NICE National Institute for
Health and Care Excellence

Parkinson's disease

Quality standard
Published: 9 February 2018

www.nice.org.uk/guidance/qs164

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This standard is based on NG71.

This standard should be read in conjunction with QS153, QS132, QS120, QS86, QS85, QS13 and QS8.

Quality statements

Statement 1 Adults with Parkinson's disease have a point of contact with specialist services.

Statement 2 Adults with Parkinson's disease taking dopaminergic therapy are given information about the risk of impulse control disorders, when starting treatment and at least annually.

Statement 3 Adults with Parkinson's disease are referred to physiotherapy, occupational therapy or speech and language therapy if they have problems with balance, motor function, activities of daily living, communication, swallowing or saliva.

Statement 4 Adults with Parkinson's disease who are in hospital or a care home take levodopa within 30 minutes of their individually prescribed administration time.

Statement 5 Services for adults with Parkinson's disease provide access to clozapine and patient monitoring for treating hallucinations and delusions.

NICE has developed guidance and a quality standard on patient experience in adult NHS services (see the NICE Pathway on patient experience in adult NHS services), which should be considered alongside these quality statements.

Other quality standards that should be considered when commissioning or providing Parkinson's disease services include:

- Multimorbidity. NICE quality standard 153
- Social care for older people with multiple long-term conditions. NICE quality standard 132
- Medicines optimisation. NICE quality standard 120
- Falls in older people. NICE quality standard 86
- Medicines management in care homes. NICE quality standard 85
- Dementia: independence and wellbeing. NICE quality standard 30
- End of life care for adults. NICE quality standard 13
- Depression in adults. NICE quality standard 8
- Dementia. NICE quality standard 1

A full list of NICE quality standards is available from the quality standards topic library.

Quality statement 1: Point of contact with specialist services

Quality statement

Adults with Parkinson's disease have a point of contact with specialist services.

Rationale

A point of contact with specialist services will facilitate continuity of care and ensure that adults with Parkinson's disease have ongoing access to information, advice, care and support when they need it. This will support self-management and informed decision-making and will help to ensure that individual needs are proactively reviewed and managed. The point of contact could be a Parkinson's disease nurse specialist.

Quality measures

Structure

Evidence of local arrangements to ensure that specialist services can provide a point of contact for adults with Parkinson's disease.

Data source: Local data collection, for example, service protocols. The UK Parkinson's Excellence Network UK Parkinson's Audit identifies whether patients in elderly care and neurology services can access a Parkinson's disease nurse specialist.

Process

Proportion of adults with Parkinson's disease who have a point of contact with specialist services.

Numerator – the number in the denominator who have a point of contact with specialist services.

Denominator – the number of adults with Parkinson's disease.

Data source: Local data collection, for example, audit of electronic patient health records.

Outcome

a) Satisfaction of adults with Parkinson's disease with ease of access to specialist services.

Data source: Local data collection, for example, patient survey.

b) Satisfaction of adults with Parkinson's disease that they have the support and knowledge they need to self-manage their condition.

Data source: Local data collection, for example, patient survey.

What the quality statement means for different audiences

Service providers (such as hospital elderly care services, neurology services and NHS community providers) ensure that adults with Parkinson's disease have ongoing access to a point of contact with specialist services. Providers should ensure that, where possible, the point of contact for adults with Parkinson's disease is a healthcare professional who they already know, and that response times are clear.

Healthcare professionals (such as Parkinson's disease nurse specialists, community matrons and allied health professionals) provide ongoing support and information about clinical and social matters to adults with Parkinson's disease within agreed response times. Support should include clinical monitoring and medicines adjustment, and home visits when appropriate.

Commissioners (such as clinical commissioning groups) commission services that ensure that adults with Parkinson's disease have ongoing access to a point of contact with specialist services, with clear response times.

Adults with Parkinson's disease have a point of contact with specialist services, such as a nurse specialising in caring for people with Parkinson's disease, who they can contact between their reviews. If they do make contact, they should know how long it will take for someone to get back to them.

