NICE National Institute for Health and Care Excellence

Date: **19th November 2014**

Minutes: Final

Guideline Development Group Meeting 1 **Parkinson's Disease**
Place: *NICE Offices & City Tower, Piccadilly Plaza, Manchester, M1 4BT*

Present:
Paul Cooper (Chair)
Alistair Church (AC)
Angela Birleson (AB) – co-opted expert
Beverly Sheaf (BS) – co-opted expert
Debbie Davies (DD)
Fiona Lindop (FL)
Graham Lennox (GL)
Ivan Benett (IB)
Jane Little (JL)
Janine Barnes (JB)
Julian Evans (JE) – co-opted expert
Lynne Osborne (LO)
Matthew Sullivan (MS)
Nicholas Miller (NM) – co-opted expert
Paul Shotbolt (PS)
Richard Grunewald (RG)
Robin Fackrell (RF)
Richard Walker (RW)

Apologies: None

In attendance:

NICE Staff:

Sue Spiers (SS)
Stephanie Mills (SM)
Steven Ward (SWard)
Gabriel Rogers (GR)
Hugh McGuire (HM)
Laura Downey (LD)
Louise Shires (LS)
Emma Chambers (EC)
Jenny Kendrick (JK)

Observers:

Jacqueline Durkin	NICE Staff	
Sharlene Ting	NICE Staff	

Wed 19th November 2014

1. PC welcomed the group to the first meeting of this guideline development group (GDG). PC began a presentation giving further background on NICE and the role of the GDG. GDG members were asked to introduce themselves and declare conflicts of interest which had been made known on appointment to the committee. All full and co-opted members declared that they knew of no personal specific, personal non-specific, non-personal specific or non-personal non-specific interest in the development of this guideline beyond those which had previously been declared.

   PC explained to the group that this guidance would be a substantive update of NICE clinical guideline 35. The scope was highlighted to be the boundary of the project and that the approach of the group must always be consistent with the scope. PC talked about how each person on a GDG is equal. PC highlighted that it was within the role of the Chair to facilitate the process of moving the group towards consensus, ensuring everyone is heard, ensuring jargon is avoided and declarations of interest are handled appropriately.

   GDG members were encouraged to express their own views and not that of their respective organisations. It was also explained that the content of meetings was confidential and this should be respected by all GDG members. PC thanked the group for committing their time to the guideline and hoped that they would enjoy the experience. PC told the group about the introduction of the new NICE guidance manual which will come into use from 1st January 2015.

2. EC talked to the GDG about the Public Involvement Programme (PIP). The importance of patient/ carer involvement in clinical guidelines was highlighted and how in writing the guideline, the views and choices of patients and carers should be an ongoing consideration. EC explained more about the public sector equality duty and also highlighted that GDG lay members will be crucial to develop understandable versions of the guideline for the public.

3. LS presented to the GDG on the role of the Guidelines Commissioning Manager (GCM) and the Commissioning team. The GDG were shown a diagram of the different centres that NICE commission to produce guidance. LS explained the importance of staying within the parameters of the guideline scope and made clear that NICE guidance is produced on the principle that it is used by trained, competent healthcare professionals. LS highlighted that she would attend many of the meetings and be a link role between the GDG, the guidance development team and the internal quality assurance team. The group also heard about the different guideline products that are produced when developing a clinical guideline and how these will support final implementation of the guidance.

4. SM talked to the group about the role of the project manager, timelines, expenses and declarations of interest. SM emphasised that a declaration of interest was an activity or work that may influence or affect your ability to participate on a guideline development group or how that participation is perceived.

5. LD talked the group through what was in and out of scope and the areas that the clinical review questions would cover.

6. LD gave a presentation on the process which the technical analyst would go through to produce an evidence review and explained to the GDG that it would be expected for them to read the summary documentation, interpret the evidence and advise on uncertainties within the evidence base. As part of this presentation JK explained the process of

systematic literature searching and demonstrated what a full search strategy for each question included within the guideline would look like.

7. Following lunch, LD continued the presentation on the process and methodology of guideline development and explained to the committee the GRADE working group approach to analysing the quality of evidence. LD was asked about how publication bias could be dealt with. It was explained that when a study was assessed for risk of bias, whether the study has reported relevant outcomes which relate to the study aims could be considered as a reason to downgrade quality.

8. SW gave a talk on the role of health economics in guideline development and why it is undertaken. The importance of considering resources in a constrained environment such as the NHS was explained to the GDG, along with some key health economic concepts such as quality-adjusted life years (QALYs).

9. SW continued to talk to the GDG about the need to prioritise areas included within the guideline scope for health economic analysis. The GDG discussed the importance of costs associated with dementia and psychosis. GDG members suggested interventions for the non-motor features of Parkinson's disease as a possible subject for modelling. Expensive interventions such as deep brain stimulation and duodopa were also considered important by the GDG. SW agreed to look further into these areas to establish what existing health economic literature and modelling there might be.

10. LD presented the evidence for review question 5 on daytime hypersomnolence to the GDG. Only one further new study had been identified since the previous guideline which met the inclusion criteria set out in the review protocol. The GDG discussed the quality of the evidence and how this could be interpreted. The group also reflected on the licensed indications for drugs for daytime hypersomnolence and how this may affect their decision-making. The GDG then went on to make recommendations. SM ran through the summary points of the committee discussions which would be put into the linking evidence to recommendations tables within the guideline.

11. The final activity of the meeting was to look at the review protocol for the next questions which would be looked at in guideline development. The GDG debated what would be the 7 most important outcomes for the analyst to look for in the literature on physiotherapy interventions. Due to time constraints within the meeting, it was not possible to go through any further review protocols but it was confirmed with the group that work on these would continue at the next committee meeting in January 2015.

Date, time and venue of the next meeting

Next meeting – 8th January 2015 at the NICE offices in London from 10am – 5pm.

- ***Review question:*** *12. What is the comparative effectiveness of physiotherapy compared with usual care?*
- ***Review protocols***