NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

HEALTH AND SOCIAL CARE DIRECTORATE

QUALITY STANDARD CONSULTATION

SUMMARY REPORT

1 Quality standard title

Parkinson's disease

Date of quality standards advisory committee post-consultation meeting:
2 November 2017

2 Introduction

The draft quality standard for Parkinson's disease was made available on the NICE website for a 4-week public consultation period between 7 September and 5 October 2017. Registered stakeholders were notified by email and invited to submit consultation comments on the draft quality standard. General feedback on the quality standard and comments on individual quality statements were accepted.

Comments were received from 19 organisations, which included service providers, national organisations, professional bodies and others.

This report provides the quality standards advisory committee with a high-level summary of the consultation comments, prepared by the NICE quality standards team. It provides a basis for discussion by the committee as part of the final meeting where the committee will consider consultation comments. Where appropriate the quality standard will be refined with input from the committee.

Consultation comments that may result in changes to the quality standard have been highlighted within this report. Comments suggesting changes that are outside of the process have not been included in this summary. The types of comments typically not included are those relating to source guidance recommendations and suggestions for non-accredited source guidance, requests to broaden statements out of scope, requests to include thresholds, targets, large volumes of supporting information, general comments on the role and purpose of quality standards and requests to change NICE templates. However, the committee should read this summary alongside the full set of consultation comments, which are provided in appendices 1 and 2.

3 Questions for consultation

Stakeholders were invited to respond to the following general questions:

1. Does this draft quality standard accurately reflect the key areas for quality improvement?

2. Are local systems and structures in place to collect data for the proposed quality measures? If not, how feasible would it be to be for these to be put in place?

3. Do you have an example from practice of implementing the NICE guideline that underpins this quality standard? If so, please submit your example to the NICE local practice collection on the NICE website. Examples of using NICE quality standards can also be submitted.

6. Do you think each of the statements in this draft quality standard would be achievable by local services given the net resources needed to deliver them? Please describe any resource requirements that you think would be necessary for any statement. Please describe any potential cost savings or opportunities for disinvestment.

Stakeholders were also invited to respond to the following statement specific questions:

4. For draft quality statement 3: Is the terminology ‘supportive therapies’ appropriate? If not, can you suggest an alternative?

5. For draft quality statement 4: Do you agree that the appropriate time for adults to take antiparkinsonian medication is within 30 minutes of the prescribed time?

4 General comments

The following is a summary of general (non-statement-specific) comments on the quality standard.

- There was general support for the quality standard and the areas identified for quality improvement.
- It was suggested that the statements should apply to atypical Parkinsonism’s such as multiple system atrophy, progressive supranuclear palsy and corticobasal degeneration.

Consultation comments on data collection

- It will be important to ensure that services are commissioned with appropriate clerical support for data collection.
- A local register of people with Parkinson’s disease established by GP’s would be helpful.

5 Summary of consultation feedback by draft statement

5.1 Draft statement 1

Adults with Parkinson’s disease have a named specialist healthcare professional.

Consultation comments

Stakeholders made the following comments in relation to draft statement 1:

- General
  - Some stakeholders suggested that the focus on a Parkinson’s disease nurse specialist should be strengthened while others felt it should be clearer that other professionals, such as allied health professionals, could take on this role.
- Statement
  - There should be more emphasis on ensuring continuity of care, for example, by specifying ‘a named Parkinson’s specialist healthcare team or provider’ rather than an individual healthcare professional.
  - A specialist consultant should also be included.
- Rationale
  - Should identify the need for the specialist healthcare professional to be part of a multidisciplinary team.
- Measures
  - An outcome focussed on take up of services could be added.
- Audience descriptors
  - It is important to emphasise that the specialist healthcare professional could equally be from a geriatrics or neurology background.

5.2 Draft statement 2

Adults with Parkinson’s disease starting dopaminergic therapy are given information about the risk of impulse control disorders.

Consultation comments

Stakeholders made the following comments in relation to draft statement 2:

- Statement
  - The statement should also include discussion about the risk of impulse control disorders before initiation and at reviews.
- Rationale
  - The rationale should emphasise the need to provide written information.
- Measures
  - The measures should specify ‘accessible’ written information to ensure compliance with the Accessible Information Standard.
  - Data sources could specify ‘electronic patient health records’ as this will make it easier to capture the data.
- Audience descriptors
  - Include allied health professionals and pharmacists in the list of healthcare professionals.

5.3 Draft statement 3

Adults with Parkinson’s disease are referred to supportive therapies if they have problems with balance, motor function, activities of daily living, communication, swallowing or saliva.

Consultation comments

Stakeholders made the following comments in relation to draft statement 3:

- General
  - It should be clearer how problems with balance, motor function, activities of daily living, communication, swallowing or saliva are detected, including who should be identifying them and when.
  - There was a concern that limited resources mean that access to supportive therapies is variable.
- Statement
  - There was concern that the statement as it stands could discourage early referral. It was suggested that the focus should be on referral to supportive therapies at diagnosis of Parkinson’s disease and before problems develop, in order to ensure that the person has strategies to help them to maintain their independence.
  - Should be extended to include support to carers.
  - Should be extended to include other health and social care professionals such as orthotists, dietitians, psychologists, social workers.
  - Wording should be ‘offered’ rather than ‘referred’ as some people decline.
- Rationale
  - It should be clear that therapists should be part of a multidisciplinary team.
- Measures
  - An additional structure measure on availability and take up of specialist training for therapists was suggested.
  - Process measures should focus on people with current problems or difficulties rather than including all referrals that could have been made several years ago.
  - Should include people who self-refer.

  - Measures should include use of NMSQuest and the PD sleep scale to identify non-motor symptoms.
- Audience descriptors
  - Pharmacists should be added to the list of healthcare professionals as they are able to refer to supportive therapies.
- Definitions
  - Consider adding a definition of activities of daily living that is broader than the patient descriptor.
  - A definition of physiotherapy and occupational therapy services specific for Parkinson’s disease is needed e.g. a dedicated service/ therapists with sufficient skills and experience.
  - It would be helpful to include more detail on the types of support provided by therapists to people with Parkinson’s disease e.g. exercise to maintain health and wellbeing, falls prevention and education, promoting social participation and recreation, supporting and maintaining wellbeing, self-management advice.

Consultation question 4

Is the terminology ‘supportive therapies’ appropriate? If not, can you suggest an alternative?

Stakeholders made the following comments in relation to consultation question 4:

- Although some stakeholders felt that the term ‘supportive therapies’ was appropriate others suggested alternatives as follows:
  - Allied health professionals
  - Therapist with expertise in Parkinson’s
  - Functional support/therapies
  - Non-pharmacological interventions

5.4 Draft statement 4

Adults with Parkinson's disease who are admitted to hospital or a care home take their antiparkinsonian medicines at the appropriate times.

