

# Parkinson's disease

## NICE quality standard

### Draft for consultation

August 2017

**This quality standard covers** diagnosing and managing Parkinson's disease in adults. It describes high-quality care in priority areas for improvement.

**It is for** commissioners, service providers, health, public health and social care practitioners, and the public.

This is the draft quality standard for consultation (from 7 September to 5 October 2017). The final quality standard is expected to publish in February 2018.

## Quality statements

[Statement 1](#) Adults with Parkinson's disease have a named specialist healthcare professional.

[Statement 2](#) Adults with Parkinson's disease starting dopaminergic therapy are given information about the risk of impulse control disorders.

[Statement 3](#) Adults with Parkinson's disease are referred to supportive therapies if they have problems with balance, motor function, activities of daily living, communication, swallowing or saliva.

[Statement 4](#) Adults with Parkinson's disease who are admitted to a hospital or care home take their antiparkinsonian medicines at the appropriate times.

[Statement 5](#) Adults with Parkinson's disease are offered clozapine to treat hallucinations and delusions, if standard treatment is not effective.

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](#) (2017) NICE quality standard 153
- [Social care for older people with multiple long-term conditions](#) (2016) NICE quality standard 132
- [Medicines optimisation](#) (2016) NICE quality standard 120
- [Falls in older people](#) (2015) NICE quality standard 86
- [Medicines management in care homes](#) (2015) NICE quality standard 85
- [Dementia: independence and wellbeing](#) (2013) NICE quality standard 30
- [End of life care for adults](#) (2011) NICE quality standard 13
- [Depression in adults](#) (2011) NICE quality standard 8
- [Dementia](#) (2010) NICE quality standard 1

A full list of NICE quality standards is available from the [quality standards topic library](#).

## Questions for consultation

### ***Questions about the quality standard***

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

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

**Question 3** Do you think each of the statements in this draft quality standard would be achievable by local services given the net resources needed to deliver them? Please describe any resource requirements that you think would be necessary for any statement. Please describe any potential cost savings or opportunities for disinvestment.

### ***Questions about the individual quality statements***

**Question 4** For draft quality statement 3: Is the terminology 'supportive therapies' appropriate? If not, can you suggest an alternative?

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

### ***Local practice case studies***

**Question 6** Do you have an example from practice of implementing the NICE guideline that underpins this quality standard? If so, please submit your example to [NICE local practice case studies](#) on the NICE website. Examples of using NICE quality standards can also be submitted.

## Quality statement 1: Named specialist healthcare professional

### *Quality statement*

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

### *Rationale*

Ongoing access to information and support from a named specialist healthcare professional, such as a Parkinson's disease nurse specialist, will facilitate self-management and informed decision-making. It will also ensure that a person's individual needs are proactively reviewed and managed.

### *Quality measures*

#### **Structure**

a) Evidence of local arrangements to ensure that adults with Parkinson's disease have a named specialist healthcare professional.

**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.

b) Evidence of local arrangements to ensure that systems are in place to coordinate care for adults with Parkinson's disease when their named specialist healthcare professional is not available.

**Data source:** Local data collection, for example, service protocols.

#### **Process**

Proportion of adults with Parkinson's disease who have a named specialist healthcare professional.

Numerator – the number in the denominator who have a named specialist healthcare professional.

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

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

### **Outcome**

a) Satisfaction of adults with Parkinson’s disease with the quality of service provided by the Parkinson’s nurse.

**Data source:** Local data collection, for example, patient survey. The UK Parkinson’s Excellence Network [UK Parkinson’s Audit](#) includes questions on satisfaction with the quality of service provided by different parts of the Parkinson’s service including Parkinson’s nurse.

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 support and information from a named specialist healthcare professional. Providers ensure that systems are in place to coordinate care for adults with Parkinson’s disease when their named specialist healthcare professional is not available.

**Healthcare professionals** (such as Parkinson’s disease nurse specialists and community matrons) provide ongoing support and information to adults with Parkinson’s disease and regularly review their individual needs.

**Commissioners** (such as clinical commissioning groups) commission services that ensure that adults with Parkinson’s disease have access to a named specialist healthcare professional and that systems are in place to coordinate care when the named specialist healthcare professional is not available.

**Adults with Parkinson’s disease** have a main point of contact such as a nurse specialising in caring for people with Parkinson’s disease.

## **Source guidance**

[Parkinson's disease in adults](#) (2017) NICE guideline NG71, recommendations 1.1.6 and 1.7.1.

## **Definitions of terms used in this quality statement**

### **Named specialist healthcare professional**

A healthcare professional who is an accessible point of contact with specialist services, such as a Parkinson's disease nurse specialist who:

- provides clinical monitoring and medicines adjustment
- provides ongoing support, including home visits when appropriate
- is a reliable source of 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 starting dopaminergic therapy are given information about the risk of impulse control disorders.

