Future Health Research

Missing the moment:

how NHS reform can better support people with advanced Parkinson's

November 2026



This independent report has been commissioned and funded by AbbVie. It is intended for parliamentarians, policymakers, advocacy professionals and individuals with a professional interest in health policy who are engaged in efforts to improve access to care for people living with Parkinson's.

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About this report

The report was commissioned and funded by AbbVie and produced by Future Health Research (FHR), which retained editorial independence over its method, findings and recommendations. It draws on four sources of evidence: a literature and evidence review of the UK and international literature on the definition, epidemiology and cost of advanced Parkinson's; a parliamentary roundtable held at Portcullis House in June 2026; an expert interview programme with clinicians, commissioners, charities and professional bodies between June and September 2026 (Annex C); and a new scale and cost analysis for England (Chapter 3 and Annex A). The report uses advanced Parkinson's as defined in the Executive Summary; Chapter 2 explains how the term is used today, why it is contested and how the line has been drawn.

About the author

Richard Sloggett is the Founder and Programme Director of Future Health Research – a health specialist policy research centre – and has over fifteen years of experience in healthcare policy.

From 2018-19 he was Special Adviser to the UK Secretary of State for Health and Social Care.

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Executive summary

Around 166,000 people in the UK are living with a confirmed diagnosis of Parkinson's, approximately 138,500 of them in England.[1]

For most, oral therapy controls the condition well for years.

However, for a substantial minority it reaches a point at which oral therapy no longer provides adequate control: motor fluctuations, OFF periods and dyskinesia become part of daily life, medication regimes become more frequent and more complex, and the need for specialist review, for care and for the involvement of family becomes constant.[2,3]

In this report, this state is defined as advanced Parkinson's and the research explores the number of people affected and the costs associated with their care. The analysis identified the population using the published 5-2-1 screening criteria (five or more oral levodopa doses a day, two or more hours of OFF time a day, and one or more hour of troublesome dyskinesia a day), requiring two or more of the three to be met.[4]

RESEARCH FINDINGS

- **There is no agreed definition of advanced Parkinson's.** Clinicians, patient groups and the published literature use different labels (advanced, advancing, complex, late stage) and different instruments, and the definitions in use capture anywhere between approximately 15% and 51% of the Parkinson's population.[5,6] The report recommends the Parkinson's community works together to build a consensus around an agreed definition.

- **This report therefore defines advanced Parkinson's by clinical situation rather than by label: a person has advanced Parkinson's if they meet at least two of the three 5-2-1 criteria set out above.** That threshold sits where clinicians place the loss of independence and is corroborated by three other published measures of the same population (Annex A).

- On this basis, **between approximately 13,500 and 18,800 people in England have advanced Parkinson's.**

- Hospital admissions and physician consultations for people with advanced Parkinson's **cost the NHS approximately £34 million to £47 million a year.** Of this, £20 million to £27 million is additional cost that arises because their condition is no longer adequately controlled.

- **The largest cost falls on families.** People with advanced Parkinson's receive roughly 21 hours a week of unpaid care from family and friends, more than twice the rate of other people with Parkinson's. Valued at the cost of replacing it with paid homecare, that is approximately £480 million to £670 million a year, of which £290 million to £400 million is the excess attributable to advanced Parkinson's.

- **The wider economic cost arises through lost work** for the minority of people with advanced Parkinson's who are still of working age, through carers reducing their hours, and through out-of-pocket costs for equipment and adaptations.
- **The care pathway breaks down at predictable points:** people are not systematically identified when oral therapy stops working; specialist review of treatment options is not consistent; access to NICE-approved therapies varies by geography and by the professional a person happens to see; time-critical medication is still missed in hospital; and support at the end of life is thin. Behind these sit three system barriers: care is commissioned by setting rather than by condition, the specialist workforce is stretched and used inefficiently, and there is no coded way to identify this population in routine data.
- **Good practice exists for every one of these challenges,** much of it developed through the Parkinson's UK Excellence Network, but it is not yet consistently adopted across services.

ADVANCED PARKINSON'S IN ENGLAND AT A GLANCE

13,500 to 18,800

people in England have advanced Parkinson's.

£34m to £47m

a year in NHS hospital admissions and physician consultations, of which £20m to £27m is excess cost.

Around 21 hours a week

of unpaid care per person, worth £480m to £670m a year.

No agreed definition,

and a care pathway that breaks down at predictable points.

Recommendations

These challenges arrive at a moment of opportunity. The 10 Year Health Plan's three shifts, from hospital to community, analogue to digital and sickness to prevention, together with the neighbourhood health service, the single patient record and the Modern Service Frameworks, give the NHS the levers to change how advanced Parkinson's is identified and managed.[7] The Casey Commission is examining the interface between health and social care, where much of this population's care sits.[8]

The recommendations below set out how those reforms can be made to work for people with advanced Parkinson's.

- **Recommendation 1: An agreed definition of advanced Parkinson's, built on the best care already in the system** – There is no agreed definition of advanced Parkinson's, and this report has had to construct its own. There is an opportunity to use this report as a catalyst for building a consensus on a definition of advanced Parkinson's. A convening authority in the sector should bring together clinicians and the professional bodies, the Parkinson's UK Excellence Network, people with Parkinson's and their carers, researchers and industry to agree a definition that combines clinical markers with the person's own account of the impact of the condition, and that can be used in guidance, in the UK Parkinson's Audit and in routine data. The same exercise should identify the services already delivering good care for this population, set out what enables them to do so, and publish the results as a model for others.
- **Recommendation 2: A defined trigger for specialist review** – NHS England, working with the Parkinson's UK Excellence Network and the professional bodies, should adopt a simple, published trigger for specialist review of treatment options. The trigger would apply at the point at which oral therapy is no longer providing adequate control, and the review would be carried out by a movement disorder specialist or a Parkinson's multidisciplinary team. Every service should have a process for applying it at the routine reviews that already take place, rather than through additional appointments. This extends the existing NNAG standard, which covers eligibility for device-aided therapies, to everyone whose oral therapy is no longer adequate.[9] The trigger should combine a treatment-burden screen such as the 5-2-1 criteria with a measure of independence, so that people whose needs are predominantly non-motor are not missed. It should be recorded in the patient record so that the population can be counted.
- **Recommendation 3: A shared care record across the Parkinson's pathway** – NHS England should work with integrated care boards to ensure that the hospital consultant, the Parkinson's specialist nurse, community therapy services and the GP can all see and contribute to a single care record for every person with Parkinson's. This should use existing shared care record infrastructure and align with the single patient record commitment in the 10 Year Health Plan.[10]
- **Recommendation 4: Review the specialist care model** – NHS England should review which elements of specialist care for advanced Parkinson's can be delivered safely through regional networks and in community and home settings, and which must remain in specialist centres. The review should cover the whole treatment pathway, from assessment through initiation to titration and monitoring. It should be taken forward through NHS England's neurosciences transformation programme and the neurology service specification built on the optimal clinical pathways, alongside GIRFT's neurology recommendations. The hub-and-spoke and home-initiation models already in use provide a starting point.[11,12] The review should also consider how a personalised care plan, of the kind the Government has committed to for people with cancer, could be offered to every person with advanced Parkinson's, with a named care co-ordinator and the plan held in the shared care record.
- **Recommendation 5: Time-critical medication, in hospital and in care packages** – Every acute trust should adopt the Parkinson's Excellence Network's ten recommendations on time-critical medication.[13] These include self-administration where the person is able, electronic prescribing alerts for time-critical medicines, and mandatory training for ward staff. Performance should be reported through the UK Parkinson's Audit. Local authorities and integrated care boards should require the same standard of competence in commissioned care packages and should treat a late dose as a patient safety incident.

- **Recommendation 6: Earlier palliative care and support for carers** – Integrated care boards and local authorities should jointly commission early palliative care, advance care planning and carer support as part of the Parkinson's pathway, rather than as a separate end-of-life service. Services should also offer a clear route to continuing specialist and palliative input, through home visits or community clinics, for people who can no longer attend hospital outpatient appointments. Carers of people with advanced Parkinson's should have access to respite, information and psychological support. The Casey Commission should consider the position of people with Parkinson's at the interface of health and social care, and how support can be better co-ordinated for them.[14]
- **Recommendation 7: Test condition-based commissioning for Parkinson's** – NHS England should invite a small number of integrated care boards to test a condition-based commissioning model for Parkinson's. Under the model, a single commissioner would be accountable for the whole pathway across acute, community and primary care, with payment linked to outcomes rather than activity. It should build on the neighbourhood health model and the Hull pathway.[15] Because much of the care people with advanced Parkinson's need is social care, the local authority should be a commissioning partner from the outset.
- **Recommendation 8: A workforce and skills plan that uses specialist capacity better** – The forthcoming NHS workforce plan should include succession planning for Parkinson's specialist nursing. Integrated care boards should review how neurology and care of the elderly capacity is used for Parkinson's. That review should ask whether routine care for other conditions could be redeployed to release specialist time, and whether the balance between medical, nursing and therapy staff reflects what this population needs.
- **Recommendation 9: Better measurement of the advanced Parkinson's population** – NHS England and the Department of Health and Social Care should agree a coding and data standard for the stage of Parkinson's. It should build on the four-stage phase and the advanced-disease markers that services already record for the UK Parkinson's Audit and add a patient-reported element. This would allow people with advanced Parkinson's to be identified in routine data, their access to specialist review and NICE-approved therapies to be monitored, and variation between systems to be seen. On that foundation, the Department should commission an assessment of the current and projected impact of Parkinson's on the NHS, social care and the economy. Workforce, service and investment decisions can then be made against a population that is expected to roughly double by 2050.[16] NHS England and HQIP should also bring Parkinson's into the national clinical audit programme, building on the UK Parkinson's Audit and working with Parkinson's UK. Participation would then be expected of every service, with results reported through Quality Accounts.[17]
- **Recommendation 10: A Modern Service Framework for neurological conditions** – The Government should commit to a Modern Service Framework for neurological conditions in the next wave of frameworks.[18] The framework should set national standards, a pathway and minimum service expectations for people with advanced Parkinson's. These should include explicit expectations for identification and specialist review, timely specialist assessment of treatment options for those eligible, and multidisciplinary therapy access for all. It should also share examples of good practice from the services described in Chapter 4, to give local systems a roadmap for improvement.

