NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

Health and social care directorate

Quality standards and indicators

Briefing paper

Quality standard topic: Parkinson's disease

Output: Prioritised quality improvement areas for development.

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Contents

1 Introduction

This briefing paper presents a structured overview of potential quality improvement areas for Parkinson's disease. It provides the committee with a basis for discussing and prioritising quality improvement areas for development into draft quality statements and measures for public consultation.

1.1 Structure

This briefing paper includes a brief description of the topic, a summary of each of the suggested quality improvement areas and supporting information.

If relevant, recommendations selected from the key development source below are included to help the committee in considering potential statements and measures.

1.2 Development source

The key development sources referenced in this briefing paper is:

Parkinson's disease in adults: diagnosis and management. NICE guideline 69 (publication expected June 2017)

Parkinson's disease NICE clinical knowledge summary (2016)

2 Overview

2.1 Focus of quality standard

This quality standard will cover the diagnosis and management of Parkinson's disease in adults.

2.2 Definition

Parkinson's disease is a progressive neurodegenerative condition in which parts of the brain become progressively damaged over many years. There is no consistently reliable test that can distinguish Parkinson's disease from other conditions that have a similar clinical presentation. The diagnosis is primarily based on a clinical history and examination.

People with Parkinson's disease classically present with the symptoms and signs described as 'parkinsonism': these include bradykinesia (slow movements), rigidity, rest tremor (shaking) and postural instability (loss of balance). The symptoms of parkinsonism are not always a result of Parkinson's disease. Other causes include side effects of medicines, vascular disease, and less common degenerative conditions.

2.3 Incidence and prevalence

Parkinson's disease is one of the most common neurological conditions. It is estimated to affect up to 160 people per 100,000, with an annual incidence in the UK of 15–20 per 100,000.

Incidence and prevalence increases with age and 1% of people older than 65 years are diagnosed with Parkinson's disease. Only 4-8% of people with Parkinson's disease are younger than 50. Parkinson's disease is thought to be 1.5 times more common in men than in women.

In the UK the prevalence of Parkinson's disease is predicted to increase by 27% between 2009 and 2020 based on the expected trend towards an ageing population.

Parkinson's disease has historically been recognised as a primary movement disorder; however, other symptoms may be prominent, such as depression, cognitive impairment and dementia. In the later stages of the disease, people may develop pain and autonomic disturbances (such as dizziness and fainting, and problems with sweating, heart rate, digestion, vision and sexual function). These other symptoms are sometimes described as the 'non-motor' manifestations of Parkinson's disease. The condition may progress to cause significant impairments, adversely affecting quality of life and, indirectly, the quality of life of family and carers. In some people Parkinson's disease is a life limiting condition, however in others Parkinson's disease runs alongside other comorbidities that may contribute to death.

2.4 Management

The way in which the diagnosis of Parkinson's disease is communicated is important and evidence indicates that it is often not well done. People with Parkinson's disease may need the information originally given at diagnosis to be repeated and will want more information as the condition progresses.

There is currently no cure for Parkinson's disease, but treatments including supportive therapies, medication and surgery can help to relieve symptoms and maintain quality of life.

Given the nature of the therapies currently available for Parkinson's disease, there are difficult trade-offs to be made over time between the beneficial therapeutic effects and the short- and long-term adverse consequences of a particular treatment. It is essential that these decisions are specific to an individual and agreed between the person with Parkinson's disease and the appropriate clinicians after a period of reflection including involvement of the family.

For people with Parkinson's disease the main objective should be collaborative care, although interventions such as the locally commissioned Expert Patient Programme, which concentrates on self-management, will have a part to play for some individuals.

2.5 National audit

The UK Parkinson's Excellence Network Parkinson's Audit[1] is a national audit of the quality of care provided to people with Parkinson's disease benchmarked against good practice standards and guidance including the 2006 NICE guideline. It includes separate service audits for Elderly Care and Neurology consultants, Parkinson's nurses, occupational therapists, physiotherapists and speech and language therapists. The 2015 audit reports on the care provided by 432 participating services to 8,846 people with Parkinson's. The audit was designed to examine how patients had been managed and assessed over the previous year rather than on a single visit. In addition to the audit data, 5,834 people with Parkinson's and their carers attending 225 of the participating services completed a patient reported experience measure (PREM) questionnaire. These are not necessarily the same patients as those included by the services in their patient audit.

2.6 Resource impact

We do not expect any of the suggested areas for quality improvement to have a significant impact on resources. Resource impact work performed during development of NICE guideline 69 suggested that implementing the guideline would cost less than £1m in England annually for a single guideline recommendation and less than £5m in England across the whole guideline.

2.7 National outcome frameworks

Tables 1–3 show the outcomes, overarching indicators and improvement areas from the frameworks that the quality standard could contribute to achieving.

Table 1 NHS outcomes framework 2016–17

Domain	Overarching indicators and improvement areas
2 Enhancing quality of life for people with long-term conditions	***Overarching indicator*** 2 Health-related quality of life for people with long-term conditions** ***Improvement areas*** **Ensuring people feel supported to manage their condition** 2.1 Proportion of people feeling supported to manage their condition **Reducing time spent in hospital by people with long-term conditions** **Enhancing quality of life for carers**

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[1] 2015 UK Parkinson's Audit UK Parkinson's Excellence Network (2016)

	2.4 Health-related quality of life for carers**
3 Helping people to recover from episodes of ill health or following injury	***Overarching indicators*** 3b Emergency readmissions within 30 days of discharge from hospital* ***Improvement areas*** **Improving outcomes from planned treatments** 3.1 Total health gain as assessed by patients for elective procedures *i Physical health-related procedures* *ii Psychological therapies* *iii Recovery in quality of life for patients with mental illness* **Helping older people to recover their independence after illness or injury** 3.6 i Proportion of older people (65 and over) who were still at home 91 days after discharge from hospital into reablement/rehabilitation service*
4 Ensuring that people have a positive experience of care	***Overarching indicators*** 4a Patient experience of primary care i GP services 4b Patient experience of hospital care 4c *Friends and family test* *4d Patient experience characterised as poor or worse* *I Primary care* *ii Hospital care* ***Improvement areas*** **Improving people’s experience of outpatient care** 4.1 Patient experience of outpatient services **Improving hospitals’ responsiveness to personal needs** 4.2 Responsiveness to inpatients’ personal needs **Improving the experience of care for people at the end of their lives** 4.6 Bereaved carers’ views on the quality of care in the last 3 months of life **Improving people’s experience of integrated care** *4.9 People’s experience of integrated care***
5 Treating and caring for people in a safe environment and protecting them from avoidable harm	***Overarching indicators*** *5b Severe harm attributable to problems in healthcare*
Alignment with Adult Social Care Outcomes Framework and/or Public Health Outcomes Framework * Indicator is shared ** Indicator is complementary Indicators in italics in development	

Table 2 Adult social care outcomes framework 2015–16

Domain	Overarching and outcome measures
1 Enhancing quality of life for people with care and support needs	***Overarching measure*** 1A Social care-related quality of life** ***Outcome measures*** **People manage their own support as much as they wish, so they are in control of what, how and when support is delivered to match their needs** 1B Proportion of people who use services who have control over their daily life **Carers can balance their caring roles and maintain their desired quality of life** 1D Carer-reported quality of life**
2 Delaying and reducing the need for care and support	***Overarching measure*** 2A Permanent admissions to residential and nursing care homes, per 100,000 population ***Outcome measures*** **Everybody has the opportunity to have the best health and wellbeing throughout their life, and can access support and information to help them manage their care needs** **Earlier diagnosis, intervention and reablement means that people and their carers are less dependent on intensive services** 2B Proportion of older people (65 and over) who were still at home 91 days after discharge from hospital into reablement/rehabilitation services* **When people develop care needs, the support they receive takes place in the most appropriate setting and enables them to regain their independence** 2C Delayed transfers of care from hospital, and those which are attributable to adult social care

3 Ensuring that people have a positive experience of care and support	***Overarching measure*** **People who use social care and their carers are satisfied with their experience of care and support services** 3A Overall satisfaction of people who use services with their care and support 3B Overall satisfaction of carers with social services *Placeholder 3E The effectiveness of integrated care* ***Outcome measures*** **Carers feel that they are respected as equal partners throughout the care process** 3C The proportion of carers who report that they have been included or consulted in discussions about the person they care for **People know what choices are available to them locally, what they are entitled to, and who to contact when they need help** 3D The proportion of people who use services and carers who find it easy to find information about support **People, including those involved in making decisions on social care, respect the dignity of the individual and ensure support is sensitive to the circumstances of each individual** This information can be taken from the Adult Social Care Survey and used for analysis at the local level.
4 Safeguarding adults whose circumstances make them vulnerable and protecting from avoidable harm	***Overarching measure*** 4A The proportion of people who use services who feel safe** ***Outcome measures*** **Everyone enjoys physical safety and feels secure** **People are protected as far as possible from avoidable harm, disease and injuries** **People are supported to plan ahead and have the freedom to manage risks the way that they wish** 4B The proportion of people who use services who say that those services have made them feel safe and secure
Alignment with NHS Outcomes Framework and/or Public Health Outcomes Framework * Indicator is shared ** Indicator is complementary Indicators in italics in development	

Table 3 Public health outcomes framework for England, 2016–2019

Domain	Objectives and indicators
2 Health improvement	***Objective*** People are helped to live healthy lifestyles, make healthy choices and reduce health inequalities 2.23 Self-reported well-being 2.24 Injuries due to falls in people aged 65 and over
4 Healthcare public health and preventing premature mortality	***Objective*** Reduced numbers of people living with preventable ill health and people dying prematurely, whilst reducing the gap between communities ***Indicators*** 4.11 Emergency readmissions within 30 days of discharge from hospital* 4.13 Health-related quality of life for older people 4.14 Hip fractures in people aged 65 and over
Alignment with Adult Social Care Outcomes Framework and/or NHS Outcomes Framework * Indicator is shared	

3 Summary of suggestions

3.1 Responses

In total 14 stakeholders (including a combined response from several key stakeholders) responded to the 2-week engagement exercise 06/04/17 to 20/04/17.

Stakeholders were asked to suggest up to 5 areas for quality improvement. Specialist committee members were also invited to provide suggestions. The responses have been merged and summarised in table 4 for further consideration by the committee.

Full details of all the suggestions provided are given in appendix 2 for information.

Table 4 Summary of suggested quality improvement areas

Suggested area for improvement	Stakeholders
Referral to a specialist	ABUHB, BP. RCGP, SCMs
Specialist support • Key contact • Multidisciplinary team	 RCGP, RCOT, SCMs ABUHB, AGILE, PA, PUK/CRGN, RCN, RCOT, SCMs, SRR, WH
Care management • Care plan • Reviews	 BP, SCMs PA, RCGP, WH
Identifying symptoms and complications • Assessment • Impulse control disorders	 ABUHB, PA, PUK/CRGN, RCPsy, SCM, SRR, WH RCPsy, SCMs
Treatment for symptoms • Pharmacological management • Deep brain stimulation	 SCMs ML, PUK/CRGN, RCN
Medicines management in hospital	PUK/CRGN,SCMs
Information and support • Information for the person with Parkinson’s disease • Information and support for carers	 BP, PA, PUK/CRGN, SCMs, WH PUK/CRGN, RCOT, SCM, SRR
Additional areas • Planning for end of life • Employment support • Data collection • NHS Continuing healthcare system	 CiD, PUK/CRGN, RCN, RCOT SRR PA, WH SCM
ABUHB, Abertawe Bromorgannwg University Health Board AGILE, AGILE (Subgroup of Chartered Society of Physiotherapy) BP, Britannia Pharmaceuticals CiD, Compassion in Dying ML, Medtronic Ltd PA, Parkinson’s Academy PUK/CRGN Parkinson’s UK and Clinical Reference Group for Neurosciences (including Association of British Neurologists Advisory Group in Movement Disorders) RCGP, Royal College of General Practitioners RCOT, Royal College of Occupational Therapists RCN, Royal College of Nursing RCPsy Royal College of Psychiatrists SCM, Specialist Committee Member SRR, Society for Research in Rehabilitation WH, Wilmington Healthcare	

3.2 Identification of current practice evidence

Bibliographic databases were searched to identify examples of current practice in UK health and social care settings; 509 papers were identified for Parkinson’s disease. In addition, 39 papers were suggested by stakeholders at topic engagement.

Of these papers, 11 have been included in this report and are included in the current practice sections where relevant. Appendix 1 outlines the search process.

4 Suggested improvement areas

4.1 Referral to a specialist

4.1.1 Summary of suggestions

Stakeholders suggested people who may have Parkinson's disease should be referred to a specialist for assessment as soon as possible. This is important because non-specialists may not correctly identify the condition. It was emphasised that, following referral, the person should be seen within 6 weeks and those with more complex problems should be seen within 2 weeks.

4.1.2 Selected recommendations from development source

Table 5 below highlights recommendations that have been provisionally selected from the development sources that may support potential statement development. These are presented in full after table 5 to help inform the committee's discussion.

Table 5 Specific areas for quality improvement

Suggested quality improvement area	Suggested source guidance recommendations
Referral to a specialist	**Diagnosing Parkinson's disease** NICE NG69 Recommendations 1.2.1 and 1.2.2

Diagnosing Parkinson's disease

NICE NG69 Recommendation 1.2.1

Suspect Parkinson's disease in people presenting with tremor, stiffness, slowness, balance problems and/or gait disorders. [2006]

NICE NG69 Recommendation 1.2.2

If Parkinson's disease is suspected, refer people quickly and untreated to a specialist with expertise in the differential diagnosis of this condition. [2006, amended 2017]

Current UK practice

A 2016 survey of patient experience carried out by the Neurological Alliance[2] found that 63% of people with Parkinson's disease saw their GP only once or twice before

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[2] Falling short: How has neurology patient experience changed since 2014? (2017) Neurological Alliance

being referred to a neurological specialist. The survey included 592 people with Parkinson’s disease within a larger sample of neurology patients.

4.2 Specialist support

4.2.1 Summary of suggestions

Key contact

Stakeholders suggested that people with Parkinson's disease should have a case manager with specialist expertise, such as a Parkinson's disease nurse or specialist healthcare professional. This will ensure that their needs are proactively reviewed and managed, that they can access services and therapies and support to help them to manage their condition. The specialist case manager can refer the person back to the consultant when required. It was reported that there is currently variability in access to nurse specialists even though stakeholders highlighted that the service may lead to cost savings.