### ***Rationale***

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

### ***Quality measures***

#### **Structure**

a) Evidence that written information about the risk of 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 starting dopaminergic therapy have a discussion with a healthcare professional about the risk of impulse control disorders.

**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 impulse control disorders.

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

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

**Data source:** Local data collection, for example, local audit of 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 medications.

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

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

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

**Data source:** Local data collection, for example, local audit of 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 medications.

## **Outcome**

Awareness of the risk of impulse control disorders among adults taking dopaminergic therapy for Parkinson’s disease.

**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 and neurology services) ensure that processes are in place to give information about the risk of impulse control disorders to adults with Parkinson’s disease starting dopaminergic therapy. Providers should 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, and Parkinson’s disease nurse specialists) provide information about the risk of impulse



control disorders to adults with Parkinson's disease starting dopaminergic therapy. 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 starting dopaminergic therapy are given information about the risk of impulse control disorders.

**Adults with Parkinson's disease** are given written information and have a discussion with their healthcare professional about the risk of impulse control disorders (impulsive behaviour) when they start taking medicine for Parkinson's disease.

### ***Source guidance***

[Parkinson's disease in adults](#) (2017) NICE guideline NG71, recommendation 1.3.8.

### ***Definitions of terms used in this quality statement***

#### **Information about the risk of 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](#) recommendations 1.3.8 and 1.4.3]

## Quality statement 3: Supportive therapies

### ***Quality statement***

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

### ***Rationale***

Adults with Parkinson's disease may experience a wide range of symptoms. Supportive therapies, including physiotherapy, occupational therapy and speech and language therapy, can help manage symptoms, maintain independence and avoid hospital admission.

### ***Quality measures***

#### **Structure**

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

**Data source:** Local data collection, for example, service specification.

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.

#### **Process**

a) Proportion of adults with Parkinson's disease and balance or motor function problems who are referred to physiotherapy specific for Parkinson's disease.

Numerator – the number in the denominator who are referred to physiotherapy specific for Parkinson's disease when balance or motor function problems are first identified.

Denominator – the number of adults with Parkinson’s disease and balance or motor function problems.

**Data source:** Local data collection, for example, audit of 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 who are referred to occupational therapy specific for Parkinson’s disease.

Numerator – the number in the denominator who are referred to occupational therapy specific for Parkinson’s disease when difficulties with activities of daily living are first identified.

Denominator – the number of adults with Parkinson’s disease and difficulties with activities of daily living.

**Data source:** Local data collection, for example, audit of 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 who are referred to speech and language therapy.

Numerator – the number in the denominator who are referred to speech and language therapy when problems with communication, swallowing or saliva are first identified.

Denominator – the number of adults with Parkinson’s disease and problems with communication, swallowing or saliva.

**Data source:** Local data collection, for example, audit of 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 aspiration pneumonia among 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** (such as hospital elderly care services, neurology services, 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, and if problems are identified they are referred to physiotherapy or occupational therapy specific for Parkinson's disease or speech and language therapy.

**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 refer adults with Parkinson's disease to supportive therapies if problems with balance, motor function, activities of daily living, communication, swallowing or saliva are identified.

**Commissioners** (such as clinical commissioning groups) commission physiotherapy, occupational therapy, and speech and language services for adults with Parkinson's disease and ensure that referral pathways to these services 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](#) (2017) NICE guideline NG71, recommendations 1.7.3, 1.7.6 and 1.7.8

**Definitions of terms used in this quality statement****Supportive therapies**

Supportive therapies are physiotherapy and occupational therapy specific for Parkinson's disease and speech and language therapy. [NICE's guideline on [Parkinson's disease in adults](#) recommendations 1.7.3, 1.7.6 and 1.7.8]

**Question for consultation**

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

## Quality statement 4: Medicines in hospital or a care home

### ***Quality statement***

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

### ***Rationale***

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

### ***Quality measures***

#### **Structure**

a) Evidence of local processes to accurately chart medicines 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 or late administration of antiparkinsonian medicines 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 doses of antiparkinsonian medicines 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 doses of antiparkinsonian medicines for adults with Parkinson's disease in hospital or a care home.

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

b) Proportion of doses of antiparkinsonian medicines for adults with Parkinson's disease in hospital or a care home that were delayed by 30 minutes or more.

Numerator – the number in the denominator that were delayed by 30 minutes or more.

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

**Data source:** Local data collection, for example, local audit of patient health 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) Perception of adults with Parkinson's disease admitted to hospital or a care home that they received their antiparkinsonian medicines on time.

**Data source:** Local data collection, for example, patient survey. The UK Parkinson's Excellence Network [UK Parkinson's Audit](#) includes questions on perception of whether medicines were received on time in hospital and whether this had any impact on the person's condition.

c) 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 medicine requirements 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 antiparkinsonian medicines at the

appropriate times, and to report any medicines-related patient safety incidents for adults with Parkinson's disease.