Consultation comments

Stakeholders made the following comments in relation to draft statement 4:

- Statement
  - Should only apply to adults with Parkinson's who indicate that timing of medication is important to symptom control as this is not an important issue for everyone.
  - The word 'appropriate' is ambiguous and could be misconstrued to mean that it fits in with drug rounds. The focus should be on the individually prescribed time.
- Measures
  - It was suggested that the National Reporting and Learning system and the Medicines and Healthcare products Regulatory Agency yellow card scheme should be identified as data sources for the process measures.
  - Electronic recording e.g. electronic devices in care homes, should be emphasised as it is difficult to verify the accuracy of paper records.
  - Documentation of administration times of medications should be included.
- Audience descriptors
  - Pharmacists should be included in the list of healthcare practitioners.
- Definitions
  - It was suggested that timing is only an issue for levodopa as dopamine agonists and monoamine oxidase B inhibitors are typically taken once daily and precision to the half hour is not a priority.

Consultation question 5

Do you agree that the appropriate time for adults to take antiparkinsonian medication is within 30 minutes of the individually prescribed administration time?

Stakeholders made the following comments in relation to consultation question 5:

- Some stakeholders agreed that 30 minutes is appropriate.
- It is important to recognise that individuals have different drug regimens and although 30 minutes is appropriate for many people, others may require their drugs within 10 minutes.

5.5 Draft statement 5

Adults with Parkinson's disease are offered clozapine to treat hallucinations and delusions, if standard treatment is not effective.

Consultation comments

Stakeholders made the following comments in relation to draft statement 5:

- Statement
  - The focus should be on adults assessed as suitable for clozapine as it may not be a good treatment choice for some people.
  - There was concern that there will be some areas that are unable to implement the statement due to not having a registered specialist practitioner and/ or being unable to undertake monitoring e.g. in remote/rural areas.
- Rationale
  - The statement will also support the integration between physical and mental health services for people with Parkinson's.
- Measures
  - Should include use of NMSQuest to identify hallucinations.
- Audience descriptors
  - Should emphasise the need for improved joint-working with/mentoring from mental health services to improve understanding of the drug and monitoring processes.

6 Suggestions for additional statements

The following is a summary of stakeholder suggestions for additional statements.

- Referral to a specialist to ensure accurate diagnosis – Early referral to a specialist is important to ensure an accurate diagnosis and access to treatment.
- Joint assessments and interventions from an MDT – to ensure individual needs are identified and addressed.
- Holistic care planning – Adults with Parkinson’s disease and their families and carers should be involved in developing a holistic care plan that is regularly updated to help improve the management of symptoms and improve individual wellbeing and outcomes.
- Information and advice - tailored written and verbal information about the condition, treatment options and sources of support and advice should be provided.
- Advance care planning – Adults with Parkinson’s disease should be given opportunities to discuss, record and share their wishes and preferences for future treatment and care as this can reduce hospital costs in the last year of life.

Appendix 1: Quality standard consultation comments table – registered stakeholders

ID	Stakeholder	Statement number	Comments[1]
1	BAPO (British Association of Prosthetists and Orthotists)	General	General: BAPO support and endorse the stated aims and recommendations of this guideline and thank the development group for their work.
2	Department of Health	General	Thank you for the opportunity to comment on the draft for the above quality standard. I wish to confirm that the Department of Health has no substantive comments to make, regarding this consultation.
3	Parkinson's UK	General	We welcome the quality standard and recommend that NICE includes that these standards should relate to people with Parkinson's and atypical Parkinsonism's like multiple system atrophy, progressive supranuclear palsy and corticobasal degeneration.
4	Royal College of Physicians	General	The RCP is grateful for the opportunity to respond to the above consultation. We would like to endorse the response submitted by the British Geriatric Society (BGS).
5	Royal Pharmaceutical Society	General	The Royal Pharmaceutical Society is the professional body for pharmacists and pharmacy in Great Britain. As professionals in pharmaceutical care, pharmacists are well equipped to offer advice on managing clinical conditions and to raise patients' and carers' awareness and increase their understanding of their condition and therapy. With an increasing number of pharmacist independent prescribers and those specialising in specific disease states such as Parkinson's disease, pharmacists are often directly involved with managing patient therapy and regular reviews.
6	Compassion in Dying	Question 1	We strongly feel that this Quality Standard should reflect the benefits of Advance Care Planning (ACP) and the importance of this for people diagnosed with Parkinson's disease. There is clear evidence that ACP results in significant benefits for individuals and care providers. The evidence is reflected in the fact that care planning features significantly in NICE guidance around care at the end of life and in disease specific guidance and Quality Standards such as Motor Neurone Disease.

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[1] PLEASE NOTE: Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how quality standards are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its staff or its advisory committees.

ID	Stakeholder	Statement number	Comments[1]
			Furthermore, the recent draft guideline for Parkinson's Disease (update) emphasised the necessity of giving individuals the opportunity to plan for their future care and providing information on the legal ACP tools available to them to do so (recommendation 87). Research shows that a reduction in emergency hospital admissions for those who have an advance care plan in place leads to fewer days in hospital in the last year of life and reduced hospital costs incurred as a result of emergency admissions - a mean reduction of 28% and 8% respectively (Abel et al. 2013). We ran an outreach service called My Life, My Decision. As part of this service our staff delivered training to health and social care professionals about end-of-life rights. The below is a quote from a member of staff of Parkinson's UK: "I give advice and support to people with Parkinson's… and by the time I actually come to see them, they are aware and accepting of the fact that they have a degenerative disease, that they aren't going to get any better, and so they are keen to put things in place and to plan ahead. I didn't know much about it at all and I was getting asked the question more and more about powers of attorney and advance decisions. Being in the dark about it, I wasn't very confident in giving advice about it". (http://compassionindying.org.uk/library/my-life-my-decision-planning-end-life/ p.60) This demonstrates the importance of ensuring those caring for people with Parkinson's recognise the benefits that ACP can yield and are encouraged to instigate the process with patients. The Government's response to a House of Lords Select Committee Report on the Mental Capacity Act stressed the urgency to: "promote better understanding among health care staff of Advance Decisions, in order to ensure that they are followed when valid and applicable [and] promote early engagement between health care staff and patients about Advance Decisions" In 2015, the Government Health Committee reported that care staff often feel that they lack understanding of the mechanisms available to patients and carers under the Mental Capacity Act which allow people to make their wishes clear. The Committee recommended that all staff who provide palliative and end of life care to people with life limiting conditions should receive training in advance care planning.