Source guidance

Parkinson's disease in adults. NICE guideline NG71 (2017), recommendation 1.1.6

Definitions of terms used in this quality statement

A point of contact with specialist services

A point of contact with specialist services that adults with Parkinson's disease can access between scheduled reviews. This could be a Parkinson's disease nurse specialist. The point of contact should provide access to:

- clinical monitoring and medicines adjustment
- ongoing support, including home visits when appropriate
- information about clinical and social matters of concern to people with Parkinson's disease and their family and carers (as appropriate).

[Adapted from NICE's guideline on Parkinson's disease in adults, recommendations 1.1.6 and 1.7.1]

Quality statement 2: Information about impulse control disorders

Quality statement

Adults with Parkinson's disease taking dopaminergic therapy are given information about the risk of developing impulse control disorders, when starting treatment and at least annually.

Rationale

Dopaminergic therapy, especially with dopamine agonists, is associated with a risk of developing impulse control disorders. It is important to discuss this risk and provide information to adults with Parkinson's disease, and their family members and carers, when starting treatment and at least annually. This will help them to recognise the symptoms and know where to get help if these develop.

Quality measures

Structure

a) Evidence that written information about the risk of developing impulse control disorders with dopaminergic therapy is available.

Data source: Local data collection, for example, information leaflets.

b) Evidence of local processes to ensure that adults with Parkinson's disease taking dopaminergic therapy have a discussion with a healthcare professional about the risk of developing impulse control disorders when starting treatment and at least annually.

Data source: Local data collection, for example, service protocol.

Process

a) Proportion of adults with Parkinson's disease starting dopaminergic therapy who are given written information about the risk of developing impulse control disorders.

Numerator – the number in the denominator who are given written information about the risk of developing impulse control disorders.

Denominator – the number of adults with Parkinson's disease starting dopaminergic therapy.

Data source: Local data collection, for example, audit of electronic patient health records. The UK Parkinson's Excellence Network UK Parkinson's Audit includes evidence of a conversation with the patient/carer and/or provision of written information regarding potential adverse effects for any new medicines.

b) Proportion of adults with Parkinson's disease starting dopaminergic therapy who have a record of a discussion about the risk of developing impulse control disorders.

Numerator – the number in the denominator who have a record of a discussion about the risk of developing impulse control disorders.

Denominator – the number of adults with Parkinson's disease starting dopaminergic therapy.

Data source: Local data collection, for example, audit of electronic patient health records. The UK Parkinson's Excellence Network UK Parkinson's Audit includes evidence of a conversation with the patient/carer and/or provision of written information regarding potential adverse effects for any new medicines.

c) Proportion of adults with Parkinson's disease taking dopaminergic therapy who have a record of a discussion within the past 12 months about the risk of developing impulse control disorders.

Numerator – the number in the denominator who have a record of a discussion within the past 12 months about the risk of developing impulse control disorders.

Denominator – the number of adults with Parkinson's disease taking dopaminergic therapy.

Data source: Local data collection, for example, audit of electronic patient health records. The UK Parkinson's Excellence Network UK Parkinson's Audit includes evidence of the extent of monitoring for compulsive behaviour in people taking dopaminergic drugs.

Outcome

a) Awareness of the risk of developing impulse control disorders among adults taking dopaminergic therapy for Parkinson's disease.

Data source: Local data collection, for example, patient survey.

b) Awareness of the risk of developing impulse control disorders among family members and carers of adults taking dopaminergic therapy for Parkinson's disease.

Data source: Local data collection, for example, survey of carers.

What the quality statement means for different audiences

Service providers (such as hospital elderly care services, neurology services and general practices) ensure that healthcare professionals are aware of the need to provide oral and written information about the risk of developing impulse control disorders to adults with Parkinson's disease when starting dopaminergic therapy (not just dopamine agonists) and to discuss this with them at least annually. Providers ensure that processes are in place to provide this information and include family members and carers in the discussion, if appropriate, so that they are aware of the symptoms and know where to get help if these develop.

Healthcare professionals (such as neurologists, elderly care consultants, Parkinson's disease nurse specialists, GPs, allied health professionals and pharmacists) provide oral and written information about the risk of developing impulse control disorders to adults with Parkinson's disease when starting dopaminergic therapy (not just dopamine agonists) and discuss this with them at least annually. They also provide information for family members and carers if appropriate.

