideline would be less applicable to clinicians working within these centres.

4.2: Setting

No objections were received to how the settings which would be covered were expressed in the scope. Stakeholders acknowledge that there are a large number of social care issues related to PD.

4.3.1 Clinical issues that will be covered

4.3.1 a) Pharmacological management

Stakeholders agreed that the proposed list of drugs to be looked at seemed comprehensive and that all preparations of these drugs should be looked at.

There were positive reactions among attendees to see that transdermal patches had been included in the updated scope, as these are an important component of pharmacological intervention.

One stakeholder highlighted that cholinesterase inhibitors for the treatment of hallucinations and PD dementia should be considered within the dementia section of the guideline.

Stakeholders commented on the proposed non-motor features to be considered. It was felt that pain which was listed should perhaps be specified more clearly as to what type of pain should be looked at. Hallucinations, drooling and thermoregulatory non-motor features were highlighted as important. The importance of looking at depression was stressed, including associated symptoms such as low mood, anxiety and apathy.

4.3.1 b) and c)Deep brain stimulation

Stakeholders were pleased to see deep brain stimulation included in the scope and clarified that this should look at the benefits of early versus late intervention.

4.3.1 d) – g)

Most stakeholders agreed it was important to cover:

- Clinical effectiveness of transdermal dopamine patches in the treatment of people with PD
- Predictors for the development of impulse control disorder as an adverse effect of the use of dopamine therapies
- Management of impulse control disorder, such as whether to reduce dopamine therapy dosage, or change from one dopaminergic therapy to another
- Information needs of people with PD in relation to impulse control disorder
- Information needs of women of child-bearing age with a diagnosis of PD

4.3.2 Clinical issues that will not be covered

4.3.2 a) Diagnosis and monitoring

Stakeholders felt that there was little value to be gained by updating this section of the current guideline and that any evidence and recommendations should be brought across into the new guideline product unchanged.

One stakeholder expressed concern that nuclear imaging (SPECT) was being overused by some clinicians where it was not appropriate, such as to discriminate between PD from parkinsonism, and that the guideline may benefit from more clarity as to when nuclear imaging can and cannot be used for diagnostic purposes.

4.3.2 b) Communication with people with PD and their carers

It was suggested that old recommendations within this section could be brought across but this section could be enhanced by looking at specific issues to ensure information giving is embedded throughout the patient pathway from diagnosis, and ensuring information on sensitive issues is delivered in a timely fashion.

4.3.2 c) Neuroprotection

Sadly the group agreed that there were few advances in this area to merit reconsideration of neuroprotection and existing recommendations could be brought across into the guideline update unchanged.

Some stakeholders noted there was new evidence (particularly the Adagio trial) in this area, but it would not change practice. Therefore this area did not need updating.

4.3.2 e) Physiotherapy, occupational therapy and speech and language therapy

Stakeholders largely thought there was a lot of new evidence in these areas and looking at these within the update could enhance the experience of patients.

Some stakeholders were aware the original recommendations were based on a Cochrane review that has recently been updated. They were happy that the updated Cochrane review would not change the recommendations and this area did not need updating.

There was discussion about the Alexander technique and it was stated that it is rarely used in NHS practice. There was a suggestion that we refer to physiotherapy and occupational therapy handbooks on how to assess and treat those with motor problems.

However, there were also thoughts that the physiotherapy, occupational therapy and speech and language therapy recommendations were superficial and needed more detail. They mentioned the "Lee Silverman Technique" for speech therapy that requires specific training. It was suggested that although existing recommendations were adequate, benefit may be derived from signposting to specialist professional bodies.

Also, the guideline needs to cover dietetics and nutrition in the non-pharmacological management section, with feeding tubes and dietary interaction with pharmacological treatment mentioned as key issues. If this was covered, dietetic representation would be necessary on the GDG.

Clinical psychology was suggested to be covered by the guideline and represented on the GDG, but noted there was limited access to services in some areas.

4.3.2 h) Palliative care

Some stakeholders felt that the current recommendations on palliative care could benefit from more detail about when to discuss end of life care issues, continuing to follow up patients who cannot attend clinic any longer, and when to either increase medication or begin to withdraw treatment.