ID	Stakeholder	Statement number	Comments[1]
			Given the above, we feel a quality statement along the lines of "Adults with Parkinson's disease are given opportunities to discuss, record and share their wishes and preferences for future treatment and care." would result in better outcomes for people diagnosed with Parkinson's disease and the committee should consider its inclusion.
7	Multiple System Atrophy Trust	Question 1	Does this draft quality standard accurately reflect the key areas for quality improvement? We think it does for people with Parkinson's Disease but we also feel that where appropriate the guidelines should also include people with Atypical Parkinsonism's such as Multiple System Atrophy, Progressive Supranuclear Palsy and Corticobasal Degeneration. Not including this group may lead to exclusion from the health benefits of this quality standard on an arbitrary basis, given that needs are equivalent.
8	NHS England – CAHPO	Question 1	Yes, particularly with reference to intervention from Allied Health Professionals
9	Parkinson's UK	Question 1	Parkinson's UK strongly believe that there needs to be another quality statement about holistic care planning added as this is an important part of ensuring that someone's health and care needs are comprehensively addressed in a planned way that can improve their outcomes. We recognise there are already 5 quality statements, but would urge NICE to consider adding a sixth statement, like the motor neurone disease standard. We would recommend that the additional statement should say: People with Parkinson's are provided with a holistic care plan to manage their condition and are involved in its development along with health professionals with specialist knowledge of Parkinson's, including a Parkinson's nurse. Rationale Timely and holistic discussions about care planning using standardised assessments should take place throughout someone's journey with the condition to help the patient manage their symptoms, maintain their wellbeing and prevent costly and unwanted interventions. It is important that people with Parkinson's and their families and carers are involved in the development of the care plan. Quality measures Structure a) Evidence of local arrangements to put a holistic care plan using standardised assessments in place with professionals with an expertise in Parkinson's. Date source: Local data collection, for example, patients notes. The UK Parkinson's Excellence Network UK Parkinson's Audit identifies whether patients have had any recorded discussions about an advanced care plan. Process Proportion of adults with Parkinson's with a holistic care plan with professionals with an expertise in Parkinson's.

ID	Stakeholder	Statement number	Comments[1]
			Numerator – The number in the denominator with a holistic care plan with professionals with an expertise in Parkinson's. Denominator – The number of adults with Parkinson's. Data source: Local data collection, for example, audit of patient health records. Outcome a) Satisfaction of adults with Parkinson's with their holistic care plan and involvement from professionals with an expertise in Parkinson's. Data source: Local data collection, for example patient survey. The UK Parkinson's Excellence Network UK Parkinson's Audit includes questions on satisfaction with the quality of service provided by different parts of the Parkinson's service.
10	Royal College of Occupational Therapists	Question 1	Please see the comments 1-4 above re: the focus of the statements covered.
11	NHS England – CAHPO	Question 2	For providers to respond to.
12	Royal College of Occupational Therapists	Question 2	For services to be routinely collating the data required, they need to be commissioned with appropriate clerical support to collate and analyse the data. It would be useful for there to be a local register of people with Parkinson's, potentially collected by GPs.
13	NHS England – CAHPO	Question 6	AHPs into Action https://www.england.nhs.uk/ourwork/qual-clin-lead/ahp/ gives a number of example of how AHPs are able to act as care co-ordinators. Case study 26 describes a single point of access for service users with long term conditions. Urgent appointments within 3 hours. 98% patient satisfaction. 93% remain in the community. Between 3% and 6% cost savings. 50% increase in admission avoidance.
14	Parkinson's UK	Question 6	Quality statement 4: In some centres across England professionals have developed approaches to tackling the challenges of ensuring people get their medication on time when in hospital. Centres we are aware of include Cambridge, Leeds and Derby.
15	Parkinson's UK	Question 6	Quality statement 5: We are aware that Dr Neil Archibald and his team in Newcastle use clozapine (when appropriate) with his patients with Parkinson's experiencing hallucinations and they have filmed a series of vimeo videos with his patients to explore the benefits and the impact on both the person with Parkinson's and their carer.

ID	Stakeholder	Statement number	Comments[1]
16	AbbVie	Statement 1	AbbVie support the sentiments behind Statement 1 (Adults with Parkinson's disease have a named specialist healthcare professional) and recognise the positive impact this will have on patients following diagnosis. Early access to accurate diagnosis and treatment is vital for people with Parkinson's. This is necessary to prevent unnecessary investigations being performed and inappropriate treatments prescribed. Most people with a form of parkinsonism have idiopathic Parkinson's disease, also known as Parkinson's. Other less common forms of parkinsonism include multiple system atrophy, progressive supranuclear palsy and drug-induced parkinsonism. Because the symptoms of idiopathic Parkinson's may be similar to other forms of parkinsonism, people can sometimes be misdiagnosed. Access to a specialist with expertise in the diagnosis of Parkinson's is therefore crucial. Patients with early stage Parkinson's disease may have significant disability which often responds well to treatment. It is therefore important that people are diagnosed and given the option to be referred to a specialist as rapidly as possible. However, in order for it make a real difference AbbVie would like to see the statement ensure that adults with Parkinson's are given information to support them. We would, therefore, propose that the following wording is added to the statement: 'Adults with Parkinson's disease have a named specialist healthcare professional and are provided with tailored written and verbal information about their condition and the treatment options available, and are provided with the details of further sources of support and advice' The opportunity to receive tailored and accessible information from the start of the Parkinson's journey is very important so that people with Parkinson's, their family and carers can understand how the condition may impact their lives, what treatment options are available, and where they can go to for care and support. Supporting Evidence • Breen D et al, 'Determinants of delayed diagnosis in Parkinson's disease', Journal of Neurology, Volume 260, Issue 8, pp 1978-1981, August 2013 • Cheung E at al, 'Association of specialist involvement and quality of care for Parkinson's disease', Movement Disorders, Volume 22, Issue 4, pages 515–522, March 2007 • Pagan FL, 'Improving outcomes through early diagnosis of Parkinson's disease', The American Journal of Managed Care, 18, S176-82, 2012 • Scottish Intercollegiate Guidelines Network, Diagnosis and pharmacological management of Parkinson's disease: A national clinical guideline, January 2010 • Shimbo T et al, 'Association between patient education and health-related quality of life in patients with Parkinson's disease', Quality of life research, Volume 13, Issue 1, pp 81-89, February 2004