Commissioners (such as clinical commissioning groups) commission services that ensure adults with Parkinson's disease are given oral and written information about the risk of developing impulse control disorders when starting dopaminergic therapy and have a discussion about impulse control disorders at least annually.

Adults with Parkinson's disease, and their family members and carers (if appropriate) are given written and verbal information about the risk of developing impulse control disorders (impulsive behaviour) when they start taking medicine for Parkinson's disease. They have a discussion with their healthcare professional about this at least once a year.

Source guidance

Parkinson's disease in adults. NICE guideline NG71 (2017), recommendation 1.3.8, 1.4.3 and 1.4.4

Definitions of terms used in this quality statement

Information about the risk of developing impulse control disorders

Oral and written information should be given about:

- the different types of impulse control disorders (for example, compulsive gambling, hypersexuality, binge eating and obsessive shopping)
- the increased risk of impulse control disorders developing with dopamine agonists
- the risk that impulse control disorders may be concealed by the person affected
- 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.

[NICE's guideline on Parkinson's disease in adults, recommendation 1.4.3]

Quality statement 3: Referral to physiotherapy, occupational therapy or speech and language therapy

Quality statement

Adults with Parkinson's disease are referred to physiotherapy, occupational therapy or speech and language therapy if they have problems with balance, motor function, activities of daily living, communication, swallowing or saliva.

Rationale

Adults with Parkinson's disease may experience a wide range of symptoms. Physiotherapy, occupational therapy and speech and language therapy can help people to manage their symptoms, maintain their independence and avoid hospital admission. After a referral to therapy services, it is important to ensure that therapists are included as part of the person's multidisciplinary team.

Quality measures

Structure

a) Evidence that physiotherapy, occupational therapy, and speech and language therapy specific for Parkinson's disease are available locally.

Data source: Local data collection, for example, service specifications.

b) Evidence of local processes to identify adults with Parkinson's disease and problems with balance, motor function, activities of daily living, communication, swallowing or saliva.

Data source: Local data collection, for example, service protocol. The UK Parkinson's Excellence Network UK Parkinson's Audit identifies whether reviews include a formal assessment tool or checklist for activities of daily living and the Parkinson's non-motor symptoms questionnaire or other form of checklist to screen for non-motor symptoms.

Process

a) Proportion of adults with Parkinson's disease and balance or motor function problems identified within the past 12 months who are referred for physiotherapy specific for Parkinson's disease.

Numerator – the number in the denominator who are referred for physiotherapy specific for Parkinson's disease.

Denominator – the number of adults with Parkinson's disease and balance or motor function problems identified within the past 12 months.

Data source: Local data collection, for example, audit of electronic patient health records. The UK Parkinson's Excellence Network UK Parkinson's Audit includes evidence of a physiotherapy referral.

b) Proportion of adults with Parkinson's disease and difficulties with activities of daily living identified within the past 12 months who are referred for occupational therapy specific for Parkinson's disease.

Numerator – the number in the denominator who are referred for occupational therapy specific for Parkinson's disease.

Denominator – the number of adults with Parkinson's disease and difficulties with activities of daily living identified within the past 12 months.

Data source: Local data collection, for example, audit of electronic patient health records. The UK Parkinson's Excellence Network UK Parkinson's Audit includes evidence of an occupational therapy referral.

c) Proportion of adults with Parkinson's disease and problems with communication, swallowing or saliva identified within the past 12 months who are referred for speech and language therapy specific for Parkinson's disease.

Numerator – the number in the denominator who are referred for speech and language therapy.

Denominator – the number of adults with Parkinson's disease and problems with communication, swallowing or saliva identified within the past 12 months.

Data source: Local data collection, for example, audit of electronic patient health records. The UK Parkinson's Excellence Network UK Parkinson's Audit includes evidence of speech and language therapy referrals for communication and swallowing.

Outcome

a) Health-related quality of life for adults with Parkinson's disease.

Data source: Local data collection, for example, patient survey.

b) Hospital admission rate for falls among adults with Parkinson's disease.