1. Introduction: Parkinson's in England



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Parkinson's is a progressive neurological condition caused by the loss of dopamine-producing cells in the brain. Its motor symptoms, tremor, slowness and rigidity, are the best known, but it also brings a wide range of non-motor symptoms including sleep disturbance, constipation, pain, depression, anxiety, hallucinations and cognitive impairment. There is no cure. Treatment aims to control symptoms, and for most people the mainstay is oral medication.[19]

The most comprehensive UK prevalence study to date, based on approximately 18 million linked GP records, estimates that around 166,000 people in the UK have a confirmed diagnosis. This equates to approximately 138,500 people in England based on ONS population estimates.[20] Parkinson's UK regards this as a conservative assessment, because new diagnoses fell during the pandemic and have not fully recovered.[21] Prevalence rises with age and Parkinson's UK projects that the number of people with Parkinson's in the UK will rise to over 300,000 by 2050; if the proportion of people with advanced Parkinson's stays constant, the number in England roughly doubles over the same period, and the care need with it.[22]

Parkinson's already has a growing impact on the NHS in England.

In 2025/26 there were approximately 112,400 hospital admissions with a Parkinson's diagnosis in England, at a total cost of approximately £448 million and accounting for approximately 831,000 bed days.[23] Admissions had risen by 8.6% in the previous year and by almost 20% over two years.[24] Many of these admissions are for the complications of the condition rather than the condition itself: falls, infections, aspiration pneumonia and delirium.

THE POINT AT WHICH ORAL THERAPY IS NO LONGER ENOUGH

As the condition progresses, the response to oral therapy becomes less predictable.

People experience OFF periods when the medication wears off before the next dose is due, dyskinesia when it peaks, and a rising number of daily doses to hold the two apart.

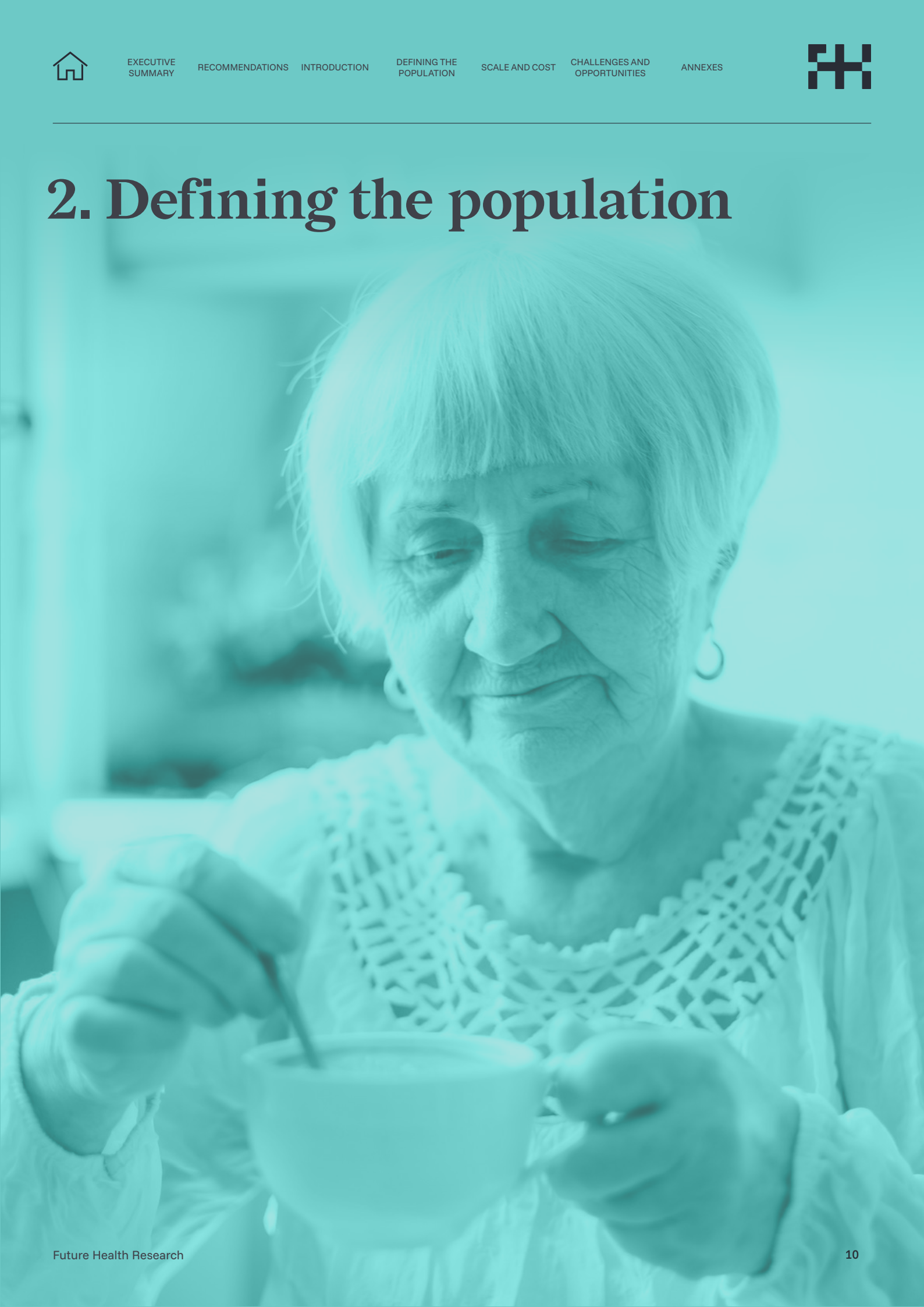
Clinical guidance recognises this point as the moment at which a specialist review of treatment options is needed, including consideration of device-aided therapies such as deep brain stimulation, apomorphine and levodopa infusion.[25] It is also the point at which the need for care rises sharply: people who screen positive for inadequate control were more than three times as likely to have been admitted to hospital in the previous year and received more than twice the hours of unpaid care.[26]

This point is often described as advanced Parkinson's, but despite its clinical and economic significance there is no clinical consensus on how the term should be defined.

In this report, advanced Parkinson's means the point at which oral therapy no longer provides adequate control. For analysis, that point is identified using the 5-2-1 screening criteria, which were developed through a consensus of movement disorder specialists: five or more oral levodopa doses a day, two or more hours of OFF time a day, and one or more hour of troublesome dyskinesia a day.[27] The report requires two or more of the three criteria to be met. Chapter 2 explains how the term is used today, the debate about it and why the line has been drawn there.

Chapter 2 explores the lack of a definition in more detail and sets out the approach this report takes. Chapter 3 estimates the number of people with advanced Parkinson's in England and the costs associated with their care. Chapter 4 examines where the care pathway breaks down, what good practice already exists and what should change, aligned to the reforms underway in the NHS in England.

2. Defining the population



2. Defining the population

THE ABSENCE OF A DEFINITIONAL CONSENSUS

As set out in Chapter 1, there is no consensus definition of advanced Parkinson's.

Research for this report found that the definitions in published use capture between approximately 15% and 51% of the Parkinson's population, depending on the instrument applied.[28,29] The choice of definition therefore changes any estimate of numbers and cost by a factor of more than three.

Part of the reason is that a definition only means something once it is clear what it is for. A clinician deciding whether to offer a treatment, a researcher stratifying a trial, a commissioner sizing a population and a clinician deciding simply to review a patient more often are asking different questions, and each will use a different definition as a result. Much of the disagreement is therefore about purpose rather than about the condition itself.[30]

The expert interviews for this report highlighted a range of views on the term 'advanced' and different perspectives on how the progression of Parkinson's should be described:

- **Advanced Parkinson's.** Used in Parkinson's UK's public information to describe a time when symptoms are more complex and have more effect on daily life, often called the complex phase; the charity notes the term is under review.[31] Where the term is given an operational definition it is usually through screening criteria such as 5-2-1, the tool this report uses, through staging scales, or through the clinician's own judgement of when oral therapy is no longer adequate.[32]
- **Advancing Parkinson's.** Used by some of those who work with the four-stage UK service model (diagnosis, maintenance, complex, palliative), on the grounds that advanced can read as though a person is at a late stage, whereas advancing supports earlier intervention.[33,34]
- **Complex Parkinson's.** Used by clinicians to describe the stage at which management becomes non-straightforward because of motor fluctuations, dyskinesia, cognitive impairment, neuropsychiatric symptoms or impulse control disorders; some of these appear early and some are partly reversible, so complexity is a different construct from progression.[35]
- **Mid-stage, late-stage and end-of-life Parkinson's.** Used by those who wish to avoid value-laden labels altogether, and who would name therapies by what they are (device-aided) rather than by a stage of disease, because most people a clinician would call advanced are frail, older, often cognitively impaired and not candidates for those therapies.[36]

Two further points were made across the expert interview series.