ID	Stakeholder	Statement number	Comments[1]
17	AGILE: an association for physiotherapists working with older people	Statement 1	Outcome Your quality measure ‘structure’ and ‘data sources’ are suggestive of collections of quantitative data e.g. percentage referred to specialist; tick box of advice types given; tick box of onward referrals etc yet the outcome as is does not currently register numbers of people who do not take up the services offered and why they choose not to. This could be redressed and made more specific in the surveys collected.
18	British Geriatrics Society	Statement 1	We agree with this principle. Defining a Parkinson’s disease specialist can present some difficulties as there is no clear definition. In the UK, Parkinson’s specialists can be from a Geriatrics background or Neurology. It is important that neither specialty is seen to be inferior in terms of relevance or value. It is essential that any service descriptors recognise this.
19	NHS England – CAHPO	Statement 1	Outcome a Refers to satisfaction with Parkinson’s nurse rather than named specialist healthcare professional identified above.
20	NHS England – CAHPO	Statement 1	What this means for healthcare professionals Mentions nurse specialists and community matrons. Should this also be care co-ordinators or named healthcare professional? AHPS involved in services for people with Parkinson’s disease, such as physiotherapists and dieticians have prescribing rights and could undertake roles similar to the community matron.
21	NHS England – CAHPO	Statement 1	Definitions Named specialist health care professional could also be an AHP. Physiotherapists have prescribing rights and are able to undertake independent prescribing when appropriately trained and registration annotated.
22	Parkinson’s UK	Statement 1	We welcome this quality statement as people with Parkinson’s should have access to a named specialist health professional and believe the statement should be strengthened so it reads ‘Adults with Parkinson’s disease have access to a Parkinson’s specialist nurse’.
23	Parkinson’s UK	Statement 1	In the rationale we would recommend that it includes the need for the Parkinson’s nurse to be a part of a multidisciplinary team so they can work with other professionals to provide holistic care for a person with Parkinson’s that keeps them healthy and independent.
24	Parkinson's Disease Nurse Specialist Association (PDNSA)	Statement 1	While an MDT approach is essential, it is usually the Parkinson's Disease Nurse Specialist (PDNS) who is a constant throughout the trajectory of this condition. Therefore it would be preferable to identify the PDNS or PDNS team as the named HCP. The role of the PDNS addresses all aspects of activities of daily living, motor and non motor issues, and medication management. This may not be the case with all other HCP's.
25	Royal College of General Practitioners	Statement 1	Consider changing “Named specialist health care professional “ to “named Parkinson specialist health care team” Focusing on a named professional won’t necessarily deliver continuity of care, The issue is they are known to a named team. With part-time working, holiday, sickness etc, not to mention difficult personality dynamics which may develop between patients/families and professionals there is a risk of this standard becoming a tick box exercise, although named case workers within a team are appropriate.

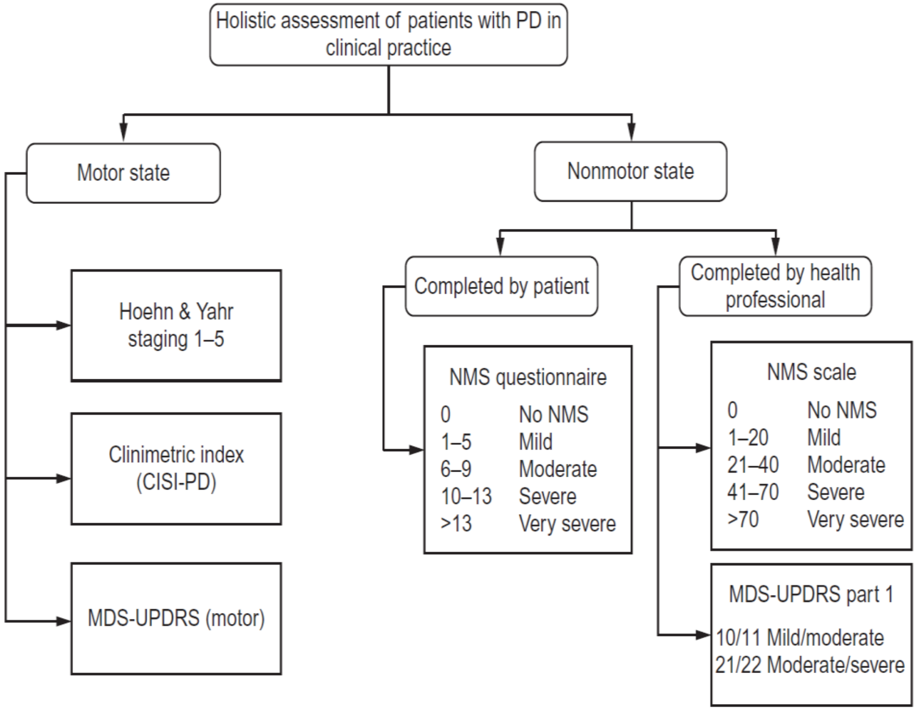
ID	Stakeholder	Statement number	Comments[1]
			At present all hospital consultant doctors in this country are considered specialists but not GPS. The GMC accept the recent arguments made by the BMA and RCGP that a single advanced register – for both specialists and GPs – would make this expertise much clearer. http://www.gmc-uk.org/news/28656.asp
26	Royal College of Occupational Therapists	Statement 1	Across this statement there is emphasis on PD specialist nurses being the named healthcare professional. This could be restrictive to other professions who are able to develop roles in medicines management whilst providing comprehensive monitoring. It may discourage evolving roles of AHPs in Parkinson's services and therefore we suggest the statement should remove 'nurse' and 'nurse specialist' and keep with 'specialist healthcare professional'.
27	Society and College of Radiographers	Statement 1	The Society and College of Radiographers feels that statement 1 should go further to ensure continuity of care from a named specialist healthcare provider (HCP). This will ensure local services establish robust succession plans and have the resources needed to deliver the standard continually for every patient. Without emphasising this there is a risk of disinvestment when HCPs move roles or when patients move to another location.
28	Welsh Branch of the UK Parkinson's Excellence Network	Statement 1	We would support the standard of having a named medical specialist (e.g. Consultant or Associate Specialist) as well as a named Parkinson's Nurse Specialist
29	AGILE: an association for physiotherapists working with older people	Statement 2	Introduction statement and Rationale The statements intimate that the warning conversation starts once the medication has been prescribed. This assumes that the conversation about risk will have been discussed before prescription, with the chance for people to opt out of taking this medication if they have a predilection to this character trait. This in not often the case with people with Parkinson's who are newly diagnosed, or about to have adjuvant therapies added. The Standard would be improved to be of quality if worded such that people, on choosing after discussion with the prescribing officer, to start of the dopaminergic medicines, would have a previously discussed message about impulsivity re-enforced.
30	Association of British Neurologists	Statement 2	NICE NG69 Recommendation 1.4.4 Discuss potential impulse control disorders at review appointments, particularly when modifying therapy, and record that the discussion has taken place. [2017] Having data on the percentage of patients who have been given this information regarding ICDs is a reasonable quality marker
31	British Geriatrics Society	Statement 2	It is important to counsel people about the risk of impulse control disorders at initiation. We would also advocate that the process of asking about these disorders should be ongoing throughout the treatment period, which is not specified in the current version of the quality standard.
32	Parkinson's UK	Statement 2	We agree with this quality statement and believe its inclusion is crucial to ensure that those starting dopaminergic therapies and their carers and families are fully aware of any side effects and that effective monitoring of the impact of