Data source: Local data collection, for example, audit of electronic patient health records.

c) Hospital admission rate for aspiration pneumonia among adults with Parkinson's disease.

Data source: Local data collection, for example, audit of electronic patient health records.

What the quality statement means for different audiences

Service providers (such as hospital elderly care services, neurology services, general practices and NHS community providers) ensure that adults with Parkinson's disease have regular assessments of balance, motor function, activities of daily living, communication, swallowing and saliva. If problems are identified they are referred for physiotherapy, occupational therapy or speech and language therapy specific for Parkinson's disease.

Healthcare professionals (such as neurologists, elderly care consultants, Parkinson's disease nurse specialists and GPs) are aware of local referral pathways to physiotherapy, occupational therapy and speech and language therapy for adults with Parkinson's disease. Healthcare professionals carry out regular assessments of balance, motor function, activities of daily living, communication, swallowing and saliva for adults with Parkinson's disease and refer them for physiotherapy, occupational therapy or speech and language therapy specific for Parkinson's disease if problems are identified.

Commissioners (such as clinical commissioning groups) commission physiotherapy, occupational therapy, and speech and language therapy specific for adults with Parkinson's disease and ensure that referral pathways are in place.

Adults with Parkinson's disease are referred to a physiotherapist for specialist treatment if they have problems with movement or balance. They are referred to an occupational therapist if they have difficulties with everyday activities such as dressing, cooking and working, and to a speech and language therapist if they have speech problems or problems with swallowing or drooling.

Source guidance

Parkinson's disease in adults. NICE guideline NG71 (2017), recommendations 1.7.3, 1.7.6 and 1.7.8

Definitions of terms used in this quality statement

Activities of daily living

Includes personal care, dressing and bathing, housework, shopping, food preparation, eating and drinking, and ability to continue with current work and usual activities.

[NICE's guideline on motor neurone disease, recommendation 1.9.1]

Physiotherapy, occupational therapy and speech and language therapy specific for Parkinson's disease

Adults with Parkinson's disease should have contact with a physiotherapist, occupational therapist or speech and language therapist with experience of Parkinson's disease to ensure disease-specific care is given.

[NICE's guideline on Parkinson's disease in adults, recommendations 1.7.2, 1.7.5 and 1.7.7 and full guideline]

Quality statement 4: Levodopa in hospital or a care home

Quality statement

Adults with Parkinson's disease who are in hospital or a care home take levodopa within 30 minutes of their individually prescribed administration time.

Rationale

Serious complications can develop if levodopa is not taken on time. These include acute akinesia and, if delays are significant, neuroleptic malignant syndrome. These complications can lead to increased care needs and increased length of stay in hospital or a care home.

Quality measures

Structure

a) Evidence of local processes to accurately document administration times for levodopa for adults with Parkinson's disease on admission to hospital or a care home to reflect timings before admission.

Data source: Local data collection, for example, service protocol.

b) Evidence of local processes to identify missed, early or late administration of levodopa for adults with Parkinson's disease in hospital or a care home.

Data source: Local data collection, for example, service protocol.

Process

a) Proportion of prescribed doses of levodopa for adults with Parkinson's disease in hospital or a care home that were missed.

Numerator – the number in the denominator that were missed.

Denominator – the number of prescribed doses of levodopa for adults with Parkinson's disease in hospital or a care home.

Data source: Local data collection, for example, audit of medicines administration records.

b) Proportion of doses of levodopa for adults with Parkinson's disease in hospital or a care home that were given more than 30 minutes before the individually prescribed administration time.

Numerator – the number in the denominator that were given more than 30 minutes before the individually prescribed administration time.

Denominator – the number of doses of levodopa for adults with Parkinson's disease in hospital or a care home.

Data source: Local data collection, for example, audit of medicines administration records.

c) Proportion of doses of levodopa for adults with Parkinson's disease in hospital or a care home that were given more than 30 minutes after the individually prescribed administration time.

Numerator – the number in the denominator that were given more than 30 minutes after the individually prescribed administration time.

Denominator – the number of doses of levodopa for adults with Parkinson's disease in hospital or a care home.