- Most of the instruments in use describe what the clinician observes rather than what the person can do, so that a person on five doses a day may be managing well while a person with no motor complications at all may be unable to work.
- Definitions in this field have tended to spread by adoption rather than by testing. One group's working definition is taken up by the next, and over time a term that was never validated for the purpose comes to determine who is offered treatment.[37]

THE LABELS AND INSTRUMENTS IN USE

The table below summarises the main instruments used to mark the point at which Parkinson's becomes 'advanced', including the 5-2-1 criteria introduced in Chapter 1. A fuller version, covering ten instruments and the origins of the 5-2-1 criteria, is at Annex D.

INSTRUMENT	WHAT IT MEASURES AND WHOSE VIEW	SHARE IDENTIFIED (POPULATION)
5-2-1 criteria[38]	Current treatment burden: five or more daily levodopa doses, two or more hours OFF, one or more hour of troublesome dyskinesia. Clinician-observed.	33% any one criterion; approximately 10% to 14% two or more (consulting population)[39]
Physician judgement[40]	The treating clinician's overall impression. Implicit and unstandardised.	Approximately 15% in general neurology; approximately 51% in movement disorder centres[41]
Hoehn and Yahr staging[42]	Disease progression as motor disability, from unilateral signs (stage 1) to wheelchair or bed-bound (stage 5). Clinician-rated.	33.5% at stage 3 to 5; 13.7% at stage 4 to 5 (same consulting population as the 5-2-1 figures)[43]
UK four-stage care model[44]	The stage of care management rather than of disease: the complex phase is when regimens become complicated and multidisciplinary input is needed.	39.5% complex and 2.9% palliative (UK Parkinson's Audit 2025)[45]
Patient-reported outcome measures[46]	The person's own account of the impact of the condition on daily life (PDQ-39 and others).	No accepted threshold; describes impact rather than stage

WHAT THE INSTRUMENTS HAVE IN COMMON

Four points stand out when the markers of advanced disease are looked at together:

- The instruments describe the same underlying event from different directions: the point at which oral therapy no longer provides adequate control, and the person begins to lose independence. Treatment-burden screening criteria express it as medication frequency and motor complications; staging scales as the degree of motor disability; the four-stage model as a change in the kind of care required; and patient-reported measures as the impact on the person's daily life.
- The instruments use different points of view. Most are clinician-rated and describe what the clinician observes; only the patient-completed parts of the rating scales and the patient-reported measures describe what the person can and cannot do.
- Many are not used in isolation but in conjunction with other instruments.
- None of them is routinely coded in NHS data, so none can be used to count or find this population in practice.

THE APPROACH TAKEN

Given the lack of a clinical consensus, this report defines advanced Parkinson's by clinical situation rather than by an individual label.

The population is people with Parkinson's in England whose symptoms are no longer adequately controlled by oral therapy, operationalised using the 5-2-1 criteria.[47] The criteria originate in a Delphi consensus of movement disorder specialists, have been applied in published cohort studies and are described in the literature as widely used on account of their simplicity.[48,49,50]

Their origins, thresholds and the debate about their purpose are set out in Annex D.[51]

Although there was no consensus on the definition, the expert interviews and discussions broadly converged on the underlying clinical state: advanced Parkinson's is the point at which oral therapy no longer adequately controls the condition. This is also what the authors of the 5-2-1 criteria state the tool was designed to identify.[52,53]

The published 5-2-1 figure of 33% counts anyone meeting at least one of the three criteria: five or more oral levodopa doses a day, two or more hours of OFF time a day, or one or more hour of troublesome dyskinesia a day. The source study also reports how many patients met each criterion individually, which allows the group meeting two or more to be bounded at approximately 10% to 14%.[54]

That range sits close to the 15% found by independent physician judgement in a separate multinational study.[55] This report therefore uses the two-or-more threshold as its base case, the published any-one-criterion figure as the upper bound, and physician judgement as external corroboration.

Requiring two or more criteria is a reasoned tightening of a screening tool whose designers left the question of combinations open: only around a third of people who screen positive on a single criterion are judged advanced by their own neurologist, and the five-dose criterion is the weakest predictor of the three. The threshold justification, and the corroboration of the resulting estimate against other published measures, are set out in Annex A.[56] The population identified also includes people who will never be eligible for device-aided therapies because of age, comorbidity, cognition or predominantly non-motor symptoms; the eligible group is a subset, and the report states which population any figure refers to. Throughout the rest of this report, advanced Parkinson's refers to the population so defined.

LIMITATIONS OF THE APPROACH

The 5-2-1 criteria capture motor symptoms and medication burden, not non-motor symptoms. The defined population in this report therefore under-represents the frailer, non-motor-driven group that patient groups and clinical interviewees both described: people who are often under the care of geriatricians rather than neurologists, are less visible to specialist services, and are the group for whom the end-of-life gap described in Chapter 4 is most acute.[57,58] The UK Parkinson's Audit 2025 recorded markers of advanced disease, such as dementia, frailty and impaired swallowing, in 22.9% of outpatients under specialist care, which gives a sense of the size of that group.[59] Further limitations are set out in Annex A.

TRANSPARENCY

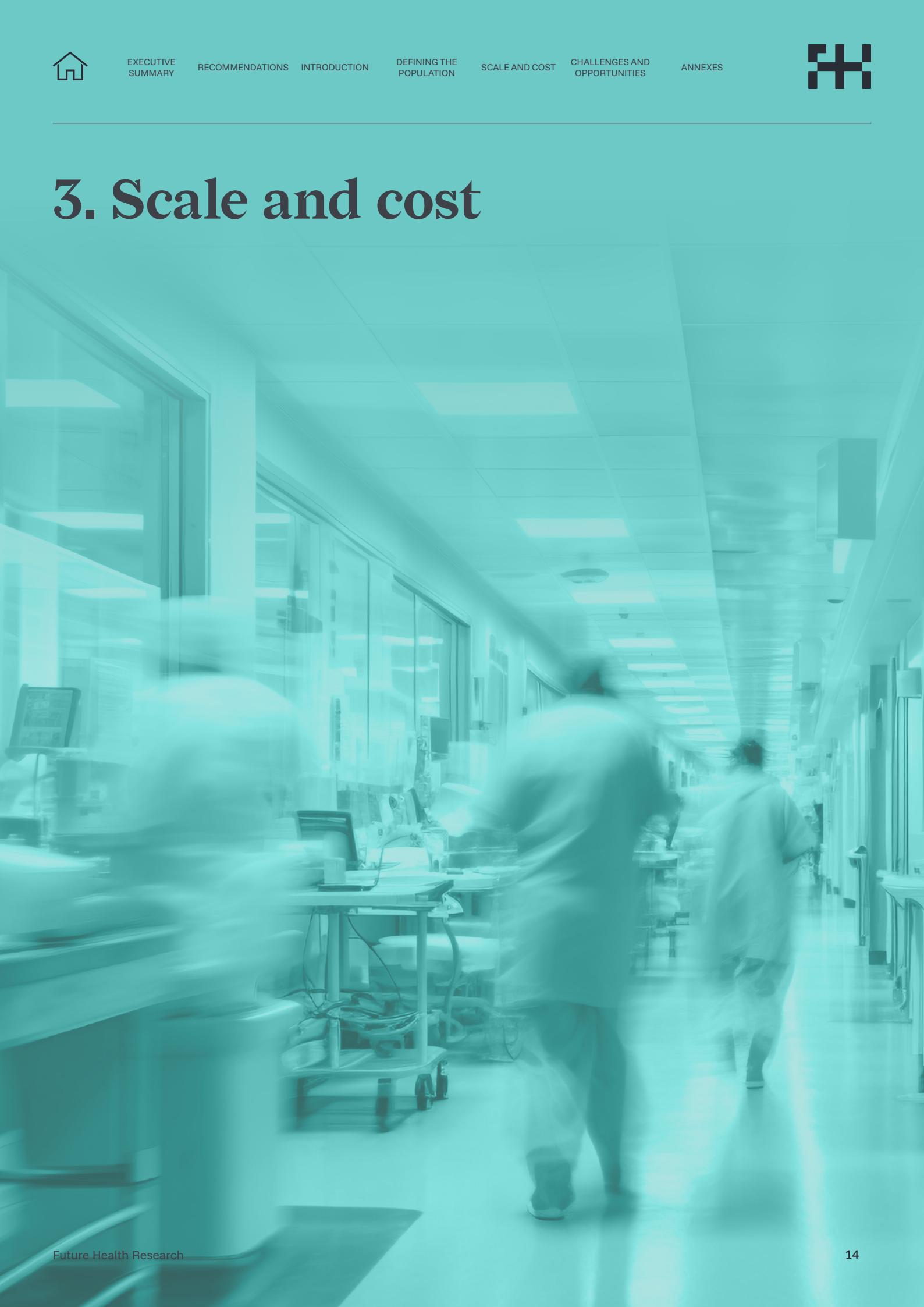
The 5-2-1 criteria and the study used to size and cost the population in this report were developed with AbbVie involvement, which is set out in full in Annex A. FHR has used the criteria to identify people who warrant clinical review and has used them because they are the only published screen with resource-use data attached. The criteria's authors have confirmed in print that they were developed to identify patients inadequately controlled on oral medication rather than to screen for device-aided therapy eligibility, which is consistent with the use made of them here.[60]

BUILDING A DEFINITION WITH CONSENSUS

The approach taken in this report is a working definition, chosen because it is published, simple and has resource-use data attached. It is not however a substitute for consensus. The lack of an agreed definition leaves clinicians applying different thresholds, leaves the population invisible in routine data, and leaves the services that have worked out how to care for these people well, many of them through the Parkinson's UK Excellence Network, without a common language to describe who they are caring for and what they do differently. The interviews for this report showed broad agreement on the underlying clinical state for people with advanced Parkinson's and that is a basis for the community to build on.