ID	Stakeholder	Statement number	Comments[1]
			the therapies takes place on a regular basis. We would recommend however that in the rationale of this quality statement it is important to ensure that discussions take place, but that these are followed up by the provision of written information on the possible side effects of these therapies.
33	Parkinson's Disease Nurse Specialist Association (PDNSA)	Statement 2	This statement has been comprehensively addressed to ensure awareness of ICD's.
34	Royal College of General Practitioners	Statement 2	Measures Consider replacing this with "accessible written information about the risk of impulse control disorders" to comply with accessible information standards DCB1605 Accessible Information https://www.england.nhs.uk/ourwork/accessibleinfo/ Can you also consider adding a hyperlink over the words impulse control disorder to the explanation provided at the bottom of page 9
35	Royal College of Occupational Therapists	Statement 2	We suggest including Allied Health Professionals in the list of Healthcare Professionals.
36	Royal Pharmaceutical Society	Statement 2	Pharmacist are suitably trained to and routinely provide advice and information on detecting and managing side effects of medicines to both patients and their carers'. Being experts in medicines, pharmacists should be included in the examples of healthcare professionals given on page 8 who provide information about the risk of impulse control disorders.
37	Welsh Branch of the UK Parkinson's Excellence Network	Statement 2	Information relating to impulse control disorders may be conveyed through a variety of media – having a central source of information would be helpful but ensuring documentation / reinforcement of ICD information is difficult to achieve due to the heterogeneity of information sources. Electronic health records can help to capture such information.
38	AGILE: an association for physiotherapists working with older people	Statement 3	AGILE members welcome the chance to comment on the proposed Quality Standards for people affected by Parkinson's. Where it is recommended that Physiotherapy and Occupational therapy services are available locally that are "specific for Parkinson's" we recommend that further work is undertaken to provide a clear definition of what is meant by this. Consideration needs to be given as to whether the Quality Standard development group is referring to :- 1) A dedicated therapy service for PD 2) Therapists with sufficient skill in managing PD are available locally.

ID	Stakeholder	Statement number	Comments[1]
			The European Guideline specifies the number of patients a physio needs to see each year to gain and maintain competence in seeing people with Parkinson's Disease.. Consideration could be given to whether this is incorporated in this recommendation.
39	AGILE: an association for physiotherapists working with older people	Statement 3	Introduction statement AGILE are pleased to note the recommendation to these 'supportive' therapies for adults with Parkinson's. However, the wording is misleading and unclear who should be detecting such aspects as balance or motor function deficits. Retrospective data analysis on people up to 10 years before diagnosis shows that motor function of balance, slowness and stiffness of movement, plus other research into reduction in activity is occurring (years) before the diagnosis. Given this increasing and emergent evidence, the Quality Standard should be about referral to support services with expertise to manage motor changes from the point of diagnosis onward, and not wait for symptoms to become apparent to a reviewing clinician who may only see a patient at consultation annually.
40	AGILE: an association for physiotherapists working with older people	Statement 3	Process and numerator Although important to record the process of referral to physiotherapy specific services for Parkinson's disease, an increasing number of physiotherapists working outside the National Health Service (NHS), e.g. for the charity Parkinson's UK, for other independent sector providers or in the private sector, are noting people with a new diagnosis are self-referring for physiotherapy. The numerators should reflect this by asking the people with Parkinson's if they have self-referred, and why? AGILE recognise the importance of physical activity in keeping people fit and well, especially when diagnosed with a complex, degenerative long-term condition like Parkinson's. Given the 'physical' side of the therapy, an increasing number of physiotherapists run condition-specific exercise classes, or are consulted by people who are newly diagnosed with Parkinson's for advice on exerciser. Some of their key members who work with people with Parkinson's are collaborating on a project with Parkinson's UK to develop an exercise framework that people with the condition, health professionals and exercise instructors can use to ensure the activity being undertaken is appropriate and will enable someone to maintain their health and wellbeing. This needs reflecting as an additional process proposal after a) on pgs 10 – 11, maybe as: 'Proportion of adults with Parkinson's disease requiring advise to remain fit and well, who are referred or self-refer to physiotherapy specific services for advise on exercise'.
41	Association of British Neurologists	Statement 3	The numerator and denominator do not match well in relation to process. eg. Numerator – the number in the denominator who are referred to physiotherapy specific for Parkinson's disease when balance or motor function problems are first identified. Denominator – the number of adults with Parkinson's disease and balance or motor function problems. eg. a patient diagnosed in 2000 and sent to physio when problems first identified in 2002, are they carried forward every year from 2002 as a 'yes' in both numerator and denominator? This is unwieldy and not all that informative. Also note that some patients are offered physio etc, but decline it, so 'offered' would be preferred.

ID	Stakeholder	Statement number	Comments[1]
			Suggest numerator = number of patients with balance and motor function problems who have been offered physiotherapy referral, denominator = number of current patients with balance and motor function problems.
42	BAPO (British Association of Prosthetists and Orthotists)	Statement 3	Quality measures "Proportion of adults with Parkinson's disease and balance or motor function problems who are referred to physiotherapy…". BAPO suggest that many people with balance and mobility issues associated with Parkinson's disease are seen by orthotists, who are autonomous allied health professionals who prescribe medical devices (orthoses) which may assist sufferers of this condition. This is poorly documented in the literature but has been recognised (see below for reference). "Proportion of adults with Parkinson's disease and balance or motor function problems who are referred to an allied health professional to address this…" would be an alternative which would recognise this. In this case, we would request that 'orthotist' is added to the list of professionals currently including physiotherapists, occupational therapists and speech and language therapists. Bracing for Persons with Parkinson Disease: A Case Series with Clinical Reasoning JPO Journal of Prosthetics & Orthotics: July 2015 - Volume 27 - Issue 3 - p 95–102 doi: 10.1097/JPO.0000000000000065 http://journals.lww.com/jpojournal/Fulltext/2015/07000/Bracing_for_Persons_with_Parkinson_Disease___A.5.aspx
43	British Geriatrics Society	Statement 3	There is a growing recognition that people with Parkinson's disease benefit from seeing specialist therapists even if do not perceive that they have a problem in particular area. The aim is to train that person in strategies to help them to maintain activity, function and independence. We recognise that at present, many areas do not have services that are sufficiently robust to provide that degree of input but feel that the direction of travel should be in that direction. We would recommend that the word 'especially' be added. Adults with Parkinson's disease are referred to supportive therapies especially if they have problems with balance, motor function, activities of daily living, communication, swallowing or saliva.
44	Neuroscience specialist group (NSG) of the British Dietetic Association (BDA)	Statement 3	Occupation therapy, physiotherapy and speech therapy are noted. However we would appreciate the inclusion of dietitians. Patients may be referred to a dietitian if they have problems with diet or nutrition. Being of a healthy nutritional status can help maintain independence and prevent hospital admission. Evidence that dietetic services specific for Parkinson disease are available locally could be collected by local service specification. The proportion of adults with Parkinson disease referred to dietetic service could be collected by local data collection and compared to those with known diet or nutrition problems.
45	NHS England – CAHPO	Statement 3	The list of reasons for referral to therapy services could be read as restrictive and does not include the breadth of interventions with which therapies may support an individual to manage their condition.