Multidisciplinary team

Stakeholders highlighted that people with Parkinson's disease should be able to access support from a multidisciplinary team to help them to manage their symptoms, maintain their independence and avoid hospital admissions. Some stakeholders emphasised the importance of the multidisciplinary team as a whole while others felt the quality standard should focus on access to specific services. The composition of the multidisciplinary team will vary depending on individual needs but stakeholders suggested it may include:

- consultant neurologist/geriatrician with special interest
- Parkinson's disease nurse
- physiotherapist (including advice on physical activity)
- occupational therapist
- speech and language therapist (including assessment of communication needs at diagnosis and access to Lee Silverman Voice Therapy)
- falls prevention service
- psychological support including neuropsychology (following diagnosis and for mental health problems)
- dietitian
- pharmacist
- social care
- GP with knowledge of Parkinson's

4.2.2 Selected recommendations from development source

Table 6 below highlights recommendations that have been provisionally selected from the development sources that may support potential statement development. These are presented in full after table 6 to help inform the committee's discussion.

Table 6 Specific areas for quality improvement

Suggested quality improvement area	Selected source guidance recommendations
Key contact	**Communication with people with Parkinson's disease and their carers** NICE NG69 Recommendation 1.1.6 **Non-pharmacological management of motor and non-motor symptoms** NICE NG69 Recommendation 1.7.1
Multidisciplinary team	**Non-pharmacological management of motor and non-motor symptoms** NICE NG69 Recommendations 1.7.2, 1.7.3, 1.7.5, 1.7.6, 1.7.7, 1.7.8, 1.7.10 NICE CKS Parkinson's disease - Confirmed Parkinson's disease/Routine review in primary care NICE CKS Parkinson's disease - Confirmed Parkinson's disease/Motor symptoms and complications NICE CKS Parkinson's disease - Confirmed Parkinson's disease/Non-motor symptoms and complications

Key contact

Communication with people with Parkinson's disease and their carers

NICE NG69 Recommendation 1.1.6

Offer people with Parkinson's disease an accessible point of contact with specialist services. This could be provided by a Parkinson's disease nurse specialist. [2006]

Non-pharmacological management of motor and non-motor symptoms

NICE NG69 Recommendation 1.7.1

People with Parkinson's disease should have regular access to:

- clinical monitoring and medicines adjustment
- a continuing point of contact for support, including home visits when appropriate

- a reliable source of information about clinical and social matters of concern to people with Parkinson’s disease and their family members and their carers (as appropriate),

  which may be provided by a Parkinson’s disease nurse specialist. [2006]

Multidisciplinary support

Non-pharmacological management of motor and non-motor symptoms

NICE NG69 Recommendation 1.7.2

Consider referring people who are in the early stages of Parkinson’s disease to a physiotherapist with experience of Parkinson’s disease for assessment, education and advice, including information about physical activity. [2017]

NICE NG69 Recommendation 1.7.3

Offer Parkinson’s disease-specific physiotherapy for people who are experiencing balance or motor function problems. [2017]

NICE NG69 Recommendation 1.7.5

Consider referring people who are in the early stages of Parkinson’s disease to an occupational therapist with experience of Parkinson’s disease for assessment, education and advice on motor and non-motor symptoms. [2017]

NICE NG69 Recommendation 1.7.6

Offer Parkinson’s disease-specific occupational therapy for people who are having difficulties with activities of daily living. [2017]

NICE NG69 Recommendation 1.7.7

Consider referring people who are in the early stages of Parkinson’s disease to a speech and language therapist with experience of Parkinson’s disease for assessment, education and advice. [2017]

NICE NG69 Recommendation 1.7.8

Offer speech and language therapy for people with Parkinson’s disease who are experiencing problems with communication, swallowing or saliva. This should include:

- strategies to improve the safety and efficiency of swallowing to minimise the risk of aspiration, such as expiratory muscle strength training (EMST)

- strategies to improve speech and communication, such as attention to effort therapies. [2017]

NICE NG69 Recommendation 1.7.10

Consider referring people with Parkinson’s disease to a dietitian for specialist advice. [2017]

NICE CKS Parkinson’s disease - Confirmed Parkinson’s disease/Routine review in primary care

A person with confirmed Parkinson's disease should be under the care of a specialist in movement disorders and a multidisciplinary team including a Parkinson's disease nurse, who can advise on management issues and provide ongoing support.

NICE CKS Parkinson’s disease - Confirmed Parkinson’s disease/Motor symptoms and complications

Most people with Parkinson's disease will be managed by a specialist in movement disorders and/or a multidisciplinary team including a Parkinson's disease nurse, physiotherapist, and occupational therapist, who can advise on the management of motor symptoms and complications.

NICE CKS Parkinson’s disease - Confirmed Parkinson’s disease/Non-motor symptoms and complications

Most people with Parkinson's disease will be managed by a specialist in movement disorders and/or a multidisciplinary team including a Parkinson's disease nurse, who can advise on the management of non-motor symptoms and complications.

4.2.3 Current UK practice

Key contact

The 2015 UK Parkinson’s audit[3] reported that 94.1% of people with Parkinson’s could access a Parkinson’s nurse, although 7/129 elderly care and 5/110 neurology services had no access to a Parkinson’s nurse. 74.6% of people with Parkinson’s responding to the PREM survey agreed that they could contact their Parkinson’s nurse for advice between review appointments.

Multidisciplinary team

The 2015 UK Parkinson’s audit indicated that only 13% of services were able to offer a fully integrated clinic model with access a consultant, a nurse specialist and other key professionals such as a physiotherapist. Only 50% of patients were referred to a

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[3] 2015 UK Parkinson’s Audit UK Parkinson’s Excellence Network (2016)

physiotherapist within two years of diagnosis. Only 14.1% of referrals to speech and language therapy were made at diagnosis. However, the majority of people with Parkinson’s disease in the audit accessed specific multidisciplinary support during the previous year:

- Physiotherapist (>80%)
- Occupational therapist (>70%)
- Speech and language therapist (>70%)
- Social work (>80%)

4.3 Care management

4.3.1 Summary of suggestions

Care plan

It was suggested that people with Parkinson's disease should have an up to date, jointly agreed personal care plan covering their health and social care needs. This can empower the person with Parkinson's disease and their carers to take control of their care and will support a shared understanding across services of how the person wants to manage their condition.

Reviews

Stakeholders identified the importance of ensuring that people with Parkinson's disease have regular reviews to monitor their condition and identify any additional support required. A stakeholder suggested that the review should be carried out by a specialist such as a neurologist, care of the elderly physician or Parkinson's disease nurse.

4.3.2 Selected recommendations from development source

Table 7 below highlights recommendations that have been provisionally selected from the development sources that may support potential statement development. These are presented in full after table 7 to help inform the committee's discussion.

Table 7 Specific areas for quality improvement

Suggested quality improvement area	**Selected source guidance recommendations**
Care plan	**Communication with people with Parkinson's disease and their carers** NICE NG69 Recommendation 1.1.5
Reviews	**Diagnosing Parkinson's disease** NICE NG69 Recommendation 1.2.5 **Pharmacological management of non-motor symptoms** NICE NG69 Recommendation 1.5.3 NICE CKS Parkinson's disease - Confirmed Parkinson's disease/Routine review in primary care

Care plan

Communication with people with Parkinson's disease and their carers

NICE NG69 Recommendation 1.1.5

People with Parkinson's disease should have a comprehensive care plan agreed between the person, their family members and carers (as appropriate), and specialist and secondary healthcare providers. [2006]

Reviews

Diagnosing Parkinson's disease

NICE NG69 Recommendation 1.2.5

Review the diagnosis of Parkinson's disease regularly, and reconsider it if atypical clinical features develop. (People diagnosed with Parkinson's disease should be seen at regular intervals of 6–12 months to review their diagnosis.) [2006]

Pharmacological management of non-motor symptoms

NICE NG69 Recommendation 1.5.3

At least every 12 months, a healthcare professional with specialist expertise in Parkinson's disease should review people with Parkinson's disease who are taking modafinil. [2017]

NICE CKS Parkinson's disease - Confirmed Parkinson's disease/Routine review in primary care

Ensure the person has a comprehensive review of all aspects of their care at least every 6–12 months.

4.3.3 Current UK practice

Care Plan

A House of Commons Committee report on services for people with neurological conditions[4] concluded that people with neurological conditions may not be offered a personalised care plan based on the following evidence:

- the 2015 GP Patient Survey suggested that only 12% of people with a neurological condition have a written care plan

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[4] Services to people with neurological conditions: progress review House of Commons Committee of Public Accounts Twenty-fourth Report of Session 2015–16

- a 2015 Neurological Alliance survey found that only 20% of people with a neurological condition had been offered a care plan.

Reviews

The 2015 UK Parkinson's audit[5] found that 98.6% of people with Parkinson's disease attending elderly care and neurology services had received a specialist review in the preceding 12 months. The majority (73.3%) of respondents to the PREM survey felt that the number of reviews carried out by their consultant met their needs, while 67.5% felt this was true for their Parkinson's nurse. Some respondents felt that they were reviewed less than was needed by either their consultant (13.2%) or Parkinson's nurse (10.2%).

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[5] 2015 UK Parkinson's Audit UK Parkinson's Excellence Network (2016)

4.4 Identifying symptoms and complications

4.4.1 Summary of suggestions

Assessment

Some stakeholders were concerned that even though standardised tools, such as the Parkinson's UK non-motor symptom questionnaire, are available, there is currently an inconsistent approach to assessing symptoms and complications. Another stakeholder suggested that although there are many varied assessment tests available, none cover all the areas required (motor, non-motor and mental health) and greater standardisation is needed. It was highlighted that an inconsistent approach may be associated with unnecessary emergency hospital admissions for people with Parkinson's disease. Specific areas for improvement were identified as:

- documentation of the side effects relating to dopamine agonists
- blood pressure
- enquiries about pain
- bone health/risk of falling
- assessment of cognition (identifying dementia)
- detecting urine and chest infections.

Impulse control disorders

Stakeholders suggested that there is a need to increase awareness that impulse control disorders are a potential complication of treatment. Providing information to people with Parkinson's disease and their carers about the risk of impulse control disorders was highlighted as a priority. It needs to be clear who to contact if they have concerns. It was suggested that impulse control disorders should be discussed at reviews (particularly when modifying therapy) and the discussion should be recorded.

4.4.2 Selected recommendations from development source

Table 8 below highlights recommendations that have been provisionally selected from the development sources that may support potential statement development. These are presented in full after table 8 to help inform the committee's discussion.

Table 8 Specific areas for quality improvement

Suggested quality improvement area	Selected source guidance recommendations
Assessment	**Pharmacological management of non-motor symptoms** NICE NG69 Recommendations 1.5.11, 1.5.12 and 1.5.25 NICE CKS Parkinson's disease - Confirmed Parkinson's disease/Routine review in primary care NICE CKS Parkinson's disease - Confirmed Parkinson's disease/Motor symptoms and complications NICE CKS Parkinson's disease - Confirmed Parkinson's disease/ Non-motor symptoms and complications
Impulse control disorders	**Pharmacological management of motor symptoms** NICE NG69 Recommendation 1.3.8 **Managing and monitoring impulse control disorders as an adverse effect of dopaminergic therapy** NICE NG69 Recommendations 1.4.3 and 1.4.4

Assessment

Pharmacological management of non-motor symptoms

NICE NG69 Recommendation 1.5.11

For guidance on identifying, treating and managing depression in people with Parkinson's disease, see the NICE guideline on depression in adults with a chronic physical health problem. **[2017]**

NICE NG69 Recommendation 1.5.12

At review appointments and following medicines changes, ask people with Parkinson's disease and their family members and carers (as appropriate) if the person is experiencing hallucinations (particularly visual) or delusions. **[2017]**

NICE NG69 Recommendation 1.5.25

For guidance on assessing and managing dementia, and supporting people living with dementia, see the NICE guideline on dementia[5]. **[2017]**

NICE CKS Parkinson’s disease - Confirmed Parkinson’s disease/Routine review in primary care

Ask about any motor or non-motor complications which may be caused by the disease itself or by anti-parkinsonian medication. Management may require specialist advice or review.

NICE CKS Parkinson’s disease - Confirmed Parkinson’s disease/Motor symptoms and complications

Motor complications (usually related to the use of anti-parkinsonian medication) include:

- Deteriorating function — immobility, slowness, withdrawal from activities, communication difficulties.
- Loss of drug effect — reduced efficacy of anti-parkinsonian medication over time.
- Motor fluctuations.
- End-of-dose fading (the benefit from levodopa wearing off before the next dose is due, usually predictable).
- On-off phenomenon (rapid and unpredictable fluctuations between 'on' and 'off' periods, due to fluctuating responses to levodopa, usually after several years of use).
- Dose failures — failure of anti-parkinsonian medication to provide symptom relief.
- Dyskinesia (involuntary movements).
    - Choreiform (quick fidgety movements).
    - Dystonic (slow, distorted movements and postures).
- Freezing of gait — the inability to start or continue walking, characterized by difficulty in stepping forward (at initiation or during walking), and inability to lift the foot from the floor.
- Falls.
    - Two-thirds of people with Parkinson's disease fall each year, and most people eventually fall, but early onset of falls may indicate an alternative cause of parkinsonism such as progressive supranuclear palsy.
    - Falls are usually multifactorial, involving freezing of gait, postural instability, postural hypotension, drug treatments, cognitive impairment, and environmental factors.

Look for and treat any acute illness (such as infection or constipation) that may exacerbate motor symptoms.

NICE CKS Parkinson’s disease - Confirmed Parkinson’s disease/ Non-motor symptoms and complications

Non-motor complications — these may be symptoms of Parkinson's disease, complications, or adverse effects of anti-parkinsonian medication. Most people are affected by non-motor problems in later Parkinson's disease.

Mental health conditions:

- Depression, anxiety, and apathy.
- Dementia and cognitive impairment.
- Impulse control disorders and psychosis.

Autonomic dysfunction:

- Constipation.
- Postural hypotension.
- Dysphagia and weight loss.
- Excessive salivation and sweating.
- Bladder and sexual problems.

Other complications:

- Nausea and vomiting.
- Pain.
- Sleep disturbance and daytime hypersomnolence.
- Aspiration pneumonia.
- Pressure sores.

Parkinson's UK has a Non-motor symptoms questionnaire that can be completed by the person and/or their family/carers, which may help healthcare professionals assess symptoms.