Recommendation 1: An agreed definition of advanced Parkinson's, built on the best care already in the system – There is no agreed definition of advanced Parkinson's, and this report has had to construct its own. There is an opportunity to use this report as a catalyst for building a consensus on a definition of advanced Parkinson's. A convening authority in the sector should bring together clinicians and the professional bodies, the Parkinson's UK Excellence Network, people with Parkinson's and their carers, researchers and industry to agree a definition that combines clinical markers with the person's own account of the impact of the condition, and that can be used in guidance, in the UK Parkinson's Audit and in routine data. The same exercise should identify the services already delivering good care for this population, set out what enables them to do so, and publish the results as a model for others.

3. Scale and cost



3. Scale and cost

With the population defined, the following examines the estimated scale and cost of the associated challenge.

The method, the corroboration of the population estimate and the limitations are set out in Annex A, and the sensitivity analysis in Annex B. All figures are at 2025/26 prices.[61] Gross figures are the total resource use of people with advanced Parkinson's. Excess figures are the cost above what the same people would incur at the resource-use rates of people with Parkinson's who do not meet the criteria; they are the cost attributable to advanced Parkinson's, and the report leads with them because they are the figures that better identification, review and treatment could change.

HOW MANY PEOPLE

Applying the thresholds set out in Chapter 2 to an England population of approximately 138,500 people with Parkinson's produces the following.

THRESHOLD APPLIED	SHARE OF PARKINSON'S POPULATION	ENGLAND POPULATION	ROLE IN THE ANALYSIS
Two or more of the three 5-2-1 criteria	Approximately 10% to 14%	13,500 to 18,800	Base case
Physician judgement[62]	15%	Approximately 20,800	External corroboration
Any one of the three criteria (as published)	33%	Approximately 45,400	Upper bound

The base case is shown as a range because the source study reports how many patients met each criterion but not how many met two or more, so the two-or-more share has to be bounded rather than read off directly.[63] Where a single figure is needed, the midpoint of approximately 16,200 is used. On the base case, roughly one in eight people with Parkinson's in England has advanced Parkinson's; on the upper bound, one in three.

The base case is corroborated by three independent published measures of the same population. Hoehn and Yahr stage 4 to 5, the point of loss of physical independence, physician judgement in general neurology, and the severe band of the MDS-UPDRS all identify between 14% and 16% of people with Parkinson's; the published any-one threshold likewise matches Hoehn and Yahr stage 3 and above and the UK Parkinson's Audit's complex phase at 33% to 42%.[64,65,66,67]

The full comparison is in Annex A, and the report has anchored its cost estimate at the conservative end of that range.

NHS COSTS

The source study reports two NHS resource-use measures for people who meet the criteria and people who do not: the share hospitalised for Parkinson's in the previous 12 months (19.3% against 5.4%) and the number of physician consultations a year (8.3 against 5.0).[68]

Our analysis converts the first into admissions and cost using the admissions-per-person, cost-per-admission and length-of-stay figures observed for people with Parkinson's in England in 2025/26, and the second into cost using national unit costs for specialist and GP consultations, assuming one-third of consultations are with a specialist (Annex A).[69,70,71]

MEASURE (BASE CASE, TWO OR MORE CRITERIA)	LOWER ESTIMATE	UPPER ESTIMATE
People with advanced Parkinson's	13,500	18,800
Hospital admissions for Parkinson's per year	4,800	6,600
Bed days per year	35,300	49,100
NHS cost of admissions and physician consultations, gross	£34.1m	£47.3m
NHS cost, excess above the rate for people not meeting the criteria	£19.7m	£27.3m
Excess NHS cost per person per year	£1,450	£1,450

It is important to note that these cost figures are partial and conservative.

They cover admissions for Parkinson's and physician consultations only; medicines, specialist nurse and therapy contacts, A&E attendances, community services and NHS-funded care in care homes are not included, and the source study reports resource use for everyone meeting at least one criterion rather than for the smaller and more affected two-or-more group.[72] The excess figure is within 1% of an independent estimate from linked NHS records, uprated to 2025/26.[73]

Annexes A and B set out why the figure is conservative and an alternative route that produces a higher one.

UNPAID CARE

The source study reports that people meeting the criteria receive 21.5 hours a week of unpaid care from family and friends, against 8.7 hours for people with Parkinson's who do not meet them, and 9.4 hours a week of paid care against 2.4.[74] The 21.5-hour figure is close to the 22 hours a week found as a cross-country average for all stages of Parkinson's in a separate systematic review, which suggests it is not inflated.[75]

The analysis multiplies unpaid hours by 52 and by the number of people with advanced Parkinson's and values each hour at the cost of replacing it with a paid homecare worker, approximately £32 an hour at 2025/26 prices.[76,77]

MEASURE (BASE CASE, TWO OR MORE CRITERIA)	LOWER ESTIMATE	UPPER ESTIMATE
Unpaid care hours per year	15.1 million	21.0 million
Unpaid care cost, replacement-cost basis, gross	£484m	£672m
Unpaid care cost, excess above the rate for people not meeting the criteria	£288m	£400m
Unpaid care hours per person per year	1,118	1,118
Gross unpaid care cost per person per year	£35,700	£35,700

The unpaid care costs are significantly larger than the NHS costs, showing the wider impacts of advanced Parkinson's.

SUMMARY OF NHS AND UNPAID CARE COSTS ASSOCIATED WITH 'ADVANCED PARKINSON'S'

Because every cost scales with the size of the population, the definitional threshold is the driver of difference in the cost projections.

The any-one-criterion reading is 2.8 times the base-case midpoint and physician judgement is 1.3 times the base case.

THRESHOLD	ENGLAND POPULATION	NHS COST, EXCESS	UNPAID CARE COST, GROSS
Two or more criteria (base case)	13,500 to 18,800	£19.7m to £27.3m	£484m to £672m
Physician judgement	Approximately 20,800	Approximately £30m	Approximately £740m
Any one criterion (upper bound)	Approximately 45,400	Approximately £66m	Approximately £1.6bn

The analysis produces a defensible indicative estimate with a stated range and visible assumptions. It does not produce a single precise figure that can be quoted without qualification, and FHR would not recommend presenting one.

The figures should be read as follows: a population of approximately 16,200 people in England, costing the NHS of the order of £20 million to £30 million a year more than they otherwise would in admissions and consultations alone, and drawing on unpaid family care worth of the order of £480 million to £670 million a year in total, of which £290 million to £400 million is the excess attributable to advanced Parkinson's.

It is important to state that the numbers cannot say how much of this cost is avoidable. The excess figures describe the difference between people whose condition is controlled and people whose condition is not; they do not describe what timely review and appropriate treatment would help recover.

THE WIDER ECONOMIC COST

The report does not put a figure on the wider economic cost of advanced Parkinson's. The UK evidence that exists is not specific to advanced Parkinson's, is drawn from member surveys rather than representative samples, and predates the pandemic. What the evidence does support is an account of how the costs associated with advanced Parkinson's arise.

Lost work. Most people with advanced Parkinson's are past working age: the mean age of people in the elderly care and neurology arm of the 2025 UK Parkinson's Audit was 78.5 years in elderly care services and 72.4 in neurology.[78] But for the minority who are not, the effect on employment is significant. The most detailed UK survey, commissioned by Parkinson's UK and covering people at all stages of the condition, found that half of respondents with Parkinson's had reduced their work hours, moved to a more manageable role or stopped work, that one in three had been forced into early retirement or out of work altogether, and that the combined loss of earnings and income across these routes came to roughly £10,700 a household a year at 2015 prices.[79]

Carer impacts. The same Parkinson's UK survey found that a quarter of carers had reduced their working hours and that a third of family members had changed their working pattern because of a relative's Parkinson's.[80] Loss of independence is the trigger: a person who can no longer drive to clinic, manage their own medication or be left alone for a working day draws a working-age relative into care. The unpaid care hours costed in this chapter are the visible part of that; the earnings the carer forgoes are not recorded.