ID	Stakeholder	Statement number	Comments[1]
46	NHS England – CAHPO	Statement 3	Quality measures. Health related quality of life outcome measures are not routinely collected. Outcome measures for AHPs are currently being developed.
47	Non Motor Parkinson's Study Group	Statement 3	Comment about lack of validated outcome measure: We are very surprised that there is absolutely no mention of outcome measures that are ESSENTIAL to ensure that these quality standards could be captured in busy clinic. The draft consultation NICE guideline appendix B, 4.4 mani outcomes included quality of life measures as well as nonmotor questionnaire (NMSQuest, currently the only globally validated and used patient completed questionnaire to flag nonmotor symptoms to doctors and nurses) and PD sleep scale (also patient completed) as routine measures in clinic. Several studies show that unless these tools are used, symptoms will be missed and many nonmotor symptoms whoch affect daily quality of life such as depression, anxiety, pain, sleep problems, dizziness, dribbling of saliva will be missed as will be problems such as reduced sense of smell which puts patients at risk of fire hazard at home and sleep attacks which puts driving patients at risk of road traffic accident. Furthermore, a simple grading of severity of nonmotor symptoms based on patient completed NMSquestionnaire can direct treatment and has a direct correlation with quality of life. The Royal College of Physician CME journal has published the simple clinical paradigm of ensuring that EVERY doctor and nurse at least once a year measure the Hoehn and Yahr stage (takes 2-3 min) and the NMSQuest grading (patient completed, while waiting to be seen) so that basic standards are met and key nonmotor symptoms are NOT MISSED. AS shown below the motor and nonmotor assessment must form the basic assessment paradigm in every clinic and trigger a severity based clinical pathway. Depending on the symptoms flagged in the NMSQuest one can address depression, dribbling, anxiety, sleep problems or constipation.

ID	Stakeholder	Statement number	Comments[1]
			 **Fig. 1** A suggested scheme of clinical examination (motor and nonmotor) that may help epidemiological clinical assessment in PD (Sauerbier, Qamar, Rajah, & Chaudhuri, 2016). *CISI-PD*, clinical impression of severity index Parkinson's disease; *MDS-UPDRS*, movement disorders society unified Parkinson's disease rating scale; *NMS*, nonmotor symptoms. Sauerbier A., Qamar M.A., Rajah T., et al. New concepts in the pathogenesis and presentation of Parkinson's disease. Clin Med (Lond) 2016; 16: 365-370.

ID	Stakeholder	Statement number	Comments[1]
			In addition robust published data show a very strong and highly significant correlation of scores obtained from patient competed NMSQuestionnaire and worsening quality of life, The higher the score, the worse the quality of life. Chaudhuri, K.R., Sauerbier A., Rojo J.M., et al. The burden of non-motor symptoms in Parkinson's disease using a self-completed non-motor questionnaire: A simple grading system. Parkinsonism & Related Disorders 2015; 21: 287-291. For holistic assessment in clinic the suggested paradigm is : HY staging: (Motor) stages 1: mild , 2-3: moderate and 4-5: severe NMSQ grading: NMSQ score 0 = no nonmotor symptoms NMSQ score 1-5: Mild Nonmotor PD NMSQ score 6-9: Moderate burden of Nonmotor symptoms NMSQ score 10-13: Severe burden NMSQ score >14: Very severe burden Severe/Very severe cases need urgent clinical and multidisciplinary assessment. We therefore propose that NICE ensures that use of NMSQuest (recommended by the International Parkinson's disease and movement disorders society as well as Parkinson's UK) and PD sleep scale is used as an absolute minimum in the clinic.
48	Parkinson's UK	Statement 3	We wholeheartedly agree with this quality statement. We would recommend that the therapists work as part of a multidisciplinary team and that the rationale is amended to reflect that the referral should be early in the condition and reviewed throughout a person's journey with the condition.
49	Parkinson's UK	Statement 3	We are however disappointed that the description on page 12 of everyday activities only includes dressing, cooking and working. Parkinson's UK recommends that this is widened to also include going to the toilet, washing and walking short distances as these are everyday activities that enable someone to maintain their health and wellbeing. They are also the descriptors used by the Department for Work and Pensions in their decision making.
50	Parkinson's UK	Statement 3	We recommend that more narrative is added to outline the role therapists play in caring for people with Parkinson's. For instance occupational therapists (OTs) are mentioned, but without any additional information on the support they can provide to people with the condition or their carers and families. For instance commissioners may be unaware of the falls prevention or education work OTs undertake alongside working with their patients on cognitive memory strategies. We therefore recommend a more holistic assessment of the value therapists with an expertise in Parkinson's offer is added to the background documents.

ID	Stakeholder	Statement number	Comments[1]
51	Parkinson’s UK	Statement 3	Quality statement 3: We suggest that other evidence that could be added to the quality measures might be that appropriate specialist training is available and is being undertaken by therapists.
52	Parkinson's Disease Nurse Specialist Association (PDNSA)	Statement 3	While we agree with the terminology and statement, there has been a concerted effort to encourage people with Parkinson's to access therapies from diagnosis to promote a proactive, rather than reactive approach. By listing examples of deterioration, there is concern that interpretation of this draft statement, could potentially discourage early referral.
53	Royal College of General Practitioners	Statement 3	The term ‘supportive therapies’ is appropriate. How specific should Physiotherapy and Occupational therapy be to solely Parkinson’s disease? It is probably is not feasible to have a therapist working only with PD patients, and this restriction in the range of their work may not be welcomed by therapists. All physiotherapists and occupational therapists and Speech and language therapists will have covered neurological conditions in their training. Will commissioners need to specify that some sort of extra PD training has been done, and if so what sort? What standards will be acceptable?
54	Royal College of Occupational Therapists	Statement 3	Rather than ‘supportive therapies’ this may be better titled non-pharmacological interventions. We suggest that mood and cognition is also covered in this section with mention of psychology, counselling and social work support. We also suggest that dietetics support is included. People with Parkinson’s often benefit from joint assessments and interventions from the MDT. It would be useful for this to be reflected in the statement. We would suggest fatigue and weight loss are also added to this section as they are very common problems.
55	Royal College of Occupational Therapists	Statement 3	Within this section the definition of Activities of Daily Living (ADL) – “everyday activities such as dressing, cooking and working” is narrow. Occupational therapy for people living with Parkinson’s disease should cover many areas including: • promoting social participation and recreation • supporting and maintaining wellbeing following diagnosis • education and self-management advice to empower living well, including addressing mental wellbeing. This needs to be considered ‘throughout the journey’ of life with the condition, encompassing end of life care. These are all common occupational therapy domains beyond simple ADL offered to this particular group of patients and it would be beneficial for this to be reflected in the quality standard. In addition consideration should be given to the role of ‘supportive therapies’ for care-givers/family/friends.