Impulse control disorders

Pharmacological management of motor symptoms

NICE NG69 Recommendation 1.3.8

When starting treatment for people with Parkinson’s disease, give people and their family members and carers (as appropriate) oral and written information about the following risks, and record that the discussion has taken place:

- Impulse control disorders with all dopaminergic therapy (and the increased risk with dopamine agonists).

Managing and monitoring impulse control disorders as an adverse effect of dopaminergic therapy

NICE NG69 Recommendation 1.4.3

When starting dopamine agonist therapy, give people and their family members and carers (as appropriate) oral and written information about the following, and record that the discussion has taken place:

- The increased risk of developing impulse control disorders when taking dopamine agonist therapy, and that these may be concealed by the person affected.
- The different types of impulse control disorders (for example, compulsive gambling, hypersexuality, binge eating and obsessive shopping).
- Who to contact if impulse control disorders develop.
- The possibility that if problematic impulse control disorders develop, dopamine agonist therapy will be reviewed and may be reduced or stopped. [2017]

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]

4.4.3 Current UK practice

Assessment

The 2015 UK Parkinson's audit[6] found that while standardised assessment tools to assess cognitive function are always/mostly always available in the majority (79.5%) of clinics there was more limited use/ access to:

- Parkinson's non-motor symptom questionnaire (not routinely available in 18.8% clinics)
- Standardised assessment tools to evaluate mood (not routinely available in 32.2% clinics)
- Activities of Daily Living tools or checklists (not routinely available in 35.6% clinics)

The UK audit also recorded whether people with Parkinson's disease were assessed for non-motor symptoms, and motor symptoms and activities of daily living during the previous year. Neurology clinics scored poorly compared with elderly care clinics in documenting blood pressure (54.6% and 81.5%, respectively) and screening for malnutrition (54.0% and 85.1%, respectively). However, assessments of pain and saliva problems were poorly documented across both services. Where there were

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[6] 2015 UK Parkinson's Audit UK Parkinson's Excellence Network (2016)

concerns about falls and/or balance, fracture risk or osteoporosis was considered in only 36.4% of people with Parkinson’s (40.6% in Elderly Care; 31.4% in Neurology).

Figure 1: Assessment of non-motor symptoms (2015 UK Parkinson’s Audit)

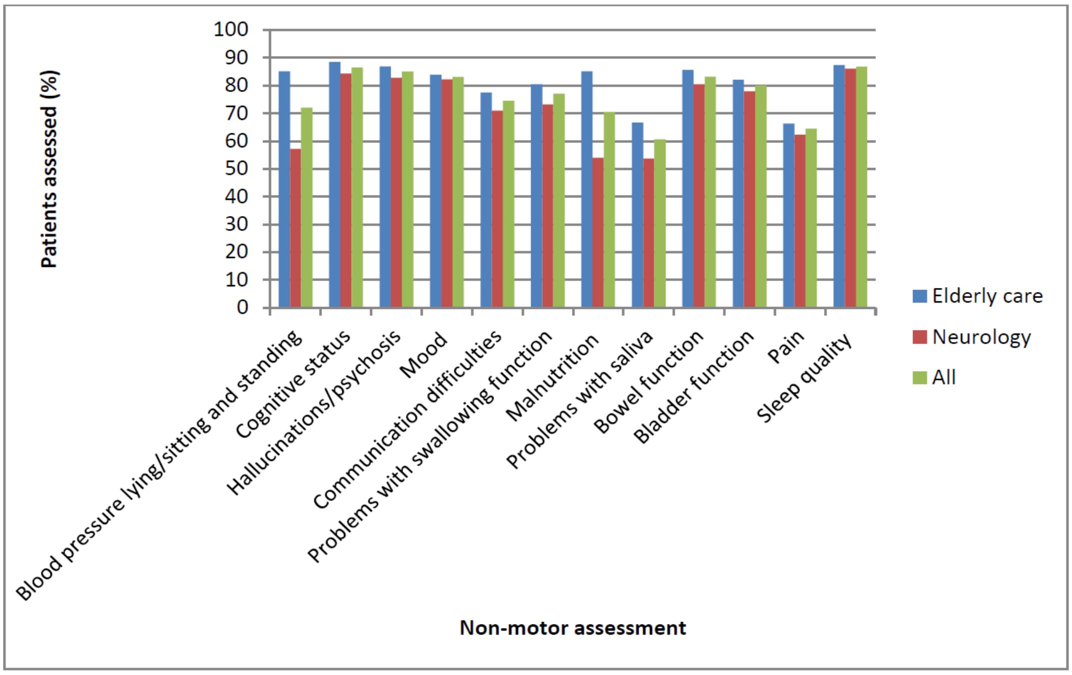
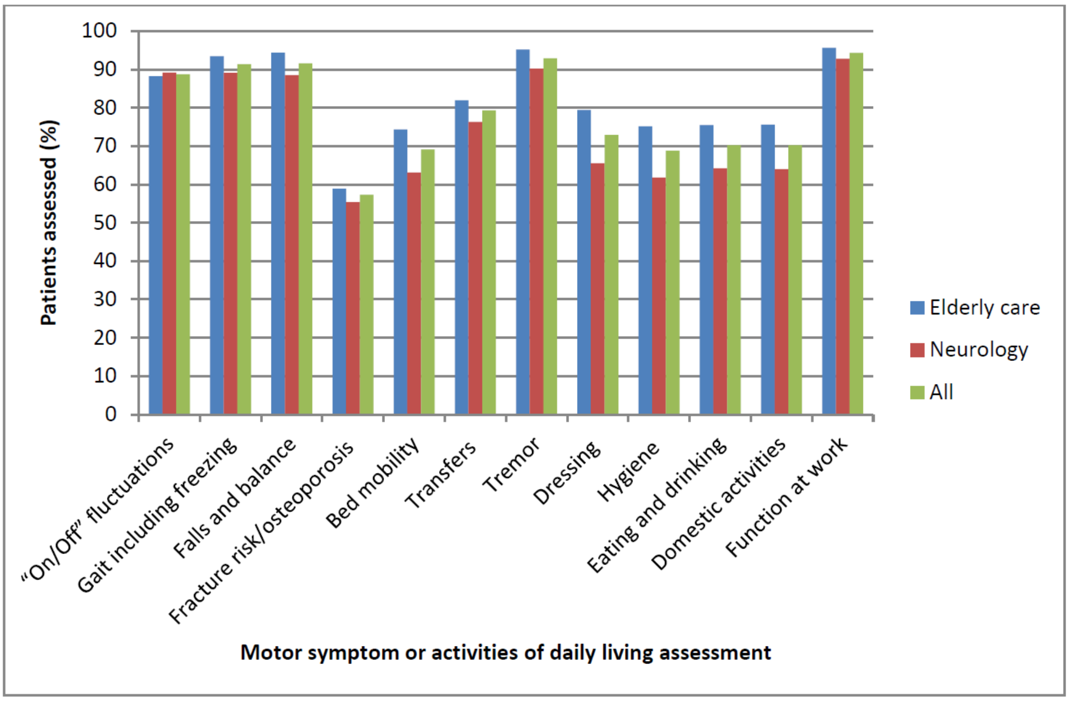


Figure 2: Assessment of motor symptoms or activities of daily living (2015 UK Parkinson’s audit)



A study of the reporting of non-motor symptoms and cognitive impairment in Parkinson's disease clinic attenders at the John Radcliffe Hospital in 2012[7] concluded that physicians under-reported urinary incontinence, constipation and depression and over-emphasised psychotic symptoms within clinic letters. Cognitive impairment was under-reported by both patients and physicians.

Impulse control disorders

The 2015 UK Parkinson's audit[8] indicated that although there has been an improvement in monitoring for compulsive behaviours since 2012, there was no evidence that 22.5% of people with Parkinson's taking dopamine agonists seen in elderly care and neurology services had received advice about potential compulsive behaviours related to their medication.

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[7] Reporting of non-motor symptoms and cognitive impairment in Parkinson's disease clinic attenders Nagaratnam et al European Geriatric Medicine (2014) S83-S158

[8] 2015 UK Parkinson's Audit UK Parkinson's Excellence Network (2016)

4.5 Treatment for symptoms

4.5.1 Summary of suggestions

Pharmacological management

It was suggested that there is a need for improved pharmacological management for:

- drooling of saliva – consider pharmacological management including referral for botulinum toxin treatment
- Parkinson's dementia – offer a cholinesterase inhibitor for mild to moderate dementia
- psychotic symptoms – access to clozapine treatment.

Deep brain stimulation

Stakeholders suggested that there is more limited access to deep brain stimulation in the UK than in other countries. Currently very few services offer this treatment which can be beneficial to people who have responded poorly to drugs, who have severe side-effects from medication or who have severe fluctuations in response to drugs.

4.5.2 Selected recommendations from development source

Table 9 below highlights recommendations that have been provisionally selected from the development sources that may support potential statement development. These are presented in full after table 9 to help inform the committee's discussion.

Table 9 Specific areas for quality improvement

Suggested quality improvement area	Selected source guidance recommendations
Pharmacological management	**Pharmacological management of non-motor symptoms** NICE NG69 Recommendations 1.5.17, 1.5.22. 1.5.26 and 1.5.28
Deep brain stimulation	**Deep brain stimulation and levodopa–carbidopa intestinal gel** NICE NG69 Recommendations 1.8.2 and 1.8.3

Pharmacological management

Pharmacological management of non-motor symptoms

NICE NG69 Recommendation 1.5.17

If standard treatment is not effective, offer clozapine to treat hallucinations and delusions in people with Parkinson's disease. Be aware that registration with a patient monitoring service is needed. [2017]

NICE NG69 Recommendation 1.5.22

Offer a cholinesterase inhibitor for people with mild or moderate Parkinson's disease dementia. [2017]

NICE NG69 Recommendation 1.5.26

Only consider pharmacological management for drooling of saliva in people with Parkinson's disease if non-pharmacological management (for example, speech and language therapy; see recommendation 1.7.8) is not available or has not been effective. [2017]

NICE NG69 Recommendation 1.5.28

If treatment for drooling of saliva with glycopyrronium bromide is not effective, not tolerated or contraindicated (for example, in people with cognitive impairment, hallucinations or delusions, or a history of adverse effects following anticholinergic treatment), consider referral to a specialist service for botulinum toxin A. [2017]

Deep brain stimulation

Deep brain stimulation and levodopa–carbidopa intestinal gel

NICE NG69 Recommendation 1.8.2

Do not offer deep brain stimulation to people with Parkinson's disease whose symptoms are adequately controlled by best medical therapy. [2017]

NICE NG69 Recommendation 1.8.3

Consider deep brain stimulation for people with advanced Parkinson's disease whose symptoms are not adequately controlled by best medical therapy. [2017]

4.5.3 Current UK practice

Pharmacological management

No current practice identified.

Deep brain stimulation

Stakeholders suggested (publication not identified) that the Society of British Neurological Surgeons audit has found that far fewer deep brain stimulation (DBS) procedures are being carried out per capita in the UK compared to similar European countries (e.g. Germany and France). Just over 400 new DBS procedures were performed per year across the UK in the last 3 years. This compares to around 1,000 in Germany.

4.6 Medicines management in hospital

4.6.1 Summary of suggestions

Stakeholders suggested that there is a need to improve medication management for people with Parkinson’s disease who are admitted to hospital. If people are not able to take their medication at the right time it can have an impact on their mobility and other symptoms, increasing their care needs and length of stay in hospital. When people are admitted to hospital it is important that their Parkinson’s is identified and that there is liaison with their specialist contact regarding medication. It was suggested that any missed or late administration of medication for people with Parkinson’s disease should be identified as a serious incident. Those who are able to self-administer their medication should be able to do so.

4.6.2 Selected recommendations from development source

Table 10 below highlights recommendations that have been provisionally selected from the development sources that may support potential statement development. These are presented in full after table 10 to help inform the committee’s discussion.

Table 10 Specific areas for quality improvement

Suggested quality improvement area	Selected source guidance recommendations
Medicines management in hospital	**Pharmacological management of motor symptoms** NICE NG69 Recommendations 1.3.2 and 1.3.4

Pharmacological management of motor symptoms

<u>NICE NG69 Recommendation 1.3.2</u>

Antiparkinsonian medicines should not be withdrawn abruptly or allowed to fail suddenly due to poor absorption (for example, gastroenteritis, abdominal surgery) to avoid the potential for acute akinesia or neuroleptic malignant syndrome. [2006]

<u>NICE NG69 Recommendation 1.3.4</u>

In view of the risks of sudden changes in antiparkinsonian medicines, people with Parkinson’s disease who are admitted to hospital or care homes should have their medicines:

- given at the appropriate times, which in some cases may mean allowing self-medication

- adjusted by, or adjusted only after discussion with, a specialist in the management of Parkinson’s disease. [2006]

4.6.3 Current UK practice

The 2015 UK Parkinson’s audit PREM survey[9] indicated that only 50% of those admitted to hospital in the last year always received their medication on time while in hospital. Of those who did not always receive their medication on time, 38.5% said this had a negative or significantly negative effect, 37.3% were unsure if it had an effect, 18.4% said it had no effect and 5.9% said it had a positive effect. 69.6% of respondents wanted to take their own medication but only 53.7% were able to.

The response to a House of Commons question raised on 7 January 2015[10] indicated that between January 2013 and December 2014 3,320 patient safety incidents were reported via the National Reporting and Learning System involving medicines and people with Parkinson’s in hospitals across England and Wales, equating to 32 incidents per week, with six causing harm.

A small survey of clinicians from 65 hospitals in the UK in 2014[11] found that 61% (56/92) of respondents were not confident that Parkinson’s medication was given on time in their hospital.

A number of small local audits and surveys carried out in 2013 identified issues with the management of medication for people with Parkinson’s disease admitted to hospital:

- An audit of inpatient management of Parkinson’s disease medication in non-elective admissions to West Suffolk hospital[12] found that 4.5% of total doses of Parkinson’s disease medication for 40 patients were missed during their inpatient stay. Only 40% of case notes/drug charts recorded the exact time that medication should be given to patients. Where an exact time was specified, 15.3% of dispensed medications were delayed by 0.5 to 2 hours.