Data source: Local data collection, for example, audit of medicines administration records.

Outcome

a) Patient safety incidents related to medicines for adults with Parkinson's disease in hospital or a care home.

Data source: Local data collection, for example, local records of patient safety incidents.

b) Length of hospital stay for adults with Parkinson's disease.

Data source: Local data collection. National data can be collected from NHS Digital's Hospital Episode Statistics.

What the quality statement means for different audiences

Service providers (hospitals and care homes) ensure that adults with Parkinson's disease are identified on admission so that their requirements for levodopa can be accurately identified and monitored to reflect timings before admission. This should include an assessment of self-medication. Providers should ensure that staff are trained to understand the importance of taking levodopa at the appropriate times, and to report any medicines-related patient safety incidents.

Health and social care practitioners (such as doctors, nurses, pharmacists, and care home managers and staff) ensure that adults with Parkinson's disease have an accurate medicines chart that reflects timings for levodopa before admission. Practitioners should support adults with Parkinson's disease to take levodopa on time, which may include self-medication. Practitioners should report any medicines-related patient safety incidents for adults with Parkinson's disease.

Commissioners (such as clinical commissioning groups and local authorities) commission services that ensure timings of administration for levodopa are accurately identified and monitored for adults with Parkinson's disease. There are examples where commissioners have used local CQUINs to ensure that levodopa is given on time and not missed for adults with Parkinson's disease.

Adults with Parkinson's disease who are admitted to hospital or a care home know that they need to take their levodopa medicine on time and are supported to do so. This will ensure that they do not develop complications that can happen when this medicine is not taken at the right time.

Source guidance

Parkinson's disease in adults. NICE guideline NG71 (2017), recommendations 1.3.2 and 1.3.4 [the timeframe of 30 minutes is based on consensus of expert opinion]

Definitions of terms used in this quality statement

Individually prescribed administration time

The time that the person routinely takes their levodopa medicine. This should be in line with timings before admission and their individual prescription. Timings should only be adjusted after discussion with a specialist in managing Parkinson's disease.

[NICE's guideline on Parkinson's disease in adults, recommendation 1.3.2 and expert opinion]

Quality statement 5: Access to clozapine for treating hallucinations and delusions

Quality statement

Services for adults with Parkinson's disease provide access to clozapine and patient monitoring for treating hallucinations and delusions.

Rationale

Medicines for Parkinson's disease can cause hallucinations and delusions. If these symptoms of psychosis are not controlled adequately, they can lead to permanent admissions to care homes. It is therefore important that specialist services ensure adults with Parkinson's disease can access clozapine and the required patient monitoring if needed. As specialist Parkinson's services may not be able to provide this directly, they should agree with other local services how access will be provided and ensure that the specific needs of adults with Parkinson's disease (such as the need for a lower dose) are understood and met.

Quality measures

Structure

Evidence of local pathways to provide access to clozapine and patient monitoring for treating hallucinations and delusions in adults with Parkinson's disease.

Data source: Local data collection, for example, service protocol and referral pathways.

Outcome

a) Prescribing rates of lower dose clozapine for adults with Parkinson's.

Data source: Local data collection, for example, Clozaril Patient Monitoring Service.

b) Satisfaction with the management of hallucinations and delusions among adults with Parkinson's disease.

Data source: Local data collection, for example, patient survey.

c) Permanent admissions to care homes for adults with Parkinson's disease and hallucinations or delusions.

Data source: Local data collection, for example, audit of patient health records.

What the quality statement means for different audiences

Service providers (such as hospital elderly care services and neurology services) ensure that adults with Parkinson's disease can access clozapine and patient monitoring for treating hallucinations and delusions. This may mean joint arrangements with mental health services are needed. Providers ensure that healthcare professionals are aware that adults with Parkinson's disease need lower doses of clozapine than adults without Parkinson's disease.

Healthcare professionals (such as neurologists, elderly care consultants and Parkinson's disease nurse specialists) follow local processes to provide access to clozapine and patient monitoring for adults with Parkinson's disease and hallucinations or delusions if needed. If this means a referral to another service, healthcare professionals ensure that the need for a lower dose of clozapine in adults with Parkinson's disease is understood.