Other stakeholders felt there would be no new evidence on palliative care, but the social and legal frameworks have shifted so the section may need updating. They also noted there is a difference between palliative care and care of the dying. Care of the dying may be different in Parkinson's disease where medications may be increased rather than decreased.

4.3.2 i) Depression and the use of anti-depressants

Stakeholders felt strongly that this section within the guideline should not be stood down. Some stakeholders felt the section needed updating but others felt that the section should be incorporated into the update because there is little new evidence within this area which would affect current recommendations.

4.3.2 j) Interventions for Parkinson's disease associated dementia

As PD associated dementia is a very specific manifestation of PD, stakeholders felt that this section of the guideline should not be stood down but updated. Stakeholders commented that they often prescribe memantine alongside rivastigmine and noted there was much new evidence on memantine. However, stakeholders acknowledged that rivastigmine was the only drug specifically licensed for the treatment of PD associated dementia.

Some stakeholders felt that as long as guidance for PD associated dementia was updated, they did not mind whether it was done in the PD guideline, or as a specific chapter on PD dementia in the an updated version of the dementia guideline. Some workshop attendees thought that in PD, it is the PD clinicians rather than psychiatrists that look after patients with PD associated dementia. Stakeholders felt this should be a consideration in deciding where this topic is most appropriately covered. Stakeholders felt that psychiatry for older people can tend to focus on the issues relating to drug use in PD, for example anti-cholinerastase inhibitors.

Early recognition of PD dementia is important as the burden on NHS/carers is great.

The MMSE was viewed as being an inappropriate outcome measure in PD dementia.

4.3.2 f) Use of duodopa

In light of the recent NHS England commissioning guidance, stakeholders still felt that this topic needed a robust evidence review. Duodopa, regardless of its expense, can be a transformative drug for patients with advanced PD. For patients who do not meet criteria for consideration of deep brain stimulation, such as those over the age of 70, duodopa can often be the only treatment option available. Stakeholders felt the guideline may lose credibility if this issue was not considered. However, workshop attendees suggested a population of around 100 people per year would be eligible to use duodopa. Some stakeholders suggested that the evidence review might focus on selection/eligibility rather than efficacy.

Stakeholders highlighted that there would be some emerging randomised controlled trial evidence in this area.

4.3.2 g) – i)

Stakeholders thought that it was reasonable that the guideline does not look at:

- Treatment of parkinsonism not caused by PD
- Treatment of other tremulous disorders
- Radical therapies
- Comorbidities in PD and other health problems not specific to PD

4.4 Main outcomes

Stakeholders suggested the following scales:

- Malnutrition Universal Screening Tool (MUST)
- Lindop Parkinson's Assessment Scale (physiotherapy)
- Parkinson's Disease Sleep Scale (PDSS2)
- Geriatric depression score
- Hospital anxiety depression scale
- Parkinson's disease questionnaire (PDQ39 & PDQ8)

- Montreal Cognitive Assessment (MOCA)
- Non-motor symptoms questionnaire (NMS Quest)
- Canadian Occupational Performance Measure (COPM) (activities of daily living measure)
- FIM+FAM -The Functional Independence Measure and Functional Assessment Measure (activities of daily living measure)
- Caregiver Strain Index
- Parkinson's disease quality of life self-assessment
- Functional independence measure & functional assessment measure
- Dopamine agonist withdrawal symptoms

Stakeholders advised that the mini mental state examination (MMSE) was not well validated although it is still widely used. Using mortality as a main outcome was also discussed. It was highlighted that there were lots of other comorbidities that can contribute to death and therefore actual PD related mortality could be under or overestimated. Quality of life measures were stated to be much more important in PD and should be the focus of any evidence reviews undertaken.

Guideline development group constituency

In addition to the proposed list of members for the guideline development group (GDG), stakeholders thought the following roles would need to be co-opted or even given full membership to the GDG, dependent on the final list of included clinical areas within the guideline scope. This would reflect the multidisciplinary nature of the management of people with PD. The following roles were suggested:

- An occupational therapist with specialist knowledge in PD
- A speech and language therapist
- A physiotherapy specialist in PD
- A dietician with a specialist interest in PD
- A palliative care physician

Some group members expressed that psychiatrists who work with older people may not always be familiar with the management of PD and therefore, that they may not

be a necessary part of the GDG constituency. Stakeholders suggested NICE might also consider extra patient/ carer membership on the GDG.