- A survey of Parkinson’s disease patients and staff at the Norwich and Norfolk University hospital[13] found that less than half reported they always received their medication on time during their stay and only a third were assessed for their suitability to self-administer their medication. Hospital records showed

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[9] 2015 UK Parkinson’s Audit UK Parkinson’s Excellence Network (2016)
[10] Response to commons question 219635 Catherine McKinnell MP, 7 January 2015
[11] Hospitalization in Parkinson’s disease: A survey of UK neurologists, geriatricians and Parkinson’s disease nurse specialists Skelly et al Parkinsonism and Related Disorders 21(2015) 277-281
[12] Inpatient management of Parkinson’s disease medication in non-elective admissions – are we delivering medications on time Amiri and Worth Journal of Neurology, Neurosurgery and Psychiatry (2014) 85(10), pp, A11
[13] Evaluation of patients with Parkinson’s disease medication experience at the Norfolk and Norwich University Hospital (NNUH) Bee et al International Journal of Pharmacy Practice 2014 supplement 2

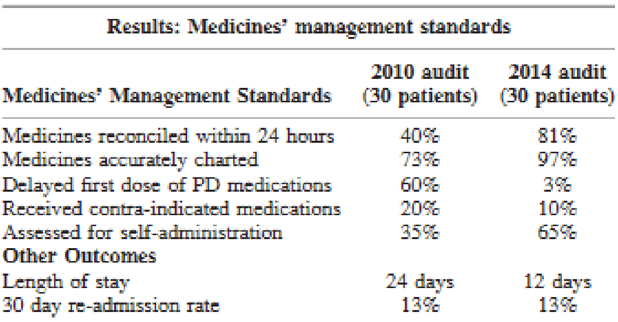
that 2% of medication incidents were related to Parkinson’s disease medicines, the most common being related to the timing of doses.

- An audit of prescribing at Barnet and Chase Farm Hospitals NHS Trust[14] found that 56% of Parkinson’s disease patients had medications incorrectly prescribed at admission; 26% received doses at incorrect times and 26% of patients self-administered their medication. Although 17 patients were ‘nothing by mouth’, only 2 patients received medications by alternative routes.

- An audit at the University Hospital of Coventry and Warwickshire found that 21% of Parkinson’s disease patients had some incorrect prescription (name, formulation, dose, timing) on their clerking notes, and 51% had a drug chart discordant from their usual regime (mainly timing and formulation errors). 47% of the audited patients missed at least one dose of their PD medications during admission, and 8 patients (9.9%) had dopamine-blocking drugs prescribed.

Following an initial audit, a hospital in Bristol made improvements to its in-patient service for people with Parkinson’s disease including: establishing a pathway for people with Parkinson’s disease; a Parkinson’s disease cohort ward with a dedicated interdisciplinary team; a daily Parkinson’s disease outreach ward for patients on other wards and quarterly Parkinson’s awareness courses. A re-audit 1 year[15] on in 2014 found that all aspects of Parkinson’s disease inpatient management had improved and length of stay had reduced.

Figure 3: Medicines management standards (Bristol hospital re-audit 2014)



Results: Medicines' management standards

Medicines' Management Standards	2010 audit (30 patients)	2014 audit (30 patients)
Medicines reconciled within 24 hours	40%	81%
Medicines accurately charted	73%	97%
Delayed first dose of PD medications	60%	3%
Received contra-indicated medications	20%	10%
Assessed for self-administration	35%	65%
Other Outcomes		
Length of stay	24 days	12 days
30 day re-admission rate	13%	13%

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[14] A prospective audit of prescribing in Parkinson’s disease Ejaz et al Journal of Neurology, Neurosurgery and Psychiatry 2014 85: e4

[15] In-patient management of Parkinson’s disease: Service evaluation of a dedicated unit one year on Sritharan et al Movement disorders (2015) 30 S127-S128

4.7 Information and support

4.7.1 Summary of suggestions

Information for the person with Parkinson's disease

Stakeholders suggested that there should be improved information for people with Parkinson's disease about long term therapeutic options and disease management, including new medication and side effects. It was recognised that information is needed at diagnosis but also as the disease progresses. Better information can support self-management and informed decision making. Expert patient programmes can help to improve knowledge about the disease. There was also a suggestion that there could be better use of information technology to support people with Parkinson's disease such as the Parkinson's Umotif app.

Information and support for carers

The important role of carers and families was recognised and it was suggested that there should be improved information and support for them. They need help to understand the condition and the best way to support the person with Parkinson's disease. Currently carer support is often ad hoc and dependent on carer's assessments carried out for social care. It was suggested that carer's should have a review of their own needs at least annually.

4.7.2 Selected recommendations from development source

Table 11 below highlights recommendations that have been provisionally selected from the development sources that may support potential statement development. These are presented in full after table 11 to help inform the committee's discussion.

Table 11 Specific areas for quality improvement

Suggested quality improvement area	Selected source guidance recommendations
Information for the person with Parkinson's disease	**Communication with people with Parkinson's disease and their carers** NICE NG69 Recommendations 1.1.1, 1.1.2 and 1.1.3 **Pharmacological management of motor symptoms** NICE NG69 Recommendations 1.3.1 and 1.3.8
Information and support for carers	**Communication with people with Parkinson's disease and their carers** NICE NG69 Recommendation 1.1.4

Information for the person with Parkinson’s disease

Communication with people with Parkinson’s disease and their carers

NICE NG69 Recommendation 1.1.1

Communication with people with Parkinson’s disease should aim towards empowering them to participate in judgements and choices about their own care. [2006]

NICE NG69 Recommendation 1.1.2

In discussions, aim to achieve a balance between providing honest, realistic information about the condition and promoting a feeling of optimism. [2006]

NICE NG69 Recommendation 1.1.3

Because people with Parkinson’s disease may develop impaired cognitive ability, communication problems and/or depression, provide them with:

- both oral and written communication throughout the course of the disease, which should be individually tailored and reinforced as necessary
- consistent communication from the professionals involved. [2006]

Pharmacological management of motor symptoms

NICE NG69 Recommendation 1.3.1

Before starting treatment for people with Parkinson’s disease, discuss:

- the person’s individual clinical circumstances, for example, their symptoms, comorbidities and risks from polypharmacy
- the person’s individual lifestyle circumstances, preferences, needs and goals
- the potential benefits and harms of the different drug classes (see table 1). **[2017]**

Table 1 Potential benefits and harms of dopamine agonists, levodopa and MAO-B inhibitors

	Levodopa	Dopamine agonists	MAO-B inhibitors
Motor symptoms	More improvement in motor symptoms	Less improvement in motor symptoms	Less improvement in motor symptoms
Activities of daily living	More improvement in activities of daily living	Less improvement in activities of daily living	Less improvement in activities of daily living
Motor complications	More motor complications	Fewer motor complications	Fewer motor complications
Adverse events	Fewer specified adverse events*	More specified adverse events*	Fewer specified adverse events*

Abbreviation: MAO-B, monoamine oxidase B.
* Excessive sleepiness, hallucinations and impulse control disorders (see the summary of product characteristics for full information on individual medicines).

NICE NG69 Recommendation 1.3.8

When starting treatment for people with Parkinson’s disease, give people and their family members and carers (as appropriate) oral and written information about the following risks, and record that the discussion has taken place:

- Impulse control disorders with all dopaminergic therapy (and the increased risk with dopamine agonists). Also see recommendations 1.4.1–1.4.9.
- Excessive sleepiness and sudden onset of sleep with dopamine agonists. Also see recommendations 1.5.1–1.5.3.
- Psychotic symptoms (hallucinations and delusions) with all Parkinson’s disease treatments (and the higher risk with dopamine agonists). Also see recommendations 1.5.12–1.5.21. [2017]

Information and support for carers

NICE NG69 Recommendation 1.1.4

Give family members and carers (as appropriate) information about the condition, their entitlement to a Carer’s Assessment and the support services available. [2006]

4.7.3 Current UK practice

Information for the person with Parkinson's disease

The 2015 UK Parkinson's audit[16] found that written information about Parkinson's and Parkinson's medication was routinely available at 82.4% of outpatient clinics (an increase from 2012). Written information about Parkinson's was not routinely available in 5.9% of clinics. The PREM survey indicated that two-thirds (64.9%) of patients felt they were given enough information at diagnosis.

In relation to information about the potential side effects of new medication, the UK Parkinson's audit indicated that there was documented evidence that 83.3% of people with Parkinson's had been given information about the potential side effects of new medication. However 17.2 % felt they had not been given enough information about new medication.

Information and support for carers

The 2015 UK Parkinson's audit indicated that the majority (over 70%) of people with Parkinson's had their carers entitlement to support considered in the previous year. The PREM survey indicated that only 23.2% of respondents were given information about carer support.

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[16] 2015 UK Parkinson's Audit UK Parkinson's Excellence Network (2016)

4.8 Additional areas

Summary of suggestions

The improvement areas below were suggested as part of the stakeholder engagement exercise. However they were felt to be either unsuitable for development as quality statements, outside the remit of this particular quality standard referral or require further discussion by the committee to establish potential for statement development.

There will be an opportunity for the committee to discuss these areas at the end of the session on 1st June 2017.

Planning for end of life

Stakeholders suggested that people with Parkinson's disease and their families should be supported to plan for the end of life. Given the risk of developing dementia it is important that this is done at an appropriate time. This should include being given information about advance care planning, discussing preferences and ensuring they are recorded and may include a referral to palliative care. It was suggested that advance care planning can reduce emergency hospital admissions and prevent costly and unwanted interventions. These issues are included in the end of life care for adult's quality standard (QS13) which covers adults who are likely to die within 12 months and will be updated in 2018. While information and support for end of life planning is included within the development source (NG69) there are no clear timescales for when this should be addressed for people with Parkinson's disease.

Employment support

A stakeholder suggested that people with early onset Parkinson's disease should be supported to remain in employment as this can improve their quality of life and protect against mood disorders. This issue is partly addressed in a separate quality standard on healthy workplaces: improving employee mental and physical health and wellbeing (QS147). This area is not included within the development source (NG69).

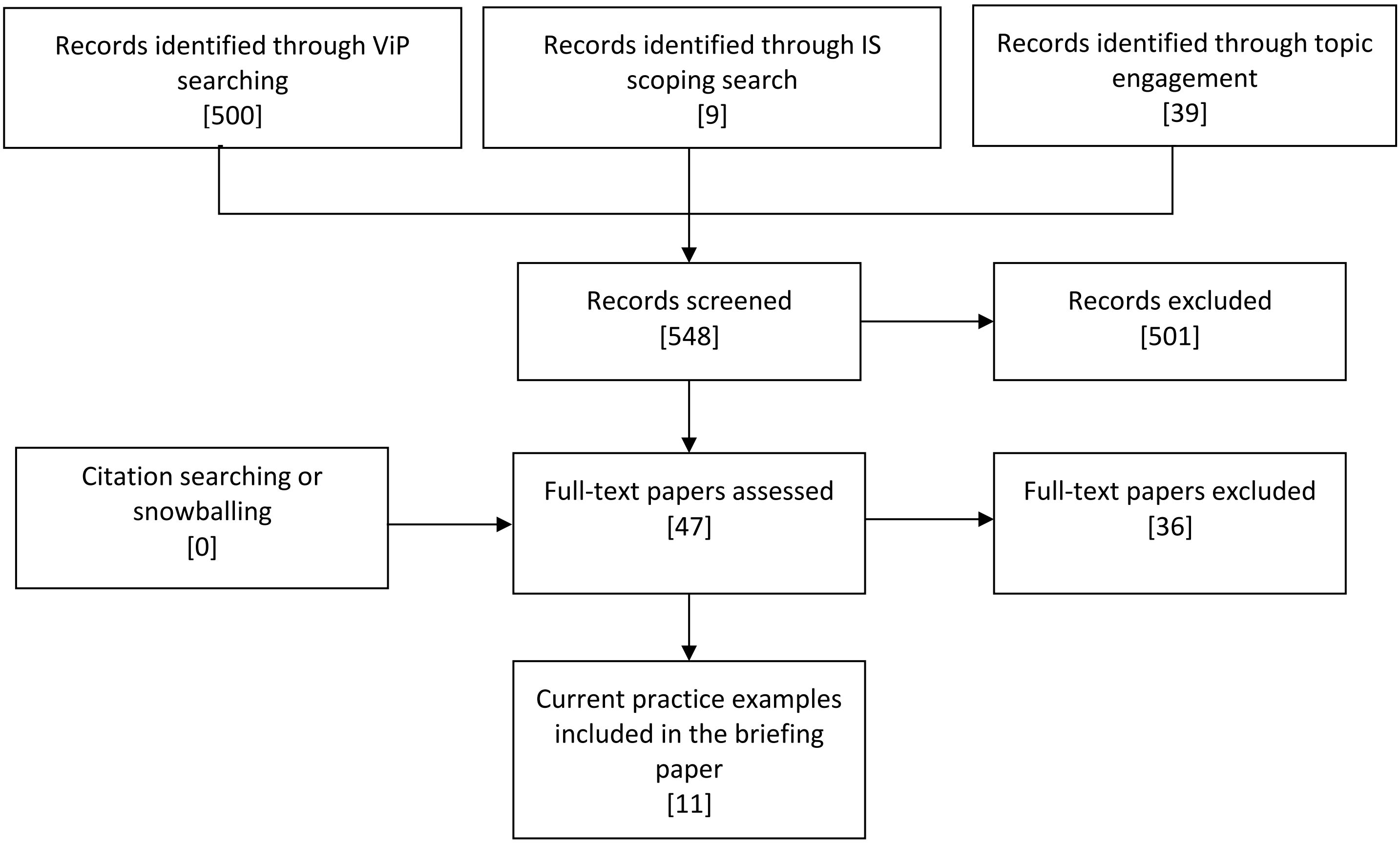
Data collection

There was a suggestion that there should be improved collection of data to monitor the performance of services for people with Parkinson's disease. The quality standard will address this by identifying measures for quality improvement.

NHS continuing healthcare

It was suggested that the NHS continuing healthcare system needs to improve to ensure that it is efficiently meeting the needs of people with neurological conditions. This is beyond the scope of this quality standard.