Out-of-pocket costs. Households with people living with Parkinson's reported spending in the order of £1,900 a year on equipment and £3,600 on adaptations, and a further loss of income from benefits that were discontinued or never claimed.[81] An earlier UK study of advanced disease found that direct medical costs were around 7% of the total cost of the condition, direct non-medical costs around half and indirect costs the remainder.[82]

4. Challenges and opportunities for improvements in patient care in the care pathway



4. Challenges and opportunities for improvements in patient care in the care pathway

The optimal pathway for Parkinson's and high quality care is well defined.

NICE guidance sets out what should happen at each stage, from prompt referral for diagnosis through regular specialist review to consideration of device-aided therapies and palliative care.[83,84] The National Neurosciences Advisory Group (NNAG) has published an optimal clinical pathway for movement disorders, with quality standards that include a requirement for every service to have a process to identify patients eligible for device-aided therapies.[85]

> The problem is therefore not the absence of a pathway. It is that the pathway breaks down at predictable points for people with advanced Parkinson's, and that the system barriers behind those breakdowns are shared.

This chapter takes each point in the pathway in turn, and then the three system-wide barriers. For each it sets out the challenge, the opportunity shown by services that have addressed it, and policy recommendations for action.

IDENTIFICATION: RECOGNISING WHEN ORAL THERAPY IS NO LONGER EFFECTIVE

THE CHALLENGE

There is no defined trigger in the NHS in England for identifying the point at which a person's Parkinson's is no longer adequately controlled on oral therapy. The 5-2-1 criteria are simple enough to apply in a routine consultation, but they are not embedded in guidance, coded in records or used systematically.[86] The NNAG pathway asks every service to have a process to identify patients eligible for device-aided therapies.[87] There is no equivalent for the larger group whose oral therapy is no longer adequate but who are not candidates for those therapies, and no national reporting of whether services apply even the NNAG standard.

Interviewees described the core problem as the system not monitoring people closely enough to notice when they begin to advance, even though the signal is visible in the number of medications in use and in symptom burden.[88] Services do already stage their patients: in the 2025 UK Parkinson's Audit, elderly care and neurology services recorded 39.5% of outpatients as being in the complex phase and recorded markers of advanced disease in 22.9%.[89] But the phase is a clinical impression recorded for the audit without a standard definition, it is not held in the patient record, and it does not trigger anything.

Identification therefore depends on the person or their carer raising the problem, and on the clinician they happen to see recognising it. Interviewees described patients who do not know what to ask for and clinicians who are unaware of the guidelines, and a system in which a person already receiving treatment is effectively hidden from scrutiny of whether that treatment remains optimal.[90]

THE OPPORTUNITY

Two Parkinson's Excellence Network projects show what systematic identification looks like.

In North Cumbria, a team led by a consultant geriatrician set out to find those with advanced Parkinson's who could not attend outpatient clinics. The team identified 168 who would benefit from a different model of care and interviewed 62 of them at home; the analysis showed that people in the more deprived parts of the county saw specialist services less often, and the electronic patient record now holds an updatable list of the affected population that drives a home-visit system.[91]

In Hull, an integrated Parkinson's and frailty pathway commissioned across the hospital, community provider, local authority and hospice uses a Comprehensive Parkinson's Assessment to classify every patient as stable, at risk, pre-crisis or palliative, with an individualised plan sent to the person, their GP and the hospital within a working day.[92]

Recommendation 2: A defined trigger for specialist review. NHS England, working with the Parkinson's UK Excellence Network and the professional bodies, should adopt a simple, published trigger for specialist review of treatment options.

The trigger would apply at the point at which oral therapy is no longer providing adequate control, and the review would be carried out by a movement disorder specialist or a Parkinson's multidisciplinary team. Every service should have a process for applying it at the routine reviews that already take place, rather than through additional appointments. This extends the existing NNAG standard, which covers eligibility for device-aided therapies, to everyone whose oral therapy is no longer adequate. The trigger should combine a treatment-burden screen such as the 5-2-1 criteria with a measure of independence, so that people whose needs are predominantly non-motor are not missed. It should be recorded in the patient record so that the population can be counted.

SPECIALIST REVIEW: CO-ORDINATED CARE AND THE RIGHT INPUT

THE CHALLENGE

Recommendation 2 asks for a trigger to be applied at routine review. The evidence suggests that review is happening; the problem lies in what the review covers and how care is co-ordinated around it.

NICE recommends that people with Parkinson's have a regular review with a specialist and a continuing point of contact with specialist services.[93] The UK Parkinson's Audit shows real progress on both: in 2025, 96% of patients in elderly care and neurology services could access a Parkinson's nurse, 80.5% had seen a doctor or specialist nurse within the previous six months, and over 86% rated their service as excellent or good.[94,95]

People are being seen, but care is fragmented. The consultant, the Parkinson's nurse, community therapy services and the GP each hold part of the picture, and there is no shared record that brings it together. Only 68.5% of services had access to a regional multidisciplinary meeting for complex cases, so nearly a third did not.[96] The split of care between neurologists and geriatricians is often a matter of local history rather than design, and some services rely on a single specialist nurse.[97,98] Whether a person gets the right input at the right time, and whether the question that matters is asked, whether oral therapy is still providing adequate control and what the options are if it is not, therefore depends on where they live and who they see.

THE OPPORTUNITY

Interviewees identified the inability to share the care record between hospital consultant, specialist nurse and community services as a basic failure that needed to be fixed, and one that the single patient record ambition of the 10 Year Health Plan is meant to address.[99,100] The Hull pathway shows what co-ordinated care looks like when the record is shared: every contact is framed by the same assessment template, coded in the shared primary care system, and a monthly multidisciplinary meeting with social care and care home staff reviews the people in crisis.[101]

Recommendation 3: A shared care record across the Parkinson's pathway. NHS England should work with integrated care boards to ensure that the hospital consultant, the Parkinson's specialist nurse, community therapy services and the GP can all see and contribute to a single care record for every person with Parkinson's. This should use existing shared care record infrastructure and align with the single patient record commitment in the 10 Year Health Plan.

ACCESS TO TREATMENT: EQUITABLE ACCESS TO NICE-APPROVED THERAPIES

THE CHALLENGE

For people who are deemed clinically eligible, NICE recommends that device-aided therapies, including deep brain stimulation and infusion therapies, be considered where symptoms are not adequately controlled by best medical therapy, and NICE's guidance and appraisals report reductions in OFF time and improvements in quality of life for people who receive them.[102,103]

Access to these therapies is variable. Patient groups described access to NICE-approved therapies as not equitable across the country, with clinicians who are aware of the guidelines often unable to offer the therapies.[104] The NNAG pathway sets a metric for the percentage of patients referred for device-aided therapies precisely because referral is the step at which access is most likely to be lost.[105]

Device-aided therapy centres typically accept referrals only from other specialists, creating blockages for those managed in general neurology, care of the elderly or primary care.[106] Where referral does happen, it is not equitable: a multicentre UK study of people undergoing deep brain stimulation found that women were markedly under-represented, at around 28% of the cohort.[107] And the integrated service model is in decline: the 2025 audit found that the fully integrated clinic model was available in only 10.8% of services, down from 17% in 2022, and that only about a quarter of hospitals had guidelines for managing patients admitted on levodopa infusion therapies.[108]

THE OPPORTUNITY

Hub and spoke care models present opportunities for combining centres of expertise with community-based teams, with the Parkinson's nurse as the personal care manager and a shared point of access for patients.[109] This can support moving specialist treatment closer to home: the regional movement disorder centre in Salford, unable to use day-case beds during the pandemic, developed a protocol to start apomorphine infusion in the patient's home, initiated 27 people with a therapeutic response in more than three quarters, cut its waiting list and has kept the approach as standard care.[110] The question for a review of the care model is which elements of specialist care, from assessment through initiation to titration and monitoring, can be delivered in this way, and which must stay in the centre.

Recommendation 4: Review the specialist care model. NHS England should review which elements of specialist care for advanced Parkinson's can be delivered safely through regional networks and in community and home settings, and which must remain in specialist centres. The review should cover the whole treatment pathway, from assessment through initiation to titration and monitoring. It should be taken forward through NHS England's neurosciences transformation programme and the neurology service specification built on the optimal clinical pathways, alongside GIRFT's neurology recommendations. The hub-and-spoke and home-initiation models already in use provide a starting point.[111,112] The review should also consider how a personalised care plan, of the kind the Government has committed to for people with cancer, could be offered to every person with advanced Parkinson's, with a named care co-ordinator and the plan held in the shared care record.

HOSPITAL CARE: TIME-CRITICAL MEDICATION

THE CHALLENGE

People with Parkinson's are admitted for the complications of the condition, stay longer than people without it, and often leave with greater care needs driven by the deterioration of their Parkinson's during the stay.[113] Levodopa must be taken at the prescribed time; NICE's quality standard sets a thirty-minute window, and a published systematic review identifies poor control of Parkinson's and medication errors as major problems for patients in hospital, with longer stays as a result.[114,115,116]

The 2025 Audit found that while 80% of individual doses were given on time, only 12.5% of patients received all of their medication on time during the audited period of their stay.[117] Of 8,706 people who completed the audit's patient questionnaire, 24% had been admitted to hospital in the previous twelve months; of those, only 41.8% said they always received their medication on time, and nearly two in five of those who did not reported a negative effect on their condition.[118] Only 38.9% of hospitals regularly audit the administration of Parkinson's medication.[119]

The same issues apply outside hospital: patient groups described care packages that deliver medication late, leading to deterioration and avoidable admissions.[120]

THE OPPORTUNITY

Published quality improvement work shows that medication timing can be improved quickly and at low cost.