ID	Stakeholder	Statement number	Comments[1]
			Assessment of carer needs is very important: a recent Parkinson's UK audit suggested people caring for someone with Parkinson's are 40% less likely to leave the house for an hour a week compared to their peers.
56	Royal Pharmaceutical Society	Statement 3	With increasing number of pharmacists and pharmacist independent prescribers working in GP practices, pharmacists may be involved in seeing patients with Parkinson's disease and are able to refer appropriately to supportive therapies as needed. Pharmacists should be included in the list of healthcare professionals that is given on page 12.
57	Welsh Branch of the UK Parkinson's Excellence Network	Statement 3	There is variation nationally in availability of therapies for many conditions. We fully support the standard but would foresee that availability of specialist services may vary by region. Financial limitations are foreseeable barriers and may curtail the frequency / intensity of therapy offered to people with Parkinson's. A gold standard service would include therapies as part of the "core PD team" however this is currently not the case.
58	BAPO (British Association of Prosthetists and Orthotists)	Statement 3 – Question 4	"Is the terminology 'supportive therapies' appropriate? If not, can you suggest an alternative?". BAPO feel that this is a reasonable term, although 'allied health professional' would be an alternative which would avoid excluding other relevant professionals who are not described as therapists.
59	NHS England – CAHPO	Statement 3 – Question 4	Supportive therapies does not adequately describe the role of these professions. Allied health professions would be a more relevant term. Allied health professionals are autonomous, regulated practitioners who can practice independently of other professionals and may well be the case co-ordinator for the individual.
60	NHS England – CAHPO	Statement 3 – Question 4	No. See comment 1 above. Allied health professions would be a more relevant term. Allied health professionals are autonomous, regulated practitioners who can practice independently of other professionals and may well be the case co-ordinator for the individual.
61	Parkinson's UK	Statement 3 – Question 4	We recommend that the statement reads a therapist with expertise in Parkinson's rather than supportive therapies so it.
62	Royal College of Occupational Therapists	Statement 3 – Question 4	We agree with the terminology used.
63	Royal College of Psychiatrists	Statement 3 – Question 4	An alternative would be functional support or functional therapies as the purpose of each is to improve functioning within a specified area.
64	Association of British Neurologists	Statement 4	The numerator proposed is problematic. "Proportion of doses of antiparkinsonian medicines for adults with Parkinson's disease in hospital or a care home that were delayed by 30 minutes or more." There are many circumstances in which this may be in the best interest of the patient, eg. person hd longer lie in so delayed dosing for that day, person opted to delay a dose as they had a bout of dyskinesia, they may have 'as required' boosters eg. of Madopar dispersible and then will delay the next routine dose (deliberately). In addition, it must be recognised that,

ID	Stakeholder	Statement number	Comments[1]
			while many people with Parkinson’s find timing very important, there are also a lot of people with Parkinson’s who do not find it makes a difference, so their timing of intake of medication is not critical. It would be better to qualify this as applicable to people with Parkinson’s who indicate that timing of their medication is important to symptom control, i.e. re-define the denominator. Failure to recognise the variation in response to medication, between individuals, runs the risk of defining a quality standard that is of poor quality! Further, the definition of which drugs this refers to is: "Antiparkinsonian medicines include levodopa, dopamine agonists and monoamine oxidase B inhibitors”. Timing for drugs other than L-dopa is not so critical (esp. once daily dopamine agonists and MAOBI-s which are typically once daily enzyme inhibitors, these drugs have a longer duration of action and precision to the half hour should not be given priority.
65	British Geriatrics Society	Statement 4	We agree strongly with this statement. Missed or delayed Parkinson’s medication can have a significantly negative impact on People with Parkinson’s disease who find themselves in hospital. The worst case scenario from missed Parkinson’s medication is death.
66	Parkinson’s UK	Statement 4	We are delighted to see quality statement 4 and welcome its inclusion as this is a regular occurrence for people with Parkinson’s when they enter hospital as an unplanned admission. Parkinson’s UK have developed resources for professionals to improve services and raise the profile of this issue in hospital and care home settings and would welcome reference to them in any supporting materials to assist professionals improve their practice. They can be accessed at https://www.parkinsons.org.uk/content/get-it-time
67	Parkinson’s UK	Statement 4	Quality statement 4: We recommend that under Process a) NICE references the data that can be sourced from the National Reporting and Learning System (database that records patient safety incidents) and also the yellow card scheme operated by the Medicines and Healthcare products Regulatory Agency. Both of these record missed medication doses, the former also noting the severity of harm on the individual.
68	Parkinson's Disease Nurse Specialist Association (PDNSA)	Statement 4	This statement is slightly ambiguous as when referring to 'appropriate times' it does not clearly state that it is referring to the prescribed time for the individual. 'Appropriate' could be interpreted as 'convenient' for all involved. The success of the 'Get it on Time' campaign has encouraged individualised timing of medication when in hospital or other care setting. 'Appropriate' could be misconstrued as meaning at appropriate routine drug rounds/times.
69	Royal College of General Practitioners	Statement 4	Seems reasonable. It is difficult to verify accuracy of paper records. Can care homes use i-pads or some other electronic recording with automatic documentation of timing – if not is this worth developing?
70	Welsh Branch of the UK Parkinson’s Excellence Network	Statement 4	We fully support this statement. Utilisation of tools to enhance “on-time” medication-administration is advocated widely (e.g. clocks). A focus on medications by admitting teams (including pharmacists) should be mandatory, including medicines reconciliation and review of timings. We would also advocate documentation of administration times of medications (particularly Parkinson’s medications) to accurately assess, audit and improve medications timing.
71	Royal College of Psychiatrists	Statement 4 – Question 5	Yes – 30 minutes remains the appropriate timescale

ID	Stakeholder	Statement number	Comments[1]
72	Royal Pharmaceutical Society	Statement 4	Pharmacists working in hospitals and care homes are often the first healthcare professionals to record a patient's medication history and do so on a regular basis. Pharmacists will also clinically screen medicines charts to ensure appropriate information in relation to medicines, such as dosing and timing is also recorded. Pharmacists should be included in the list of health and social care practitioners that is provided on page 16.
73	Parkinson's UK	Statement 4 – Question 5	The drug regime for someone with Parkinson's is personal and will have taken some time to develop. For many people with Parkinson's having their medication within 30 minutes will work, whereas for others they must have their medication within 10 minutes of their medication timing. We would therefore recommend that this point is made within the rationale.
74	Association of British Neurologists	Statement 5	The numerator should be the proportion assessed for suitability for clozapine, not the proportion offered it, since it may not be a good treatment choice for some patients (eg. prevailing blood dyscrasia, poorly controlled epilepsy).
75	British Geriatrics Society	Statement 5	Clozapine can be an effective treatment for hallucinations in Parkinson's disease but it is not without its problems. Closer reading of what is defined as standard treatment for hallucinations and delusions in Parkinson's disease shows that Clozapine represents the current end of a long line of other options and approaches. On that basis we support the standard.
76	Non Motor Parkinson's Study Group	Statement 5	Above statement is also valid for this statement and capture of this and other nonmotor issues. An European study in 2010 showed that without the use of NMS questionnaire hallucinations are missed in the clinic in over 50% of cases !! AS shown below. (Taken from