Appendix 1: Review flowchart



Appendix 2: Suggestions from stakeholder engagement exercise – registered stakeholders

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
Referral to a specialist					
1	Abertawe Bromorgannwg University Health Board	ALL patients should have an assessment by PD specialist	NICE guideline and PD UK recommended and one of the National Audit tool Markers	National PD audit by PD UK has made this as standard.	Parkinson's NICE Guideline key priorities for implementation Appendix A
2	Britannia Pharmaceuticals	Key area for quality improvement 1 Equality of Access to a high quality Parkinsons Specialist Service.	There is good evidence that indicates better outcomes for patients who are treated in specialist clinics. Not all hospitals run specific Parkinsons clinics. Patients are often managed via general neurology clinics with disjointed access to services and inequality of access to advanced therapies. The NSF Long Term Conditions 5 Next Steps: 3. b. building capacity in staffing, facilities, equipment and range of service providers to ensure access to appropriate services for people with longterm neurological conditions; c.developing a more integrated approach to delivering services	House of Commons Committee of Public Accounts – Services to people with neurological conditions: progress review Recommendation: to make best use of the available neurologists and reduce the variations in access, including through re-designing services and making more use of other clinical staff, particularly specialist nurses. Parkinsons UK Nurse report demonstrates improved service with affordable care. Parkinson's 2015 – Your life, your services survey results highlight poor access to an expert, integrated multidisciplinary team.	Please see the Parkinsons UK audit which highlights the need for a specialist parkinsons service with fully integrated MDT. Only 13% of those who took part in the audit offer a fully integrated service. https://www.parkinsons.org.uk/sites/default/files/audit2015_summaryreport.pdf Please see House of Commons Committee of Public Accounts – Services to people with neurological conditions: progress review : 'There is scope to give patients better access to neurologists by using existing resources more effectively.' https://www.publications.parliament.uk/pa/cm201516/cmselect/cmpubacc/502/502.pdf

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
			with an increase in working with a range of agencies and using joint budgets. NICE guidance 5.2.4 Recommendations 14. If Parkinson's disease is suspected, refer people quickly and untreated to a specialist with expertise in the differential diagnosis of this condition. [2006, amended 2017]		Please see the Parkinsons UK Nurses Report. https://www.parkinsons.org.uk/sites/default/files/publications/download/english/englandnursereport.pdf Please see Your life, your services survey results https://www.parkinsons.org.uk/sites/default/files/your_services_2015_results.pdf
3	RCGP	Key area for quality improvement 2	People who are thought to have Parkinson's Disease should be seen by a specialist within 6 weeks of referral.	NICE Guidelines	Locally the delay for an initial specialist consultation is significantly longer than six weeks. During these months, patients suffer significant levels of anxiety, and are often symptomatic from the disease. Reducing the delay from referral to diagnosis would improve the quality of care by enabling them to start treatment much more quickly.
4	SCM6	Key area for quality improvement 2	If Parkinson's disease is suspected, refer people quickly and untreated to a specialist with expertise in the differential diagnosis of this condition.	There is continuing concern that the condition may not be correctly identified by non specialists. The diagnosis is really the province of a neurologist, but unfortunately neurology services can	

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
				be stretched. It is important to put out the message that people with PD should be seen by a neurologist.	
5	SCM7	Key area for quality improvement 2	If Parkinson's disease is suspected, refer people quickly and untreated to a specialist with expertise in the differential diagnosis of this condition. (People with suspected mild Parkinson's disease should be seen within 6 weeks, but new referrals in later disease with more complex problems require an appointment within 2 weeks.) [2006]	Very often late referral for definitive diagnosis is delayed and therefore interventions are also delayed	Recommendation1.2.2
Specialist support – Key contact					
6	RCGP	Key area for quality improvement 1	People with Parkinson's Disease should have direct access to a Parkinson's Disease Nurse Specialist	NICE Guidelines	According to NICE guidelines patients should have an accessible point of contact to specialist care, but locally the availability of Parkinson's Disease Nurses is variable. The availability of Nurse Specialists to all patients would significantly improve the quality of their care.
7	Royal College of Occupational Therapists	**Key area for quality improvement 3**	There is good evidence for ongoing and regular review from PD nurses.	Condition specific Specialist nurses and AHP save costs elsewhere within the health care system; increase the	Please refer to guidance developed by the MS Trust following a national programme

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
		People with Parkinson's with complex needs should be provided with case management from a Specialist Nurse or Allied Health Professional with expertise in Parkinson's so that their cognitive, physical and emotional needs are proactivity reviewed and managed.	This is recommended in the NICE guideline, but varies in practice.	capacity of other staff (particularly neurologists); improve outcomes; and improve the quality of life for people living with long term neurological conditions.	of work to demonstrate the impact of specialist teams in relation to long term neurological conditions. https://www.MSTrust/support.mstrust.org.uk
8	SCM1	Key area for quality improvement 4 **Access to Parkinson's Nurse Specialist**	The Parkinson's Nurse Specialist (PDNS), with their specialist knowledge and expertise in Parkinson's, is able to help the person with Parkinson's manage their condition (including medication management)n effectively, thus improving quality of life. They are also able to provide some consultations with the patient which might otherwise need to be with the consultant (which may be less readily available, and more costly)	Not all areas of the country have a PDNS	Parkinson's UK Audit of NICE Guidelines for Parkinson's 2015
9	SCM3	There were no changes to the Parkinson's Nurse Specialist Role within the recent NICE Scope.	Integrated care, patient self-management & cost savings are major drivers within the NHS Plan / STP plans.	Nationally there is vast duplication within PDNS / Medical review times. The 6-12 monthly follow up review time within NICE recommendations is medically orientated and it is known	The Parkinson's UK Clinical Excellence Network has a vast amount of information looking at ways in which to enhance patient care, which takes self

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
				that patients require review out of these specified times.	management, integrated care and cost into account. https://www.parkinsons.org.uk/professionals/working-together-change A clinical standard incorporating the need to be reviewed by the most appropriate HCP (or voluntary sector role) incorporating the PDNS role would be valuable as a clinical standard. Referral back to the consultant when required would be a better use of consultant time and would be more cost effective. This would also support the recent changes to the other therapy parts updated within the NICE scope
10	SCM6	Key area for quality improvement 1	Offer people with Parkinson's disease an accessible point of contact with specialist services. This could be provided by a Parkinson's disease nurse specialist.	This was a strong theme from throughout the guideline development that people with PD felt that they had difficulty accessing advice about their condition.	See 2015 PD society audit: https://www.parkinsons.org.uk/professionals/uk-parkinsons-audit/audit-2015
Specialist support – Multidisciplinary team					
11	Abertawe Bromorgannwg	Access to Multi Disciplinary team	Parkinson patients at any stage of their disease should be able to access Physiotherapist / Occupational Therapist / Speech	This is NICE standard and PD UK accepted as quality marker	Parkinson's NICE Guideline key priorities for implementation Appendix A

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
	University Health Board	throughout the course of disease	therapist / PD Nurse and Doctor without any barriers		
12	Abertawe Bromorgannwg University Health Board	All patients should have access to falls service locally	Falls are very common in mid to late Parkinson's disease and can be have devastating effect on people with PD.	Local falls prevention service looking at multufactorial causes, osteoporosis and gait / balance / postural balance are very important to prevent fractures and associated morbidity.	Ref: Gait and step training to reduce falls in Parkinson's disease; Protas, Elizabeth J. | Mitchell, Katy | Williams, Amanda | Qureshy, Huma | Caroline, Kavitha | Lai, Eugene C. Neurorehabilitation, vol. 20, no. 3, pp. 183-190, 2005
13	Abertawe Bromorgannwg University Health Board	Patients with Parkinson's disease should have access to Neuropsychology where needed	To improve their anxiety, life coping mechanism and depression without resorting to drug therapy and improve their self management skills.	Neuropsychiatry services in NHS are very limited with access restricted to certain speciality only.	Ref: Aarsland D, Karlsen K. Neurospychiatric aspects of Parkinson's disease. Curr Psychiatry Rep 1999;1:61-8.
14	AGILE (Subgroup of Chartered Society of Physiotherapy)	Exercise for people with Parkinson's Disease.	People with Parkinson's Disease experience immobility, postural instability, frailty, sarcopenia and falls. Exercise is evidence based in managing all of these presentations and therefore exercise should be a key feature of management of the condition from an early stage.	The Cochrane review of Physiotherapy for people with Parkinson's Disease highlights the high degree of variability in practice of Physiotherapists when treating patients with Parkinson's Disease using exercise as a modality.	Suggested wording for a possible quality standard :- "People with Parkinson's should be referred for exercise appropriate to the stage of the condition and their age/ fitness utilising guidance from the Exercise Framework for Parkinson's "(due for publication due for release on Friday 21st April 2017).

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
					This publication is part of an initiative of Parkinson's UK (in part through the Excellence network) to launch an Exercise Framework for Parkinson's. It is a one size fits all model that it is hoped can be used by anyone with an interest in knowing more about exercise and Parkinson's - this is whether a person is diagnosed with the condition, whether they are family or friends looking to support them, whether they are qualified exercise professionals or health professionals.The aim of the Exercise Framework is to implement a paradigm shift from the current negative view of instigating exercise mid-way through the condition when falls and balance loom, to an investment of the mind-set and exercise-focussed lifestyle from the point of diagnosis to keep people as fit and healthy as possible. It is pre-emptive behaviour and not reactive and based on increasing evidence about the previously unrealised physical and cognitive

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
					impairments people experience, even early into diagnosis, as well as the evidence of benefits of exercise at all stages of the condition Cochrane reviews on Falls Prevention, Falls Prevention in Parkinson's Disease and Physiotherapy in Parkinson's disease support the premise of using exercise to keep patients with PD more mobile and safer.
15	Parkinson's Academy	Key area for quality improvement 1	Psychological care following diagnosis	There is very little structured national support or directives for psychological support for people with Parkinson's. Whilst Parkinson's nurses can provide some support there are insufficient clinical psychologists and key contributions that can be made by clinical psychologists and neuropsychologists include: ● Assessment of mood and adjustment issues; ● Neuropsychological assessment; ● Psychotherapeutic intervention for depression, anxiety and for the management of psychosis;	In the Parkinson's UK audit of Parkinson's services 2015 only 13% of those who participated had access to the full multidisciplinary team. Clinical psychology is lagging behind as mainly physiotherapy, occupational therapy and speech and language therapy were noted in this audit www.parkinsons.org.uk Source: UK Parkinson's Audit summary report 2015 https://www.parkinsons.org.uk/professionals/resources/psychological-services-people-parkinsons

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
				● Specific interventions to promote psychological adjustment and cognitive rehabilitation; ● Promotion of long-term psychological adjustment; ● Family interventions; ● Dissemination of psychological skills/understanding of Parkinson's issues;	
16	Parkinson's UK; Clinical Reference Group for Neurosciences (including Association of British Neurologists Advisory Group in Movement Disorders)	Enable everyone diagnosed with Parkinson's to have access to a multidisciplinary team	As Parkinson's is a complex, fluctuating condition that can affect every aspect of daily life, effective access to an expert multidisciplinary team is crucial to help people manage symptoms and maintain independence. This includes access to a consultant neurologist or geriatrician with a special interest in Parkinson's, a Parkinson's nurse specialist, Speech and Language Therapist, Occupational Therapist, Physiotherapist, mental health professional, dietitian and pharmacist, working in an integrated way across acute and community services.	The 2015 Parkinson's Clinical audit found that 13% of those that took part offered a fully integrated service.	Please see the Parkinson's Clinical 2015 audit which highlights limitations in access to a multidisciplinary team to successfully manage their condition. https://www.parkinsons.org.uk/sites/default/files/audit2015_referencereport.pdf At any given time up to 40% of people with Parkinson's will have depression[1] and up to 40% of people with Parkinson's will experience anxiety.[1] [1] **Aarsland, D. et al. Depression in Parkinson's disease – epidemiology, mechanisms and**

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			All members of the team should have specific knowledge and skills in Parkinson's. Timely access to expert therapists is important in addressing some of the leading causes of costly, unplanned hospital admissions such as infections and falls. For example, speech and language therapists have a key role to play in preventing aspiration pneumonia, which can result from swallowing difficulties associated with Parkinson's, whilst physiotherapists can play an important part in managing problems with gait and balance that can result in falls and fractures. This QI supports recommendations 60-69 in the draft Parkinson's NICE guideline.		**management. Nat. Rev. Neurol. 8, 35–47, 2012.** [1] **Broen, M. P. G., Narayen, N. E., Kuijf, M. L., et al. Prevalence of anxiety in Parkinson's disease: A systematic review and meta-analysis. Mov. Disord., 31: 1125–1133. 2016.** Evidence demonstrates that progressive resistance strength training and movement strategy training (both combined with fall prevention education) are most effective in reducing falls, resulting in an 85% and 61% reduction in falls respectively. **Morris ME, Menz HB, McGinley JL, et al. A Randomized Controlled Trial to Reduce Falls in People With Parkinson's Disease. Neurorehabilitation & Neural Repair 2015;29(8):777-85.**
17	Royal College of Nursing	Key area for quality improvement 1 **Access to the Speech and Language therapy**	There is good evidence that appropriate and effective speech and language therapy provision can have significant improvements in the quality of life	National data from Parkinson's UK national audit, however, shows a lack of access to this therapy. In the PUK	UK Parkinson's Excellence Network (2016) 2015 UK Parkinson's Audit

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
			and health status of people with Parkinson's Disease (PD). NICE Parkinson's Disease guideline recommends that the Speech and Language therapy should be available for people with PD.	audit only 13% PD patients had a fully integrated service.	
18	Royal College of Nursing	Key area for quality improvement 5 **Communication needs at diagnosis**	There is good evidence that appropriate and effective assessment of the communication needs of people with Parkinson's Disease during diagnosis is important and can have significant improvements in the quality of life and health status of people with Parkinson's Disease (PD). NICE Parkinson's Disease guideline recommends that people with Parkinson's Disease should be assessed for their communication needs at diagnosis.	The PUK audit showed that only 65% of respondents felt they received enough information on diagnosis. PD is a progressive disease which affects people's communication ability as it progresses and people's needs can vary. It is, therefore, essential that more is done to ensure that people with Parkinson's disease have their communication needs assessed at the diagnosis stage to ensure that the care they receive with this respect is person centred and effective.	UK Parkinson's Excellence Network (2016) 2015 UK Parkinson's Audit
19	Royal College of Nursing	Key area for quality improvement 2 **Access to physiotherapy**	There is good evidence that appropriate and effective physiotherapy can have significant improvements in the quality of life and health status of	National data from Parkinson's UK national audit, however, shows a lack of access to this therapy. In the PUK audit only 13% PD patients had a fully integrated service.	UK Parkinson's Excellence Network (2016) 2015 UK Parkinson's Audit