Commissioners (such as clinical commissioning groups) commission a clozapine service for adults with Parkinson's disease and hallucinations or delusions that includes monitoring. Commissioners should encourage joint working between services to ensure that the specific needs of adults with Parkinson's disease are understood and met.

Adults with Parkinson's disease and hallucinations or delusions can have treatment with clozapine if they need to. If they start clozapine, they will need to be registered with a monitoring scheme to have regular blood tests.

Source guidance

Parkinson's disease in adults. NICE guideline NG71 (2017), recommendation 1.5.17

About this quality standard

NICE quality standards describe high-priority areas for quality improvement in a defined care or service area. Each standard consists of a prioritised set of specific, concise and measurable statements. NICE quality standards draw on existing NICE or NICE-accredited guidance that provides an underpinning, comprehensive set of recommendations, and are designed to support the measurement of improvement.

Expected levels of achievement for quality measures are not specified. Quality standards are intended to drive up the quality of care, and so achievement levels of 100% should be aspired to (or 0% if the quality statement states that something should not be done). However, this may not always be appropriate in practice. Taking account of safety, shared decision-making, choice and professional judgement, desired levels of achievement should be defined locally.

Information about how NICE quality standards are developed is available from the NICE website.

See our webpage on quality standard advisory committees for details of standing committee 1 members who advised on this quality standard. Information about the topic experts invited to join the standing members is available from the webpage for this quality standard.

This quality standard has been incorporated into the NICE Pathway on Parkinson's disease, which brings together everything we have said on a topic in an interactive flowchart.

NICE has produced a quality standard service improvement template to help providers make an initial assessment of their service compared with a selection of quality statements. This tool is updated monthly to include new quality standards.

NICE produces guidance, standards and information on commissioning and providing high-quality healthcare, social care, and public health services. We have agreements to provide certain NICE services to Wales, Scotland and Northern Ireland. Decisions on how NICE guidance and other products apply in those countries are made by ministers in the Welsh government, Scottish government, and Northern Ireland Executive. NICE guidance or other products may include references to organisations or people responsible for commissioning or providing care that may be relevant only to England.

Improving outcomes

This quality standard is expected to contribute to improvements in the following outcomes:

- health-related quality of life
- carer quality of life
- self-management
- patient experience
- falls
- hospital admissions and readmissions
- length of hospital stay
- patient safety incidents in hospital
- mortality.

It is also expected to support delivery of the Department of Health's outcome frameworks:

- Adult social care outcomes framework
- NHS outcomes framework
- Public health outcomes framework for England
- Quality framework for public health.

Resource impact

NICE quality standards should be achievable by local services. The potential resource impact is considered by the quality standards advisory committee, drawing on resource impact work for the source guidance. The guideline was not expected to have a significant impact on resources.

Diversity, equality and language

During the development of this quality standard, equality issues were considered and equality assessments for this quality standard are available. Any specific issues identified during development of the quality statements are highlighted in each statement.

Commissioners and providers should aim to achieve the quality standard in their local context, in light of their duties to have due regard to the need to eliminate unlawful discrimination, advance equality of opportunity and foster good relations. Nothing in this quality standard should be interpreted in a way that would be inconsistent with compliance with those duties.

ISBN: 978-1-4731-2823-1

Endorsing organisation

This quality standard has been endorsed by NHS England, as required by the Health and Social Care Act (2012)

Supporting organisations

Many organisations share NICE's commitment to quality improvement using evidence-based guidance. The following supporting organisations have recognised the benefit of the quality standard in improving care for patients, carers, service users and members of the public. They have agreed to work with NICE to ensure that those commissioning or providing services are made aware of and encouraged to use the quality standard.

- Parkinson's UK
- British Geriatrics Society
- Association of Chartered Physiotherapists in Neurology
- Association of British Neurologists (ABN)
- Royal College of Occupational Therapists (RCOT)
- Royal College of General Practitioners (RCGP)
- Parkinson’s Disease Nurse Specialist Association
- Royal Pharmaceutical Society