Northumbria Healthcare's two-year quality improvement project combined three-minute in-situ teaching for 250 ward and emergency department staff, built around a video of one patient before and after a delayed dose, with bedside prompts, ward champions, a medication conversion calculator for patients who cannot swallow and a swallow assessment that any qualified member of staff can complete. More than 90% of doses were given within 30 minutes and delays over an hour fell below 5%, both sustained for six months after the project ended.[121]

Leeds reported similar gains from a comparable package.[122] The Excellence Network has distilled the approach into ten recommendations for hospitals, with case studies from Bradford, Leicester and South Tyneside and Sunderland, and a dashboard that estimates for every trust and integrated care board what late and missed doses are costing them.[123]

Recommendation 5: Time-critical medication, in hospital and in care packages. Every acute trust should adopt the Excellence Network's ten recommendations on time-critical medication. These include self-administration where the person is able, electronic prescribing alerts for time-critical medicines, and mandatory training for ward staff. Performance should be reported through the UK Parkinson's Audit. Local authorities and integrated care boards should require the same standard of competence in commissioned care packages, and should treat a late dose as a patient safety incident.

END OF LIFE: PALLIATIVE CARE AND SUPPORT FOR CARERS

THE CHALLENGE

Interviewees described the last year of life, even for people known to secondary care, as often very difficult, particularly where there is psychosis, incontinence, severe fluctuation and a carer left to manage significant amounts of care. These people are not suitable for device-aided therapies, often have little consultant input, and fall into a gap between secondary care that cannot see them, palliative care services that do not have the capacity to pick them up, and old-age psychiatry.[124]

Between 2018 and 2022, 39% of deaths mentioning Parkinson's in England and Wales occurred in hospital and 39% in care homes; people with Parkinson's were half as likely to die in a hospice as the general population.[125] The literature finds that palliative care is introduced late, if at all, and that carers are under-supported.[126]

The 2025 Audit found that only 34% of people had been given information about lasting power of attorney and that, where markers of advanced disease had been recorded, an end-of-life discussion or care plan was documented within the previous twelve months for fewer than half of patients.[127,128] The issues carers raise repeatedly are respite, support in managing fluctuating symptoms, advance care planning, help with medicines for psychiatric symptoms, and emotional and psychological support.[129]

The boundary between health and social care is a major barrier here: people need social care before anything that could be labelled 'advanced', cannot access preventative support at social care thresholds, and rarely qualify for NHS Continuing Healthcare.[130]

THE OPPORTUNITY

The Hull pathway includes a palliative care route for people who have chosen not to be readmitted, with district nursing, the local hospice and social services sharing data with the Parkinson's team, so that the decision to stop attending hospital

does not mean the end of specialist input.[131] Patient groups stress that palliative care is not synonymous with end-of-life care and that early access, including advance care planning, matters.[132]

Recommendation 6: Earlier palliative care and support for carers. Integrated care boards and local authorities should jointly commission early palliative care, advance care planning and carer support as part of the Parkinson's pathway, rather than as a separate end-of-life service. Services should also offer a clear route to continuing specialist and palliative input, through home visits or community clinics, for people who can no longer attend hospital outpatient appointments. Carers of people with advanced Parkinson's should have access to respite, information and psychological support. The Casey Commission should consider the position of people with Parkinson's at the interface of health and social care, and how support can be better co-ordinated for them.

THE SYSTEM BARRIERS

The pathway challenges identified above are not independent failures and are the result of a set of well established system barriers.

A FRAGMENTED SYSTEM

Acute, community and primary care services are usually commissioned by different bodies, on the basis of activity rather than by condition or outcome.[133,134,135] A person whose Parkinson's is no longer adequately controlled needs all three working together, and no single commissioner is accountable for that pathway or paid for the outcome it produces. Because the population is not clearly counted, its demand for specialist review, device-aided therapy assessment and community care is not planned for, and services respond to it as unplanned pressure. Hull's Parkinson's Hub, commissioned as part of a frailty strategy with a team drawn from the hospital trust, the community provider and the local authority working to one assessment, one plan and one dataset, provides a model of how this can be done.[136]

Recommendation 7: Test condition-based commissioning for Parkinson's. NHS England should invite a small number of integrated care boards to test a condition-based commissioning model for Parkinson's. Under the model, a single commissioner would be accountable for the whole pathway across acute, community and primary care, with payment linked to outcomes rather than activity. It should build on the neighbourhood health model and the Hull pathway. Because much of the care people with advanced Parkinson's need is social care, the local authority should be a commissioning partner from the outset.

WORKFORCE GAPS AND PRESSURES

Neurology services are under sustained pressure. Neurology is one of the worst performing specialties against the 18-week standard, with only 61.4% of pathways within 18 weeks at the end of May 2026, and GIRFT's national review found wide variation in staffing and service models between providers.[137,138]

The specialist workforce for Parkinson's is thin: interviewees described services reliant on a single Parkinson's nurse, high rates of sickness and burnout, a large share of specialist nurses expected to retire with no plan for succession, and gaps in Parkinson's expertise in the care of the elderly workforce that manages a growing share of this population.[139]

The question is therefore not only how many specialists the NHS has but how their time is used and which patients they see. Much consultant neurologist time goes to conditions that could be managed by other professionals, and the teams that deliver device-aided therapies are the same teams that carry routine Parkinson's care, so efficiency anywhere in the pathway releases specialist time.[140,141]

The evidence for the nurse-led part of the mix is established: a randomised trial of community-based Parkinson's nurse specialists found that they maintained patients' wellbeing at no additional overall cost to the NHS.[142] The 2025 Audit found that while 95.8% of services can offer a Parkinson's nurse, only one in ten offers an integrated clinic with consultant, nurse and therapy input together.[143]

Recommendation 8: A workforce and skills plan that uses specialist capacity better. The forthcoming NHS workforce plan should include succession planning for Parkinson's specialist nursing. Integrated care boards should review how neurology and care of the elderly capacity is used for Parkinson's. That review should ask whether routine care for other conditions could be redeployed to release specialist time, and whether the balance between medical, nursing and therapy staff reflects what this population needs.

INCOMPLETE DATA

There is no coded, agreed way to identify people with advanced Parkinson's in routine NHS data. None of the instruments in Chapter 2 is recorded in GP or hospital systems, the UK Parkinson's Audit stages are recorded only for the services and patients audited, and the NHS neurology dashboard reports headcount rather than whole-time equivalent and has no sub-specialty granularity.[144] The consequences run through this report: the population had to be sized from a multinational survey rather than from English records, access to device-aided therapies cannot be measured because referral and treatment are not counted, and the case for including neurological conditions in a Modern Service Framework is weakened by the absence of the data that would clearly demonstrate the inequality and the cost.

The Parkinson's UK Audit shows what is possible: when asked, services were able to record a phase for every patient and to say whether markers of advanced disease were present, and North Cumbria and Hull have both shown that the population can be coded locally where there is a local effort to do so.[145,146] The UK Parkinson's Audit is on NHS England's Quality Accounts list, the annual list of national audits that trusts are expected to take part in and report on, but it sits outside the national

clinical audit programme commissioned by the Healthcare Quality Improvement Partnership (HQIP), which carries stronger expectations of participation and gives commissioners powers to act where services do not take part.[147]

Recommendation 9: Better measurement of the advanced Parkinson's population. NHS England and the Department of Health and Social Care should agree a coding and data standard for the stage of Parkinson's. It should build on the four-stage phase and the advanced-disease markers that services already record for the UK Parkinson's Audit and add a patient-reported element. This would allow people with advanced Parkinson's to be identified in routine data, their access to specialist review and NICE-approved therapies to be monitored, and variation between systems to be seen.

On that foundation, the Department should commission an assessment of the current and projected impact of Parkinson's on the NHS, social care and the economy. Workforce, service and investment decisions can then be made against a population that is expected to roughly double by 2050.[148] NHS England and HQIP should also bring Parkinson's into the national clinical audit programme, building on the UK Parkinson's Audit and working with Parkinson's UK. Participation would then be expected of every service, with results reported through Quality Accounts.

BRINGING IT TOGETHER: A MODERN SERVICE FRAMEWORK FOR NEUROLOGICAL CONDITIONS

The recommendations above are addressed to health and social care together.

This is a population whose care needs sit mostly outside hospital, but whose treatment needs sit inside it, whose costs fall first on families and then on local authorities, and which is growing. Several of the recommendations are near-term fixes, and could be delivered within the reform agenda in the next twelve to eighteen months. The others are structural asks that belong in the national policy frameworks now being developed, and the vehicle for them is the Modern Service Framework.

Recommendation 10: A Modern Service Framework for neurological conditions. The Government should commit to a Modern Service Framework for neurological conditions in the next wave of frameworks. The framework should set national standards, a pathway and minimum service expectations for people with advanced Parkinson's. These should include explicit expectations for identification and specialist review, timely specialist assessment of treatment options for those eligible, and multidisciplinary therapy access for all. It should also share examples of good practice from the services described in this chapter, to give local systems a roadmap for improvement.