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			people with Parkinson's Disease (PD). NICE Parkinson's Disease guideline recommends that people with Parkinson's Disease should have access to physiotherapy.		
20	Royal College of Nursing	Key area for quality improvement 3 **Access to Occupational Therapy (OT)**	There is good evidence that appropriate and effective access to occupational therapy (OT) can have significant improvements in the quality of life and health status of people with Parkinson's Disease (PD). NICE Parkinson's Disease guideline recommends that OT should be available for people with PD.	National data from Parkinson's UK national audit, however, shows a lack of access to this therapy. In the PUK audit only 13% of PD patients had a fully integrated service.	UK Parkinson's Excellence Network (2016) 2015 UK Parkinson's Audit
21	Royal College of Occupational Therapists	**Key area for quality improvement 1** Early and ongoing access to an MDT (medic, PD CNS, Neuro PT, Neuro OT, SLT, dietician) with experience of treating people with	There is good evidence that MDT input in long term neurological conditions can improve quality of life. MDT care is recommended in the PD NICE guideline, but is not often available in practice.	MDT care remains variable for people with Parkinson's. Proactive and timely care allows people to stay well for longer, reducing overall burden on health and social care.	Please see the summary of the 2015 Parkinson's UK Audit which highlighted only 13% of respondents offered an integrated service https://www.parkinsons.org.uk/professionals/uk-parkinsons-audit/audit-2015

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		Parkinson's with the aim of keeping them as active and independent as possible, through proactive education and symptom management. (Yearly review of: medication management, function in mobility, ADL; social care needs; carer's assessment; mood, thinking skills and bladder and bowel management).			
22	Royal College of Occupational Therapists	**Key area for quality improvement 2** Access to occupational therapy in a timely fashion, for assessment and provision of equipment and adaptations, wheelchairs, and assistive technology as needed to support independence and function.	There is evidence that equipment provision and adaptations supports people to maintain independence and improve quality of life, but this does not always happen in a timely manner.	Individual access to occupational therapy varies across and between services.	Please see the summary of the 2015 Parkinson's UK Audit which highlighted that only 24% of people with Parkinson's felt able to contact an occupational therapist in between scheduled reviews https://www.parkinsons.org.uk/sites/default/files/audit2015_patientandcarerreport.pdf Please see the recommendations in the best practice guideline Occupational Therapy for people with Parkinson's

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					https://www.cot.co.uk/publication/cot-publications/occupational-therapy-people-parkinsons-disease
23	Royal College of Psychiatrists	**Key area for quality improvement 2**	Management of Non-Motor disorders	These two areas are very common and often the most problematic for other specialists managing patients with Parkinson's disease, especially Psychiatrists, and there are often not enough long term support options, including specialist community care.	
24	SCM1	Key area for quality improvement 1 **Access to physiotherapy assessment at diagnosis/early stage**	Early referral is recommended within NICE guidance, and people diagnosed with Parkinson's can be assessed and advised on maintaining or increasing their exercise levels. There is mounting evidence that exercise is beneficial in ameliorating motor symptoms. The physiotherapy advice offered should be from a physiotherapist with a good knowledge of Parkinson's.	Across the country, there is a disparity of access to physiotherapy for those newly diagnosed with Parkinson's, and it is also important that the physiotherapist has a good knowledge and experience of Parkinson's. This is not always the case.	Parkinson's UK Audit of NICE Guidelines for Parkinson's 2015
25	SCM1	Key area for quality improvement 2 **Access to a Multidisciplinary team (MDT) for management**	Because of the variation of motor and non-motor symptoms in Parkinson's, and the impact on activities of daily living (ADL) and quality of life (QoL), there is evidence that access to an MDT is the optimum therapy approach,	Access to an MDT for Parkinson's is not available in many parts of the country. MDT working can be cost-effective and avoids duplication of intervention.	Parkinson's UK Audit of NICE Guidelines for Parkinson's 2015

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		of Parkinson's symptoms	with a positive impact on ADLs and QoL.		
26	SCM1	Key area for quality improvement 3 **Access to Lee Silverman Voice Therapy (LSVT)**	LSVT is evidence-based speech therapy programme, which improves speech volume and other factors. This can then enable the person with Parkinson's to communicate more effectively and enhances quality of life. It is delivered by Speech and Language therapists who have been trained in LSVT.	There is limited access to LSVT across the country, due to training and intensity of intervention (frequency and length of sessions) - although it is effective.	Parkinson's UK Audit of NICE Guidelines for Parkinson's 2015
27	SCM2	2 Access to a multidisciplinary Team for health and social care	Parkinson's disease can impact each individual in different ways and changes are experienced throughout the duration of the disease.	The complex nature of the impact of Parkinson's disease is recognised and to obtain the best quality of life each individual person with Parkinson's Disease would benefit from having access to a full range of health and social support services. People with Parkinson's disease often have support of a consultant and a GP but do not obtain easy access to any other services that may be of benefit to them. When is receipt of care from other services the People with Parkinson's disease and their carers also gain more understanding of the disease and things they can do to help them manage their condition in a way that is	2015 UK Parkinson's Audit

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28	SCM2	5 Early access support services	Helping and supporting People with Parkinson's disease early in their disease can support understanding and self management longer into the disease	Ensuring provision of physiotherapy, speech therapy, Occupation Therapy, Mental health support, Dietician and other associated at the outset of the disease helps a person with Parkinson's disease understand and manage some of the issues that can cause a large impact but are not consistently available to all people with Parkinson's disease	2015 UK Parkinson's Audit Parkinson's disease (update)
29	SCM2	Additional forward Planning GP Responsibility for people with Parkinson's and their carer to be with a GP with Parkinson's Disease Knowledge	Within GP Practices it is not unusual to have a consultation with a GP who has no knowledge of Parkinson's Disease and this is not beneficial for the patient	With reduction in NHS services People with Parkinson's disease need to be able to access a GP with knowledge of their condition who is able to understand information from their specialist, and the reason they are seeking an appointment with their GP. GP Appointment times are becoming precious and time spent with a GP who has no knowledge of the disease is not of any benefit to the Person with Parkinson's, their carer or the GP.	
30	SCM4	Key area for quality improvement 2 **Prevention and management of falling.**	Falls can lead to injury requiring further treatment and result in loss of mobility and independence.	Falls and balance was the topmost issue in the Parkinson's UK Unmet Needs survey. What is best practice? Is technology of value?	https://www.parkinsons.org.uk/content/our-priority-research-areas-improving-everyday-life
31	SCM4	Key area for quality improvement 4 **Integrated healthcare**	Degenerative neurological conditions bring multiple and	Progress on 5 of the 6 Public Accounts Committee recommendations on	Progress has been mixed in implementing recommendations made by the

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			changing needs throughout a lifetime.	neurological conditions 2015 is poor or moderate. www.nao.org.uk	Public Accounts Committee in 2012 aimed at improving services and achieving better outcomes for people with neurological conditions, according to the National Audit Office. www.nao.org.uk
32	SCM7	Key area for quality improvement 5	Offer Parkinson's disease-specific physiotherapy for people who are experiencing balance or motor function problems.	Disease specific physiotherapy can make a dramatic difference to some people. Currently poorly available and so poorly provided	Rec 1.7.3
33	SCM7	Additional developmental areas of emergent practice	Offer Parkinson's disease-specific occupational therapy for people who are having difficulties with daily living activities.	As with physiotherapy, some people benefit dramatically from this input. Currently poor availability	Rec 1.7.5
34	Society for Research in Rehabilitation	Key area for quality improvement 1 Psychological support post diagnosis	Even early in its course PD can lead to non-physical "invisible" consequences – anxiety/depression/trauma. This is being hidden by failure to formally assess or often even ask the relevant questions, despite these problems being associated with reduced quality of life. There is also no real focus upon self-management of problems. When treatment is given it is commonly pharmacological treatment which	Senior clinical colleagues tell us of the lack of neuropsychological rehabilitation for people with PD diagnoses, especially in early onset. Increasing evidence indicates that early-onset PD is significantly different and thus requires different care pathways. But without multidisciplinary teams that include neuropsychologists this is unlikely to happen.	Ivan Koychev & David Okai (2017) Cognitive–behavioural therapy for non-motor symptoms of Parkinson's disease: a clinical review Evid Based Ment Health 20 (1), 15-20. 2017

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			may interfere with medication already taken.		
35	Society for Research in Rehabilitation	Key area for quality improvement 5 Adjustment	People with PD, particularly early onset PD have significant needs in terms of adjustment which are currently not being addressed. This is vital given that progression of the condition will require stepwise adjustments	It is currently not well understood how adjustment overlaps with mood disorders such as anxiety and depression. Approaches such as cognitive behavioural therapy and a focus on self-management are likely to benefit adjustment but require specialist psychological support	Illness beliefs and psychological outcome in people with Parkinson's disease Jane Simpson, Godwin Lekwuwa, Trevor Crawford First Published April 12, 2013 Helping patients to adjust life goals to accommodate PD and employ adaptive coping strategies may help to relieve depressive symptoms in PD.
36	Society for Research in Rehabilitation	Additional developmental areas of emergent practice	Physical therapy and Exercise	Barriers and facilitators to participating in exercise	Young Onset Parkinson's Disease and Physical Therapy
37	Wilmington Healthcare	Key area for quality improvement 1	Psychological care following diagnosis	There is very little structured national support or directives for psychological support for people with Parkinson's. Whilst Parkinson' nurses can provide some support there are insufficient clinical psychologists and key contributions that can be made by clinical psychologists and neuropsychologists include:	In the Parkinson' UK audit of Parkinson's services 2015 only 13% of those who participated had access to the full multidisciplinary team. Clinical psychology is lagging behind as mainly physiotherapy, OT and speech and language

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				● Assessment of mood and adjustment issues; ● Neuropsychological assessment; ● Psychotherapeutic intervention for depression, anxiety and for the management of psychosis; ● Specific interventions to promote psychological adjustment and cognitive rehabilitation; ● Promotion of long-term psychological adjustment; ● Family interventions; ● Dissemination of psychological skills/understanding of PD issues;	therapy were noted in this audit www.parkinson's.uk Source: UK Parkinson's Audit summary report 2015 https://www.parkinsons.org.uk/professionals/resources/psychological-services-people-parkinsons
Care management – Care plan					
38	SCM2	4 Establish Personal Care Plan	To establish and regularly review a personal care Plan established for each person with Parkinson's Disease	At the outset people first diagnosed with Parkinson's disease react in different ways but within the first 6 months to establish the a care plan identifying both medical and social care needs and treatment that is owned by the patient but shared with all necessary parties including the carer can be beneficial in empowering the person with Parkinson's disease to take personal control of what they want. A care plan is a living document that	NICE Guideline Parkinson's Disease 2017 Parkinson's disease (update) National Audit office review 2016 services for people with Neurological conditions Services for people with

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				allows for update, changes and additions at any consultation throughout the lifetime of the Person with Parkinson's Disease. It will also permit for forward planning and allow the Person with Parkinson's Disease to plan for the care they want in the later stages of the disease. The Care plan shared with a multidisciplinary team help for cross understanding of how an individual person is wishing to manage their disease	neurological conditions: progress review 2015 UK Parkinson's Audit anticipatory care planning
39	SCM7	Key area for quality improvement 1	People with Parkinson's disease should have a comprehensive care plan agreed between the person, their family members and carers (as appropriate), and specialist and secondary healthcare providers. [2006]	Very few patients have a care plan, and rarely have carers involved	Recommendation 1.1.5
Care management - Reviews					
40	Parkinson's Academy	Key area for quality improvement 4	Comprehensive review	A comprehensive review for people with Parkinson's ensures that they have the opportunity to hear from healthcare professionals about any new treatments, to be kept informed of their options, and for any issues or changes that might need referral to different	There are still people with Parkinson's who are not accessing regular reviews on their condition – again evidenced in the Parkinson's audit of 2015 www.parkinsons.org.uk

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				services or other healthcare professionals to be identified. A planned review will also pick up people who have not been in contact with services, whose condition is not being monitored and who are not receiving support. These people may have more unmet needs than those in regular contact.	
41	RCGP	Key area for quality improvement 3	All people with Parkinson's to have their symptoms, diet and medication reviewed every 6 months by a specialist in Parkinson's (for example, a neurologist, care of the elderly physician, or specialist Parkinson's nurse)	UK Parkinson's survey 2006	The medication regimes and their potential side-effects require frequent specialist input to maximise the quality of life for people with PD and their carers. It is important to consider protein redistribution diet for people with motor fluctuations.
42	Wilmington Healthcare	Key area for quality improvement 4	Comprehensive review	A comprehensive review for people with Parkinson's ensures that they have the opportunity to hear from healthcare professionals about any new treatments, to be kept informed of their options, and for any issues or changes that might need referral to different services or other healthcare professionals to be identified. A planned review will also pick up people who have not been in contact with services, whose condition is not being	There are still people with Parkinson's who are not accessing regular reviews on their condition – again evidenced in the Parkinson's audit of 2015 www.parkinsons'org.uk

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				monitored and who are not receiving support. These people may have more unmet needs than those in regular contact.	
Identifying symptoms and complications – Assessment					
43	Abertawe Bromorgannwg University Health Board	Patients with Parkinson's disease should have their cognition assessed and effect documented at least once a year	Prevalence of Dementia and MCI are very common in this neurodegenerative disease and early recognition and management improves quality of life as well as carer burden.	There is research evidence that identifying and managing Dementia in PD improves quality of life issues and carer burden	Ref: Emre M et al. Rivastigmine for the dementia associated with Parkinson's Disease. N Engl J Med 2004;351:29-38. Aarsland D, Andersen K, Larsen JP et al. Risk of dementia in Parkinson's disease: a community-based, prospective study. Neurology 2001;56:730-6. Cognitive impairment in patients with Parkinson's disease: diagnosis, biomarkers, and treatment; Lancet Neurology Volume 11, Issue 8, August 2012, Pages 697–707 http://www.nejm.org/doi/full/10.1056/nejmoa041470