<table>
<tr><th>ID</th><th>Stakeholder</th><th>Statement number</th><th>Comments[1]</th></tr>
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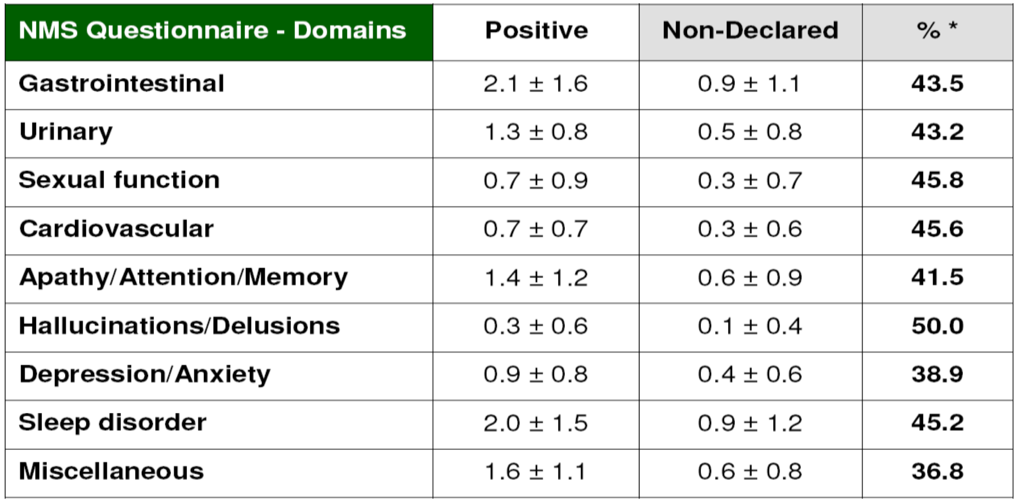
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<tr><th>NMS Questionnaire - Domains</th><th>Positive</th><th>Non-Declared</th><th>% *</th></tr>
<tr><td>Gastrointestinal</td><td>2.1 ± 1.6</td><td>0.9 ± 1.1</td><td>43.5</td></tr>
<tr><td>Urinary</td><td>1.3 ± 0.8</td><td>0.5 ± 0.8</td><td>43.2</td></tr>
<tr><td>Sexual function</td><td>0.7 ± 0.9</td><td>0.3 ± 0.7</td><td>45.8</td></tr>
<tr><td>Cardiovascular</td><td>0.7 ± 0.7</td><td>0.3 ± 0.6</td><td>45.6</td></tr>
<tr><td>Apathy/Attention/Memory</td><td>1.4 ± 1.2</td><td>0.6 ± 0.9</td><td>41.5</td></tr>
<tr><td>Hallucinations/Delusions</td><td>0.3 ± 0.6</td><td>0.1 ± 0.4</td><td>50.0</td></tr>
<tr><td>Depression/Anxiety</td><td>0.9 ± 0.8</td><td>0.4 ± 0.6</td><td>38.9</td></tr>
<tr><td>Sleep disorder</td><td>2.0 ± 1.5</td><td>0.9 ± 1.2</td><td>45.2</td></tr>
<tr><td>Miscellaneous</td><td>1.6 ± 1.1</td><td>0.6 ± 0.8</td><td>36.8</td></tr>
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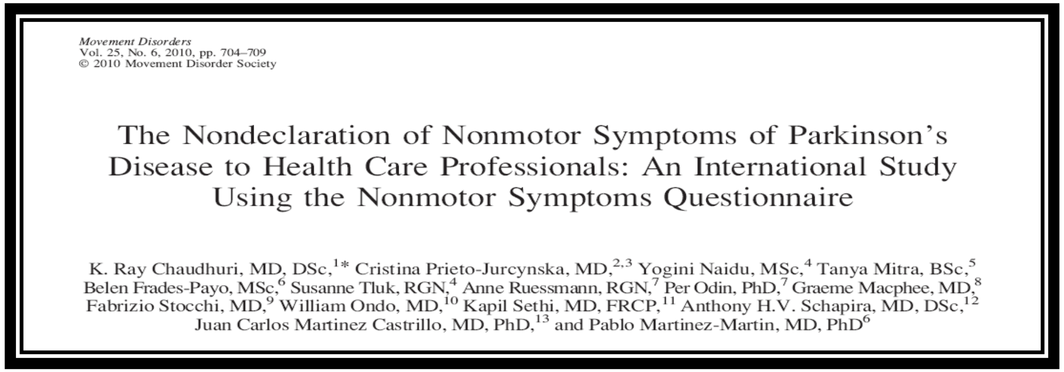
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The Nondeclaration of Nonmotor Symptoms of Parkinson’s Disease to Health Care Professionals: An International Study Using the Nonmotor Symptoms Questionnaire

K. Ray Chaudhuri, MD, DSc,[1*] Cristina Prieto-Jurcynska, MD,[2,3] Yogini Naidu, MSc,[4] Tanya Mitra, BSc,[5] Belen Frades-Payo, MSc,[6] Susanne Tluk, RGN,[4] Anne Ruessmann, RGN,[7] Per Odin, PhD,[7] Graeme Macphee, MD,[8] Fabrizio Stocchi, MD,[9] William Ondo, MD,[10] Kapil Sethi, MD, FRCP,[11] Anthony H.V. Schapira, MD, DSc,[12] Juan Carlos Martinez Castrillo, MD, PhD,[13] and Pablo Martinez-Martin, MD, PhD[6]
</td></tr>
<tr><td>77</td><td>Parkinson’s UK</td><td>Statement 5</td><td>We fully support the inclusion of quality statement 5 and think it is important in tackling the poor access people with Parkinson’s have to clozapine currently. This statement could also help to address the lack of integration between physical and mental health services for people with Parkinson’s.</td></tr>
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ID	Stakeholder	Statement number	Comments[1]
78	Parkinson's Disease Nurse Specialist Association (PDNSA)	Statement 5	While we would agree with the principles of this statement in view of recent NICE guidance, local services will need to review their current service provision , and where needed commission new services to ensure equity and availability. We are concerned that there will be areas where this may not be possible due to a lack of registered specialist practitioner and the inability to undertake the strict monitoring required (i.e. Remote/rural areas).
79	Welsh Branch of the UK Parkinson's Excellence Network	Statement 5	Whilst there are pockets of familiarity and confidence in the use of clozapine, the drug is still relatively underutilised given the evidence base. Anecdotally the Excellence Network feel this stems from unfamiliarity with the drug and fear of side effect profile coupled with a lack of knowledge around processes such as registration with the monitoring service. We feel this could be improved by enhanced joint-working with mental health services and education and/or mentorship.

Registered stakeholders who submitted comments at consultation

- AbbVie
- AGILE
- Association of British Neurologists
- BAPO (British Association of Prosthetists and Orthotists)
- British Dietetic Association (BDA)
- British Geriatrics Society
- Compassion in Dying
- Department of Health
- Multiple System Atrophy Trust
- NHS England – CAHPO
- Non Motor Parkinson's Study Group
- Parkinson's Disease Nurse Specialist Association (PDNSA)

- Parkinson’s UK
- Royal College of General Practitioners
- Royal College of Occupational Therapists
- Royal College of Physicians
- Royal Pharmaceutical Society
- Society and College of Radiographers
- Welsh Branch of the UK Parkinson’s Excellence Network