SUMMARY OF RECOMMENDATIONS

RECOMMENDATION	PATHWAY POINT	LEAD	SUPPORTED BY
1. An agreed definition of advanced Parkinson's, built on the best care already in the system	Definition and measurement	Convening authority in Parkinson's community	Parkinson's UK Excellence Network; professional bodies; NNAG; NHS England; people with Parkinson's and carers; industry
2. A defined trigger for specialist review	Identification	NHS England	Parkinson's UK Excellence Network; professional bodies
3. A shared care record across the Parkinson's pathway	Specialist review	NHS England	Integrated care boards
4. Review the specialist care model	Access to treatment	NHS England (neurosciences transformation programme)	GIRFT; NNAG pathway authors
5. Time-critical medication in hospital and in care packages	Hospital care	Acute trusts	Integrated care boards; local authorities; Parkinson's UK Excellence Network
6. Earlier palliative care and support for carers	End of life	Integrated care boards	Local authorities; Casey Commission
7. Test condition-based commissioning for Parkinson's	Commissioning	NHS England	Integrated care boards; local authorities
8. A workforce and skills plan that uses specialist capacity better	Workforce	Department of Health and Social Care (NHS workforce plan)	NHS England; integrated care boards
9. Better measurement of the advanced Parkinson's population	Data	NHS England	Department of Health and Social Care; HQIP; Parkinson's UK
10. A Modern Service Framework for neurological conditions	Whole pathway	Department of Health and Social Care	NHS England; Parkinson's UK; Neurological Alliance

Annex A: Methodology

EVIDENCE BASE

The report draws on four sources of evidence.

- A literature and evidence review, conducted in April 2026 and updated through the project, covered the UK and international literature on the definition, epidemiology and cost of advanced Parkinson's and the UK policy and guidance landscape
- A parliamentary roundtable was held at Portcullis House in June 2026, chaired by Graeme Downie MP with clinicians, patient groups and academics
- An expert interview programme was conducted between June and September 2026 with the individuals and organisations listed in Annex C, using open-ended topic guides; interviews were recorded with consent and summarised, and figures stated in interview that could not be verified against a primary source have not been used.
- A scale and cost analysis.

THE SCALE AND COST ANALYSIS: SIX STAGES

The analysis runs in six steps, summarised in the table below.

STEP	WHAT IT DOES	PRIMARY SOURCES
1. Denominator	England population living with Parkinson's	Parkinson's UK prevalence estimate; ONS mid-2024 population estimates
2. Cohort	Share of that population meeting 5-2-1, at three thresholds	Malaty et al (2022); Chaudhuri et al (2024)
3. NHS cost	Hospital admissions and physician consultations for the cohort, converted to cost	Malaty et al; Parkinson's UK Excellence Network admissions dashboard; NHS National Cost Collection 2024/25; PSSRU Unit Costs 2025
4. Unpaid care	Unpaid carer hours for the cohort, valued on a declared basis	Malaty et al; PSSRU Unit Costs 2025; ONS earnings
5. Cross-checks	Model per-person values tested against the UK literature	Weir et al (2018); Findley et al (2011); Wijers et al (2024)
6. Sensitivity	Results across thresholds and every assumption	All of the above

Stage 1

The base is the Parkinson's UK estimate of approximately 166,000 people in the UK with a confirmed diagnosis.[149] Because prevalence is concentrated in older ages and England is younger than the other UK nations, the UK figure is scaled to England using England's share of the UK population aged 65 and over rather than its share of the total population, giving approximately 138,500; the all-ages basis is a sensitivity.[150] The denominator is not adjusted upward for undercounting and the direction of bias is stated.

Stage 2

The thresholds in Chapter 2 are applied to the denominator. The two-or-more share is bounded from the criterion counts in the source study rather than reported by its authors, and is presented as a range.[151] The source study reports resource use for the 5-2-1-positive group as a whole; applying those rates to the smaller two-or-more cohort understates its per-person resource use, and the base case is conservative in that respect.

Stage 3

The share of patients hospitalised for Parkinson's in the previous 12 months (19.3% against 5.4%) is converted to admissions and cost using the admissions per hospitalised person (approximately 1.8), cost per admission (approximately £3,980) and bed days per admission (approximately 7.4) observed for people with Parkinson's in England in 2025/26.[152,153]

The dashboard does not publish a methods page; the analysis assumes that Parkinson's means any recorded Parkinson's diagnosis and that costs are on a national reference cost basis. Physician consultations (8.3 against 5.0 a year) are not split by type in the source study; because 8.3 consultations a year cannot all be specialist contacts in an English pathway that calls for specialist review every six to twelve months, and because the multinational sample was drawn largely from systems in which neurologists carry routine management, the analysis assumes one-third are specialist, costed at the 2024/25 National Cost Collection consultant-led follow-up attendance split evenly between neurology and geriatric medicine, and two-thirds are GP consultations costed at the PSSRU 2025 per-consultation cost.[154,155,156] The specialist share is an FHR assumption and is tested at 20% and 50%. Admissions and consultations are summed; all other NHS costs are excluded.

Stage 4

Unpaid carer hours (21.5 against 8.7 a week, population means) are multiplied by 52 and by the cohort.[157] The base case values each hour at replacement cost, the PSSRU 2025 homecare worker rate, consistent with the convention used in the UK literature.[158] The sensitivity values it at opportunity cost using ONS median hourly earnings.[159] Paid carer hours (9.4 against 2.4 a week) are reported descriptively and not costed.

Stage 5

Per-person values are compared with the UK literature as a check on plausibility. The model is not calibrated to those figures, so the comparison is an independent test rather than a fitted result. Weir et al, using linked primary care and hospital records, found an excess annual NHS cost of approximately £1,069 (2013 prices) for patients with markers of advanced disease.[160] Uprated to 2025/26 using the HCHS pay and prices index for 2014/15, the NHS Cost Inflation Index to 2024/25 and the 2025/26 Payment Scheme uplift, that is approximately £1,455 against the model's £1,453.[161,162,163] Findley et al reported informal care of approximately £12,454 per patient per year (2008/09 prices, replacement cost) for a UK advanced sample.[164] Uprated by the PSS pay and prices index to 2025/26 that is approximately £21,700 against the model's £35,700, a gap explained by homecare hourly rates having risen faster than the index since 2008/09. Wijers et al report 22 hours a week of informal care across all stages as a cross-country average, against 21.5 hours for the 5-2-1-positive group.[165]

Stage 6

Every assumption is tested one at a time; the results are in Annex B. Price year: all figures are at 2025/26 prices. Unit costs published at 2024/25 prices are uplifted by 4.15%, the cost uplift factor in the 2025/26 NHS Payment Scheme.[166] The homecare rate and the Findley comparator are uplifted by 6.5%, the PSS pay and prices increase for 2024/25, as the best available proxy.[167]

WHY TWO OR MORE CRITERIA

The published 5-2-1 figure of 33% counts anyone meeting at least one of the three criteria.

The source study also reports how many patients met each criterion individually, which allows the group meeting two or more to be bounded at approximately 10% to 14%; the study does not report the overlap directly, so this is a derived range.[168] That range sits close to the 15% found by independent physician judgement in a separate multinational study.[169]

Two further findings support the higher bar. Of patients who screened positive on any one criterion, only around a third were judged advanced by their own neurologist; the criteria's authors read this as evidence of a screen that catches people early and state that it mandates further investigation rather than diagnosing anything.[170] And the five-dose criterion, the one most often met on its own, is the weakest predictor of the three. The Delphi consensus that produced the criteria recorded that it was premature to determine which combinations of indicators need to be present (Annex D), so the two-or-more threshold is FHR's choice where the source left the question open.

CORROBORATING THE POPULATION ESTIMATE

The table sets the report's two thresholds against estimates of the same population made with different instruments, in different settings and from different data, including the largest and most recent UK dataset, the 2025 UK Parkinson's Audit. Every comparator except the last comes from people attending a service and so over-represents advanced disease relative to all people with Parkinson's; the England equivalents apply the same proportions to the same denominator and are illustrative. The rows shaded coral are this report's own figures.

SOURCE AND SETTING	INSTRUMENT	SHARE	ENGLAND EQUIVALENT (APPROXIMATE)
This report: base case	5-2-1, two or more criteria	10% to 14%	13,500 to 18,800
Malaty et al 2022, G7 consulting neurology, 4,714 patients[171]	Hoehn and Yahr stage 4 to 5 (loss of physical independence)	13.7%	19,000
Chaudhuri et al 2024, multinational consulting sample, UK subgroup[172]	Physician judgement	14.7% UK; 15% overall	20,500
Martinez-Martin et al 2015, international specialist clinics, dementia excluded[173]	MDS-UPDRS severity level: severe	16%	22,000
UK Parkinson's Audit 2025, 7,088 elderly care and neurology outpatients[174]	Markers of advanced disease recorded (dementia, frailty, swallowing, nursing-level care)	22.9%	32,000
This report: upper bound	5-2-1, any one criterion, as published	33%	45,400
Malaty et al 2022, same sample[175]	Hoehn and Yahr stage 3 to 5	33.5%	46,500
UK Parkinson's Audit 2025, same sample[176]	Four-stage care model: complex phase (plus palliative)	39.5% (42.4%)	55,000 to 59,000
Fasano et al 2019, movement disorder centres, 2,615 patients[177]	Physician judgement	51%	71,000
Weir et al 2018, UK population-based, 7,060 patients followed from diagnosis[178]	Proxy markers in routine records, cumulative over ten years	56% ever; 2% at year 1, 49% at year 10	Not comparable (incidence, not prevalence)

The comparators fall into four bands.