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44	Parkinson's Academy	Key area for quality improvement 2	Management of non-motor symptoms (NMS)	Despite the availability of the NMS symptom questionnaire (Chaudhuri et al) there is still inconsistency in the way patients' NMS symptoms are managed https://www.parkinsons.org.uk/professionals/resources/non-motor-symptoms-questionnaire	The Parkinson's UK audit of Parkinson's services 2015 NMS symptoms stated that several non-motor areas could be improved particularly documentation of the side effects relating to dopamine agonists and enquiries about pain. The frequent falls and resulting hospital admissions in Parkinson's also suggests bone health as a priority area for improvement www.parkinsons.org.uk Source: UK Parkinson's Audit summary report 2015
45	Parkinson's Academy	Key area for quality improvement 3	Anticipatory care	There is a large expenditure annually on crisis admissions in Parkinson's mainly related to falls, urine and chest infections, and dementia. Community support and preventative support needs to be in place to address these issues; anticipating problems before they arise is crucial for improving patient outcomes and efficiency in the NHS	As part of work undertaken with Parkinson's UK Wilmington Healthcare have developed a data dashboard to highlight the numbers of emergency admissions and costs to the health economy for Parkinson's emergency admissions. Anticipating problems before they arise is crucial Data dashboard to prevent variations in care enables benchmarking of CCG emergency admissions:

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					https://www.parkinsons.org.uk/search/site/data%20dashboard
46	Parkinson's UK; Clinical Reference Group for Neurosciences (including Association of British Neurologists Advisory Group in Movement Disorders)	Consistent use of standardised assessments	Standardised, evidence-based assessments should be used consistently to enable everyone affected by Parkinson's to receive optimal treatments, therapy and surgical interventions that are appropriate for their individual circumstances.	The 2015 Parkinson's Clinical audit found that around 40% of people were not standardly assessed for blood pressure, pain and bone health in neurology services	Please see the Parkinson's Clinical 2015 audit which highlights findings around the need for professionals to use standardised assessments to track the progression of their patient's condition. https://www.parkinsons.org.uk/sites/default/files/audit2015_referencereport.pdf The Society of British Neurological Surgeons has been conducting a national audit programme since 2013. Their audit finds that far fewer DBS procedures are being carried out per capita in the UK compared to similar European countries (e.g.: Germany and France). Just over 400 new DBS procedures were performed per year across the UK in the last 3 years. This compares to around 1,000 in Germany. https://www.hed.nhs.uk/sbns One neurosurgeon shared that they run a DBS service in Malta where 6 to 8 patients undergo

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					the therapy per year from a population of 400,000. This suggests that around 15 patients per million benefit from DBS. This translates to around 1,000 new patients per year that could benefit from the therapy in the UK.
47	SCM2	3 Disease assessment standardisation	There are many varied assessment tests used none provide all the information required and omit assessment in areas that have found to be significant since they were introduced	In recognising that the impact of Parkinson's disease is much wider than originally thought, or even thought to be 20 years ago, an assessment that considerers all the areas of impact (Motor, non Motor and Mental Health) would provide a better picture of the current situation of any Person with Parkinson's disease. Some People with Parkinson's Disease are seen by Elderly Care Consultants and some by Neurology Consultants, standardisation throughout a multidisciplinary support network would be beneficial for all people with Parkinson's and members of the team caring for them. Research is also an area that uses assessment tools for Parkinson's Disease and the standardisation of measurement would allow for the results of research to be considered	2015 UK Parkinson's Audit consistent use of standardised assessments

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				with more confidence and for better comparison.	
48	Society for Research in Rehabilitation	Key area for quality improvement 3 Recognition of non-motor symptoms	Assessment and management of cognitive impairments. It has been shown that cognitive impairments can be present even early on in PD. Impairments are often quite specific and subtle and require careful assessment which may require a neuropsychologist.	Senior clinical colleagues tell us of the lack of neuropsychological assessment and rehabilitation for people with PD diagnoses, especially early onset. Care pathways do not normally include provision for this.	http://www.bps.org.uk/sites/default/files/documents/psychological_services_for_people_with_parkinsons_disease.pdf
49	Wilmington Healthcare	Key area for quality improvement 2	Management of non-motor symptoms	Despite the availability of the NMS symptom questionnaire (Chaudhuri et al) there is still inconsistency in the way patients NMS symptoms are managed https://www.parkinsons.org.uk/professionals/resources/non-motor-symptoms-questionnaire	The Parkinson's UK audit of Parkinson's services 2015 NMS symptoms stated that several non- motor areas could be improved particularly documentation of the side effects relating to dopamine agonists and enquiries about pain. The frequent falls and resulting hospital admissions in Parkinson's also suggests bone health as a priority area for improvement www.parkinson's.uk Source: UK Parkinson's Audit summary report 2015
50	Wilmington Healthcare	Key area for quality improvement 3	Anticipatory care	There is a large expenditure annually on crisis admissions in Parkinson's mainly related to falls, urine and chest infections and dementia. Community	As part of work undertaken with Parkinson's UK Wilmington Healthcare have developed a data dashboard to highlight the

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				support and preventative support need to be in place to address these issues anticipating problems before they arise is crucial for improving patient outcomes and efficiency in the NHS	numbers of emergency admissions and costs to the health economy for Parkinson's emergency admissions. Anticipating problems before they arise is crucial Data dashboard to prevent variations in care enables benchmarking of CCG emergency admissions: https://www.parkinsons.org.uk/search/site/data%20dashboard
Identifying symptoms and complications – Impulse control disorders					
51	Royal College of Psychiatrists	Key area for quality improvement 1	Diagnosis and management of Impulse control disorders	These two areas are very common and often the most problematic for other specialists managing patients with Parkinson's disease, especially Psychiatrists, and there are often not enough long term support options, including specialist community care.	
52	SCM5	Key area for quality improvement 1 Managing dopaminergic therapy in people who have developed impulse control disorder	Impulse control disorder is now the most challenging aspect of care for people with Parkinson's	Provision of oral and written information about the risks and types of impulse control disorders associated with Parkinson's treatment is important to avoid adverse effects. Advice on who to contact in the event of the impulse control disorder developing can ensure that patients and carers receive prompt support	

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53	SCM6	Key area for quality improvement 3	When starting dopamine agonist therapy, give people and their family members and carers (as appropriate) oral and written information about impulse control disorders, and continue to review this at follow up.	Impulse control disorders are an important and under-recognised complication of the treatment for PD, and awareness needs to be raised.	
54	SCM7	Key area for quality improvement 3	Discuss potential impulse control disorders at review appointments, particularly when modifying therapy, and record that the discussion has taken place.	Impulse control disorders are little recognised in primary care, but can have a devastating effect on the individual and their carers	Recommendation 1.4.4
Treatment for symptoms – Pharmacological management					
55	SCM5	Key area for quality improvement 2 Drooling of saliva	This is a major disability for many patients with Parkinson's and is relatively easy to manage	Consider medical treatment can be helpful and if not available referral for consideration of botulinum toxin treatment can provide rapid relief of symptoms with minimal adverse effects	
56	SCM5	Key area for quality improvement 3 Parkinson's disease dementia	The development of PDD is stressful for patients and carers and is susceptible to treatment	Patients and carer stress can be relieved by information and by treatment	
57	SCM5	Key area for quality improvement 4 Psychotic symptoms	Psychosis is a major cause of avoidable admission and morbidity in Parkinson's	Relatively few centres in the UK are currently set up to provide clozapine treatment, which may have significant advantages in terms of efficacy and adverse effects compared with other antipsychotic drugs	

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58	SCM7	Key area for quality improvement 4	Offer a cholinesterase inhibitor for people with mild or moderate Parkinson's disease dementia.	Dementia in Parkinson's Disease is poorly recognised and even less well managed	Recommendation 1.5.25
Treatment for symptoms – Deep brain stimulation					
59	Medtronic Ltd	Key area for quality improvement 1: **Deep brain stimulation in movement disorders**	According to NHS England's clinical commissioning policy for Deep brain stimulation in movement disorders, 'DBS provides significant therapeutic benefits for otherwise treatment resistant movement and affective disorders such as Parkinson's disease, tremor and dystonia.'	The clinical commissioning policy states 'A crude pro rata to England's population would indicate about 300 patients per year plus patients for dystonia and tremor' However, HES analysis shows since the policy was published in December 2013, the following numbers of patients with Parkinson's disease have been implanted with DBS: 2013/14:168 2014/15:173 2015/16: 214 Over a three year period, that is a cumulative under-treatment of approximately 345 patients. Efforts need to be made to ensure the optimal and timely implementation of the policy for the benefit of the	Please find the link to NHS England's clinical commissioning policy for Deep brain stimulation in movement disorders https://www.england.nhs.uk/commissioning/wp-content/uploads/sites/12/2013/10/d03-p-b.pdf

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				appropriate number of patients year on year.	
60	Royal College of Nursing	Key area for quality improvement 6 **Access to Deep Brain Stimulation**	NICE published interventional guidance that deep brain stimulation can be considered in people with Parkinson's Disease who have responded poorly to drugs, who have severe side-effects from medication, or who have severe fluctuations in response to drugs (on-off syndrome).	There are benefits with this treatment, however, we are aware that there is variation of practice as only very few places in the UK offer this treatment.	Deep brain stimulation for Parkinson's disease NICE Interventional procedures guidance [IPG19] Published date: November 2003
Medicines management in hospital					
61	Parkinson's UK; Clinical Reference Group for Neurosciences (including Association of British Neurologists Advisory Group in Movement Disorders)	Address issues with inpatient management to ensure that people with Parkinson's receive treatment from health professionals that fully understand their condition	People with Parkinson's admitted to hospital as an emergency are often prevented from taking their Parkinson's medicines when prescribed. This can have a significant impact on their ability to function. The results can include significant increases in care needs and costs to the point of prolonged hospital stays and significant worsening of their symptoms. When people with Parkinson's are admitted to hospital for a planned procedure it is crucial their care planning takes	The 2015 Parkinson's Clinical audit found that less than 50% of those admitted to hospital always got their Parkinson's medication at the right time.	Please see the Parkinson's Clinical 2015 audit which highlights findings around the need for people with Parkinson's to receive better inpatient care. https://www.parkinsons.org.uk/sites/default/files/audit2015_referencereport.pdf Between January 2013 and December 2014 3,320 patient safety incidents were reported via the National Reporting and Learning System involving medicines and people with Parkinson's in hospitals across

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			account of their need for timely medication. It is essential that when people with the condition are admitted to hospital their Parkinson's is identified, and their named specialist is contacted. Changes to medication regimes should be in consultation with the person's Parkinson's specialist. Common Parkinson's medications should be kept in stock in hospital pharmacies and drug cupboards. Administration standards should require staff to record missed/ untimely drugs administration as serious incidents, as the number of recorded incidents does not reflect the data on administration errors. Self-administration of medication policies should be in place and those able to administer their own medication should be empowered to do so. This QI area could deliver cost savings and improve patient outcomes.		England and Wales. This equates to 32 incidents per week, with six causing harm to someone with Parkinson's. **Catherine McKinnell MP, response to commons question 219635, 7 January 2015** Ashford and St Peter's Hospitals NHS Foundation Trust and Royal Surrey County Foundation Trust reported a combined 44 errors in that two year period via the NRLS. However, research carried out at these two trusts between June-October 2014, found there were 685 medication errors which equated to mistakes being made in the care of 75% of people with Parkinson's. **Dr Nicola Carey et al, *Parkinson's in-patient medicines management: PIMMS*. University of Surrey, 2015.**

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					Research Newsnight featured in 2013 found that medication errors are not just causing personal harm to patients and carers but are also costing the NHS money. In 2012/13 in England more than £20 million was wasted on 128,513 excess bed days for people with Parkinson's as they stayed in hospital longer than they should. http://www.bbc.co.uk/news/health-24493420 **Health and Social Care Information Centre. Hospital Episodes Statistics (HES) QMAS database, 2012/13**
62	SCM1	Key area for quality improvement 5 **Medication management for inpatients with Parkinson's**	People with Parkinson's are more likely to be admitted to hospital (unplanned) and generally have a longer length of stay, with increased mortality. Getting medication on time is a vital aspect of managing the condition.	Many hospital wards do not understand the importance of medication being given on time, or follow any guidance. Patients are given their medication when the ward medication trolley is brought round rather than when the individual's medication is due. This can impact mobility and recovery, as well as increase length of stay (and therefore costs)	Parkinson's UK Audit of NICE Guidelines for Parkinson's 2015

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63	SCM4	Key area for quality improvement 3 **Getting meds on time in hospital.**	The best person to manage timing of meds is the patient themselves. Lack of control of meds can lead to sudden immobility and other symptoms.	Improvement in this was identified by Parkinson's UK as a major campaign in the last few years.	www.Parkinsons.org.uk
Information and support – Information for the person with Parkinson's disease					
64	Britannia Pharmaceuticals	Key area for quality improvement 2 Better provision of information for patients relating to the long term therapeutic options and disease management.	Patient experience in NHS Services Quality statement 5 Understanding Treatment Options. Quality measure Structure: Evidence of local arrangements to ensure that healthcare professionals support patients to understand relevant treatment options, including benefits, risks and potential consequences. NICE Recommends 3.5.1 5. People with Parkinson's disease should have a comprehensive care plan agreed between the person, their family members and carers (as appropriate), and specialist and secondary healthcare providers. [2006]	House of Commons Committee of Public Accounts Services to people with neurological conditions: progress review. "everyone with a long-term condition should be offered a personalised care plan." Parkinsons UK Audit Timely provision of patient information: Only 65% of respondents felt they received enough information on diagnosis Anticipatory care planning Only 28% of those with markers of advanced Parkinson's had any recorded discussion of end of life care issues. Q5. When being prescribed any new medication, do you feel you are given enough information, including potential side effects?	Please see House of Commons Committee of Public Accounts - Services to people with neurological conditions: progress review : https://www.publications.parliament.uk/pa/cm201516/cmselect/cmpubacc/502/502.pdf Please see the Parkinsons UK audit which highlights poor care planning and provision of information.. https://www.parkinsons.org.uk/sites/default/files/audit2015_summaryreport.pdf

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				Many respondents reported they were given enough information about any new medication they were prescribed (48%). But 30% said they were not sure if this was the case, and 20% said they were not given enough information.	
65	Parkinson's Academy	Key area for quality improvement 5	Use of big data and information technology to support patients	There is still a paucity of easily accessible data available to monitor how services are performing and a lack of social media type support that patients can access. Information technology needs to be prioritised as a means to support improvements in services.	Dr Neil Archibald from South Tees has highlighted how they have used data to inform practice whilst IT is helping monitor patients' symptoms https://www.southtees.nhs.uk/services/neurology/parkinsons-disease-service/parkinsons-advanced-symptom-unit-pasu/ Other initiatives like the Parkinson's Umotif has shown how an iPhone can support patients to understand how they can better manage their symptoms and what affects their overall well being http://parkinsonsmovement.com/100-4-parkinsons/umotif/ http://www.medgadget.com/2014/09/parkinsons-kinetigraph-wrist-worn-datalogger-for-motion-tracking-receives-fda-clearance.html