**Health and social care practitioners** (such as doctors, nurses, and care home managers and workers) ensure that adults with Parkinson's disease have an accurate medicines chart that reflects timings before admission and take their medicines on time. If appropriate, they should support adults with Parkinson's disease to self-medicate. 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 that medicine requirements are accurately identified and monitored for adults with Parkinson's disease. Commissioners may wish to use a local CQUIN to ensure that medicines are 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 medicines on time and are supported to do so. This will ensure that they do not develop complications that can arise when medicines are not taken at the right time.

### ***Source guidance***

[Parkinson's disease in adults](#) (2017) NICE guideline NG71, recommendations 1.3.2 and 1.3.4.

### ***Definitions of terms used in this quality statement***

#### **Antiparkinsonian medicines**

Antiparkinsonian medicines include levodopa, dopamine agonists and monoamine oxidase B inhibitors. [NICE's guideline on [Parkinson's disease in adults](#) recommendations 1.3.1]

#### **Appropriate times**

Within 30 minutes of the individually prescribed administration time. [Expert opinion]



***Question for consultation***

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

## Quality statement 5: Clozapine for hallucinations and delusions

### ***Quality statement***

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

### ***Rationale***

Pharmacological treatments for Parkinson's disease can potentially cause hallucinations and delusions. If symptoms of psychosis are not controlled adequately they can lead to unnecessary permanent admissions to care homes. Clozapine is the recommended second line treatment option as other antipsychotics, such as phenothiazines and butyrophenones, may cause difficulties for adults with Parkinson's disease.

### ***Quality measures***

#### **Structure**

a) Evidence that clozapine is available to adults with Parkinson's disease.

**Data source:** Local data collection, for example, service specification.

b) Evidence of local processes to ensure that adults with Parkinson's disease are offered clozapine to treat hallucinations and delusions, if standard treatment is not effective.

**Data source:** Local data collection, for example, local protocols.

c) Evidence of local processes to monitor adults with Parkinson's disease taking clozapine.

**Data source:** Local data collection, for example, local protocols.

#### **Process**

a) Proportion of adults with Parkinson's disease non-responsive to standard treatment for hallucinations or delusions who are offered clozapine.

Numerator – the number in the denominator who are offered clozapine.

Denominator – the number of adults with Parkinson's disease non-responsive to standard treatment for hallucinations or delusions.

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

### **Outcome**

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

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

b) Permanent admissions to care homes for adults with Parkinson's disease.

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

National data on permanent admissions to residential or nursing care are available as part of the [Adult social care outcomes framework](#) – indicator 2A.

### ***What the quality statement means for different audiences***

**Service providers** (such as hospital elderly care services, neurology services, mental health services and NHS community providers) ensure that adults with Parkinson's disease and hallucinations or delusions can access clozapine with appropriate monitoring if symptoms do not respond to standard treatment. Providers ensure that healthcare professionals are aware that adults with Parkinson's disease need lower doses of clozapine than in other indications and that some antipsychotic medicines (such as phenothiazines and butyrophenones) can worsen the motor features of Parkinson's disease.

**Healthcare professionals** (such as neurologists, elderly care consultants, Parkinson's disease nurse specialists and mental health practitioners) ensure that adults with Parkinson's disease and hallucinations or delusions can access clozapine with appropriate monitoring if symptoms do not respond to standard treatment.

**Commissioners** (such as clinical commissioning groups) commission a clozapine service that includes monitoring for adults with Parkinson's disease and hallucinations or delusions that do not respond to standard treatment.

**Adults with Parkinson's disease and hallucinations or delusions** are offered clozapine if their symptoms do not improve with standard treatment. If they start clozapine they will be registered with a monitoring scheme to have regular blood tests.

### ***Source guidance***

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

### ***Definitions of terms used in this quality statement***

#### **Standard treatment**

Standard treatment for hallucinations and delusions for adults with Parkinson's disease is as follows:

- Perform a general medical evaluation and offer treatment for any conditions that may have triggered the hallucinations or delusions.
- Do not treat hallucinations or delusions if they are well tolerated by the adult with Parkinson's disease and their family members and carers (if appropriate).
- Seek agreement with a healthcare professional with specialist expertise to reduce the dosage of any antiparkinsonian medicines that might have triggered hallucinations or delusions, taking into account the severity of symptoms and possible withdrawal effects.
- Consider quetiapine to treat hallucinations and delusions in adults with Parkinson's disease who have no cognitive impairment.

[NICE's guideline on [Parkinson's disease in adults](#) recommendations 1.5.13, 1.5.14, 1.5.15 and 1.5.16]

## 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 [quality standard advisory committees](#) on the website 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 on the [quality standard's webpage](#).

This quality standard has been incorporated into the NICE pathway on [Parkinson's disease](#).

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
- 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 2015–16](#)
- [NHS outcomes framework 2016–17](#)
- [Public health outcomes framework for England, 2016–19](#).

### ***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](#) 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.

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