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66	Parkinson's UK; Clinical Reference Group for Neurosciences (including Association of British Neurologists Advisory Group in Movement Disorders)	Ensure there is timely provision of information to patients about Parkinson's, treatment and therapy options.	It is important that everyone living with Parkinson's and their carers have access to information from diagnosis about living positively with the condition, managing symptoms, and the range of treatment and therapy options available to them, in order to promote self-management and informed decision making. It is also important to ensure information is provided to carers when people with Parkinson's have cognitive impairment, dementia, and depression or impulse control disorders. This QI supports recommendations 1-4 in the draft Parkinson's NICE guideline.	The 2015 Parkinson's Clinical audit found that 35% of people with Parkinson's felt they did not receive enough information at diagnosis.	Please see the Parkinson's Clinical 2015 audit which highlights findings around the need for people to receive timely information about their condition. https://www.parkinsons.org.uk/sites/default/files/audit2015_referencereport.pdf The recent Neurological Alliance patient experience report found that almost 30% of people with Parkinson's were unsatisfied with the information they were provided by professionals about their condition at diagnosis. **Neurological Alliance, Falling short: How has the neurology patient experience changed since 2014, 2016** http://www.neural.org.uk/updates/278-New-Neurological-Alliance-patient-experience-report-2017 People with Parkinson's shared their views on timely access to information to help them manage their condition: *"I'm still floundering since being diagnosed early 2014 with next*

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					to no information as to what to expect." *"I have a particular concern about the lack of information given when I was diagnosed. Told I had Parkinson's and would be seen by the Parkinson's nurse – an appointment which turned out to be five months ahead – but no other information."* *"I was diagnosed and then left with no advice or support. Luckily, the Parkinson's UK website has been more useful than the health services I've received."* *"When diagnosed I feel there should be a one stop shop approach, with the nurse/consultant/other giving you all the information you'll need for the future and the numbers to contact etc."* *"When my husband was first diagnosed we were not informed about Parkinson's health services."* *"Have not been told we could use an occupational therapist,*

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					physiotherapist or speech and language therapist." **Parkinson's UK; Your life your services survey, 2015** https://www.parkinsons.org.uk/sites/default/files/your_services_2015_results.pdf
67	SCM2	1 Provision of information and availability of information when required by patient and Carer	Parkinson's disease is a complex disease and while historically it was seen as a movement disorder knowledge and understanding has increased understanding and it is now recognises that it impacts many functions of the body both motor and non motor and can impact mental health.	Patients and carers are looking for more information, the need for information comes at different times for all individuals but it needs to be recognised that patients are more informed in this current generation and this will continue to increase. Understanding all the potential issues that may be experienced can be beneficial for some people and to be able to choose to become knowledgeable about the condition can be beneficial in informing a patients choice when making decisions about their personal care. Expert patient programmes run throughout England and providing information that supports patients knowledge.	Parkinson's disease (update) 2015 UK Parkinson's Audit
68	SCM4	Key area for quality improvement 1	Information at diagnosis on the disease and its progression, and on side effects of dopamine	The UK Parkinson's Audit found only 2/3 of patients felt they received sufficient information at diagnosis. The draft Guidelines include reference to a	UK Parkinson's Excellence Network (2016) 2015 UK Parkinson's Audit Draft Guideline 2017.

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		Information needs of people with Parkinson's and carers.	agonists and other drugs, is key to positive self-management.	number of key points where information and support is recommended.	
69	Wilmington Healthcare	Key area for quality improvement 5	Use of BIG data and information technology to support patients	There is still a paucity of easily accessible data available to monitor how services are performing and a lack of social media type support that patients can access for support. IT needs to be prioritised to support improvements in services	Dr Neil Archibald from South Tees has highlighted how they have used data to inform practice whist IT is helping monitor patient's symptoms https://www.southtees.nhs.uk/services/neurology/parkinsons-disease-service/parkinsons-advanced-symptom-unit-pasu/ Other initiatives like the Parkinson's Umotif has shown how an Iphone can support patients to understand how they can better manage their symptoms and what affects their overall well being http://parkinsonsmovement.com/100-4-parkinsons/umotif/ http://www.medgadget.com/2014/09/parkinsons-kinetigraph-wrist-worn-datalogger-for-motion-tracking-receives-fda-clearance.html
Information and support – Information and support for carers					

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70	Royal College of Occupational Therapists	**Key area for quality improvement 5** Carers of people with Parkinson's should be provided with information to support them to manage the needs of their family member/friend, with access to support services as needed (e.g. day care/respite/peer support groups). The carer's own emotional wellbeing should be reviewed at least annually,	Carers are integral to the person with Parkinson's care and their welfare needs to be supported to allow them to continue with this.	Carer support is often ad hoc and reliant on carer's assessments via social services.	Please see the summary of the 2015 Parkinson's UK Audit which highlighted underuse of Parkinson's local advisors (information and support workers) https://www.parkinsons.org.uk/sites/default/files/audit2015_patientandcarerreport.pdf Please refer to the following reference: McLaughlin D, Hasson F, Kernohan WG, Waldron M, McLaughlin M, Cochrane B, Chambers H 2011) Living and coping with Parkinson's disease: perceptions of informal carers. Palliative Medicine, 25(2): 177-82
71	Society for Research in Rehabilitation	Key area for quality improvement 2 Family support & interventions	Families need help to understand the condition to help them to know how best to support their loved ones and to safeguard their own well-being. They require quick	Senior clinical colleagues tell us of the lack of systemic interventions for people with PD diagnoses, especially early onset. In other neurological conditions such as head injury there is increasing recognition of the need to	Schrag, A., Morley, D., Quinn, N. Jahanshahi, M. (2004) Impact of Parkinson's disease on patients' adolescent and

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			and accessible support to cope with diagnosis and changes after diagnosis. The economic impact when ability to work is reduced also deserves consideration.	involve families in treatment. It is also vital that support is given to help people to know when and how to inform children given that a significant number of people will have children still living at home. Children are likely to also have support needs in their own right.	adult children Parkinsonism & Related Disorders October 2004, Vol.10(7):391–397, doi:10.1016/j.parkreldis.2004.03.011
Additional areas – Planning for end of life					
72	Compassion in Dying	Advance Care Planning (ACP)	There is clear evidence that Advance Care Planning (ACP) results in significant benefits for individuals and care providers. Timely conversations about ACP for people with Parkinson's Disease and taking steps to ensure recorded wishes are updated, communicated and respected should therefore form a key part of the Quality Standard. 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.	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".*	

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			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).	(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	

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				palliative and end of life care to people with life limiting conditions should receive training in advance care planning.	
73	Parkinson's UK; Clinical Reference Group for Neurosciences (including Association of British Neurologists Advisory Group in Movement Disorders)	Ensure timely conversations about advanced care planning that are formally recorded on the patients notes to facilitate better person-centred care	Timely discussion of advanced care planning involving people affected and significant others is important in light of the risks of developing dementia in Parkinson's. It is also important that preferences for palliative care are discussed and recorded, as this can prevent costly and unwanted interventions. Professionals should lead and record timely discussions about aids and adaptations based on the progression of their patients' condition to enable to enable the person with Parkinson's to maintain independence. This QI supports recommendations 86-89 of the draft Parkinson's NICE guideline.	The 2015 Parkinson's Clinical audit found that only 28% of those with markers of advanced Parkinson's had any recorded discussion of end of life care issues	Please see the Parkinson's Clinical 2015 audit which highlights findings around the need for people with Parkinson's to have discussions around their future care planning. https://www.parkinsons.org.uk/sites/default/files/audit2015_referencereport.pdf This paper highlights the need for carers receiving good information and support and access to palliative care and clinical services was uncoordinated and patchy. Carers had to actively seek out information and access services on the patients' behalf. All were frustrated that professional care was not in place for patients at the start of the disease trajectory. It also talks about while specialists seen as invaluable – accessing

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					them was problematic with length waiting times. There was also a lack of referral by primary care professionals to specialist palliative care and preventing access to hospice service. **Felicity Hasson, W George Kernohan, Marian McLaughlin, Mary Waldron, Dorry McLaughlin, Helen Chambers and Barbara Cochrane: Fragmentation and lack of comprehensiveness of palliative care service delivery. Palliative medicine, 4 June 2010** **http://pmj.sagepub.com/content/24/7/731**
74	Royal College of Nursing	Key area for quality improvement 4 **Access to palliative care provision**	There is good evidence which makes clear the importance of ensuring that those with Parkinson Disease (PD) have access to palliative care provision as it can have significant improvements in their quality of life and including their end of life care. .	National data from Parkinson's UK national audit, however, shows a lack of this nationally. The PUK audit showed that only 28% of those with advanced Parkinson's had any recorded discussion of end of life care issues.	UK Parkinson's Excellence Network (2016) 2015 UK Parkinson's Audit

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			NICE Parkinson's Disease guideline recommends that steps be taken to ensure people have access to palliative care provision and their palliative care requirements are considered through all phases of the disease.		
75	Royal College of Occupational Therapists	**Key area for quality improvement 4** Opportunity to discuss arrangements and plans for end of life management.	End of life care is a key quality requirement for all progressive neurological conditions. This is recommended in the NICE guideline, but varies in practice.	Access to support to manage end of life needs allows people to feel more in control and can reduce the burden on family and carers. Occupational therapy interventions at end of life traditionally include: • Addressing activities of daily living • Providing education for energy conservation and relaxation techniques • Addressing positioning, seating and mobility needs • Improving comfort • Provision of adaptive equipment • Providing support and education for family caregivers • Carrying out home assessments (Park Lala and Kinsella, 2011)	Please see the summary of the 2015 Parkinson's UK Audit which highlighted 28% of those with indicators of advanced Parkinson's had a recorded discussion of end of life issues https://www.parkinsons.org.uk/sites/default/files/audit2015_patientandcarerreport.pdf Please refer to the following references: Park Lala A and Kinsella A (2011) A phenomenological inquiry into the embodied nature of occupation at end of life. Canadian Journal of Occupational Therapy, 78(4):246-254 HassonF, Kernohan WG, McLaughlin M, Waldron M, McLaughlin D, Chambers H,

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					Cochrane B (2010) An exploration into the palliative and end-of-life experiences of carers of people with Parkinson's disease. Palliative Medicine, 24(7);731-736
Additional areas – Employment support					
76	Society for Research in Rehabilitation	Key area for quality improvement 4 Support with regard to employment	In early onset PD people have unmet needs in supporting them in employment and in dealing with issues which may affect employment such as fatigue, sleep problems, and cognitive impairments.	Studies show that in early onset PD, employment is beneficial to quality of life and well-being and has a protective benefit against mood disorders. There is currently no formal support given to people surrounding work and this is especially important in considering the likely difficulty of retraining if employment is lost.	Parkinson's disease: how is employment affected?: Murphy, R., Tubridy, N., Kevelighan, H. et al. Ir J Med Sci (2013) 182: 415. doi:10.1007/s11845-013-0902-5 Slowness, fatigue and tremor were the most challenging symptoms at work. Changes in work schedule and type of work were suggested helpful adjustments.
Additional areas – Data collection					
77	Parkinson's Academy	Key area for quality improvement 5	Use of big data and information technology to support patients	There is still a paucity of easily accessible data available to monitor how services are performing and a lack of social media type support that patients can access.	Dr Neil Archibald from South Tees has highlighted how they have used data to inform practice whilst IT is helping monitor patients' symptoms https://www.southtees.nhs.uk/s

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				Information technology needs to be prioritised as a means to support improvements in services.	ervices/neurology/parkinsons-disease-service/parkinsons-advanced-symptom-unit-pasu/ Other initiatives like the Parkinson's Umotif has shown how an iPhone can support patients to understand how they can better manage their symptoms and what affects their overall well being http://parkinsonsmovement.com/100-4-parkinsons/umotif/ http://www.medgadget.com/2014/09/parkinsons-kinetigraph-wrist-worn-datalogger-for-motion-tracking-receives-fda-clearance.html
78	Wilmington Healthcare	Key area for quality improvement 5	Use of BIG data and information technology to support patients	There is still a paucity of easily accessible data available to monitor how services are performing and a lack of social media type support that patients can access for support. IT needs to be prioritised to support improvements in services	Dr Neil Archibald from South Tees has highlighted how they have used data to inform practice whist IT is helping monitor patient's symptoms https://www.southtees.nhs.uk/services/neurology/parkinsons-disease-service/parkinsons-advanced-symptom-unit-pasu/ Other initiatives like the Parkinson's Umotif has shown how an Iphone can support

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					patients to understand how they can better manage their symptoms and what affects their overall well being http://parkinsonsmovement.com/100-4-parkinsons/umotif/ http://www.medgadget.com/2014/09/parkinsons-kinetigraph-wrist-worn-datalogger-for-motion-tracking-receives-fda-clearance.html
Additional areas – NHS Continuing Healthcare system					
79	SCM4	Key area for quality improvement 5 **Continuing care**	The NHS Continuing healthcare system needs to run efficiently and successfully from the patient perspective.	The Continuing Healthcare Alliance believes that NHS continuing healthcare (NHS CHC) is failing people across England.	Continuing to care report written by Parkinson's UK in association with the Continuing Healthcare Alliance. Services to people with neurological conditions: progress review inquiry.
General comments					
80	SCM2	Additional evidence sources for consideration	Ensuring new and evolving treatments are available for people with Parkinson’s Disease including information of research and trials that are open for recruitment.		

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81	Parkinson's UK; Clinical Reference Group for Neurosciences (including Association of British Neurologists Advisory Group in Movement Disorders)	*Additional developmental areas of emergent practice*: The UK Parkinson's Excellence Network is committed to tackling the quality improvement priorities highlighted above and is keen to engage with NICE to help achieve this.	The UK Parkinson's Excellence Network brings together the expertise of Parkinson's professionals the resources and leadership of Parkinson's UK and the voice of people affected to drive improvements in Parkinson's care. Education, service improvement and collaborative activities across the Network, including its 22 Excellence Network regions, are focussed on tackling the priorities emerging from the UK Parkinson's Clinical audit.	The 2015 Parkinson's Clinical audit.	Please see the Parkinson's Clinical 2015 audit. https://www.parkinsons.org.uk/sites/default/files/audit2015_referencereport.pdf
82	RCP	The RCP is grateful for the opportunity to respond to the above consultation. We would like to endorse the response submitted by the Association of British Neurologists.			