- At around 14% to 16% sit the base case, Hoehn and Yahr stage 4 to 5 in the same patients the 5-2-1 figures come from, physician judgement in general neurology and the severe band of the MDS-UPDRS: four instruments and three datasets give the same answer, and it is the point at which people lose independence.
- At around 23% sits the audit's advanced-disease markers, the only UK figure at scale, which uses a frailty and non-motor definition and measures the group a motor screen misses.
- At around 33% to 42% sit the any-one threshold, Hoehn and Yahr stage 3 and above and the audit's complex phase, the broad definitions.
- Above 50% sit specialist-centre judgement and ten-year cumulative incidence, which are explained by setting and by time rather than by definition.

The report's range is therefore not an artefact of the instrument chosen. One caution applies: convergence on size does not mean the instruments identify the same individuals, and establishing the overlap would require the competing definitions to be applied to a single UK population.

THE NHS COST FIGURE: PARTIAL AND CONSERVATIVE

The source study does not split consultations by physician type. FHR has assumed that one-third are with a specialist, which is consistent with the UK Parkinson's Audit finding that the great majority of patients see a specialist doctor or nurse at least every six months, implying two to three specialist contacts a

year within a total of eight; the assumption is tested both ways in Annex B.[179] The NHS figure covers admissions for Parkinson's and physician consultations only.

It is conservative in two further respects. The source study counts admissions for Parkinson's, whereas English hospital data counts every admission a person with Parkinson's has; on the base case people with advanced Parkinson's are roughly 12% of people with Parkinson's but accounts for only around 5% of recorded Parkinson's admissions. An alternative route, which starts from the admissions the NHS actually records and apportions them to people with advanced Parkinson's using the source study's relative hospitalisation rate, gives an NHS excess of approximately £96 million to £124 million; it counts admissions for any cause and rests on an unproven assumption, so it is presented as a sensitivity in Annex B. And the source study reports resource use for everyone meeting at least one criterion, not for the two-or-more group, so per-person resource use is understated.[180] The headline figure is corroborated by an independent study using linked NHS records, which found an excess annual NHS cost for patients with markers of advanced disease that, uprated to 2025/26, is within 1% of the figure produced here.[181]

VALUING UNPAID CARE

The replacement-cost basis values each hour of unpaid care at what it would cost to buy the same care from a paid homecare worker, approximately £32 an hour at 2025/26 prices.[182] The opportunity-cost basis values each hour at what the carer could otherwise have earned, using ONS median earnings; on that basis the figure falls by around 40%, to roughly £21,000 per person per year.[183] The only published UK estimate of informal care costs for an advanced Parkinson's population, uprated to today's prices, lands close to the lower figure.[184] The replacement-cost convention is declared as the estimate and the opportunity-cost figure is shown as a conservative comparator. NHS and unpaid care figures rest on different methodological bases and are not additive.

SUMMARY OF LIMITATIONS

- The resource-use data is multinational rather than English, drawn from a consulting population on oral therapy and naive to device-aided therapy, and relies on patient and carer recall. The excess figures, where recall error largely cancels, are the more reliable and are the ones the report leads with.
- Resource use is reported for everyone meeting at least one criterion, not for the two-or-more subgroup; the base case understates per-person resource use for the smaller, more affected cohort.
- The hospitalisation measure counts admissions for Parkinson's only, whereas English data counts any admission of a person with Parkinson's; the base case is conservative on that account and Annex B shows the alternative.
- The consultation count is not split by physician type; the one-third specialist share is an FHR assumption and is tested both ways.
- The NHS figure covers admissions and physician consultations only.
- The valuation basis for unpaid care moves the figure by around 40%; the replacement-cost convention is declared and the opportunity-cost basis is shown.
- The 5-2-1 criteria capture motor symptoms and do not capture non-motor symptoms; the estimate under-represents the frailer, non-motor-driven group.
- The any-one-of-three logic of the published criteria was never assessed by the consensus that produced them, and the two-or-more threshold used here is FHR's choice where the source left the question open. The choice is justified in Chapter 2 and tested against other instruments in Chapter 3.
- Convergence between the base case and other instruments supports the size of the population, not the identity of its members. The instruments overlap only partly and the extent of the overlap has not been measured.
- The Parkinson's UK dashboard does not publish its definitions; the assumptions made are stated.
- NHS and unpaid care figures rest on different methodological bases and are not additive.

TRANSPARENCY STATEMENT

The 5-2-1 criteria were developed with AbbVie involvement: the 2018 Delphi consensus from which they derive was designed, conducted and funded by AbbVie, three of its authors were AbbVie employees and its steering committee received AbbVie honoraria. The study used to size and cost the population was funded by AbbVie: seven of its authors were AbbVie employees, the survey provider was commissioned by AbbVie to perform the analysis, and the underlying survey was sponsored by several pharmaceutical companies of which AbbVie was one.[185] This report was commissioned by AbbVie. FHR retained editorial independence over method, findings and recommendations, and has used the criteria to identify people who warrant clinical review rather than to size a treatment population.

Annex B: Sensitivity analysis

The tables show the effect on the base-case midpoint of changing each assumption in turn, with all others held at base case. Percentages are approximate and are computed in FHR's scale and cost model, which is available on request.

NHS COST (CHANGE TO THE BASE-CASE MIDPOINT EXCESS OF APPROXIMATELY £23.5 MILLION)

ASSUMPTION CHANGED	EXCESS, LOWER	EXCESS, UPPER	CHANGE VS BASE
Base case	£19.7m	£27.3m	
Cost per admission: national reference cost instead of observed dashboard cost	£16.3m	£22.6m	minus 17%
Admissions: emergency only, at emergency cost per admission	£22.1m	£30.6m	plus 12%
Consultation split: 50% specialist	£21.5m	£29.8m	plus 9%
Consultation split: 20% specialist	£18.2m	£25.3m	minus 7%
Specialist unit cost: service average instead of face-to-face follow-up	£20.1m	£27.8m	plus 2%
Denominator: all-ages share instead of age-weighted	£20.0m	£27.7m	plus 1%
GP unit cost: excluding qualification costs	£19.5m	£27.0m	minus 1%
Admissions: observed Parkinson's admissions apportioned to the cohort (any cause)	£96m	£124m	plus 370%

The last row is the dashboard-anchored alternative described in Chapter 3. It starts from the approximately 112,400 admissions recorded for people with Parkinson's in England in 2025/26 and apportions them between people with advanced Parkinson's and the rest of the Parkinson's population using the source study's relative hospitalisation rate of 3.6.[186,187] On that route the population in scope has approximately 2.2 admissions per person a year and accounts for 28% to 36% of all Parkinson's admissions. It counts admissions for any cause rather than for Parkinson's and assumes that the relative rate observed for Parkinson's-related admissions also holds for all-cause admissions, which is unproven. It is presented as a single labelled sensitivity and not as part of the headline range.

UNPAID CARE (CHANGE TO THE BASE-CASE MIDPOINT GROSS OF APPROXIMATELY £578 MILLION)

VALUATION BASIS	HOURLY VALUE	GROSS, LOWER	GROSS, UPPER	CHANGE VS BASE
Base case: replacement cost, PSSRU homecare worker hour uplifted to 2025/26	£31.95	£484m	£672m	
Opportunity cost: ONS all-employee median hourly earnings	£17.96	£272m	£378m	minus 44%
Comparator: Findley et al (2011) informal care cost per patient, uprated	n/a	£293m	£408m	minus 39%
Denominator: all-ages share instead of age-weighted	£31.95	£491m	£682m	plus 1%

THE DEFINITIONAL THRESHOLD

THRESHOLD	SHARE OF POPULATION	ENGLAND POPULATION	NHS EXCESS	UNPAID CARE, GROSS	RATIO TO BASE MIDPOINT
Two or more criteria, lower	Approximately 10%	13,500	£19.7m	£484m	0.84
Two or more criteria, upper	Approximately 14%	18,800	£27.3m	£672m	1.16
Physician judgement	15%	Approximately 20,800	Approximately £30m	Approximately £740m	1.3
Any one criterion	33%	Approximately 45,400	Approximately £66m	Approximately £1.6bn	2.8

Because every cost scales linearly with the cohort, the definitional threshold moves the totals far more than any unit-cost or resource-use assumption. No costing assumption moves the NHS figure by more than about a fifth; the definitional upper bound nearly triples it.

Annex C: Interview programme

The following individuals and organisations contributed to the expert interview programme between June and September 2026. FHR is grateful to all of them, including other experts who were interviewed but did not wish to be named. Interview evidence is reported in this report on a non-attributed basis unless the interviewee has agreed to be named.

NAME	ROLE AND ORGANISATION
Professor Camille Carroll	Professor of Clinical Neuroscience, Newcastle University
Sue Thomas	Neurology commissioning specialist; co-author of the four-stage UK Parkinson's service model
Professor Alastair Noyce	Professor of Neurology and Neuroepidemiology, Queen Mary University of London
Caroline Rassell and Claire Cope	Chief Executive and Head of Policy, Parkinson's UK
Dr Catherine Penman	Geriatric Medicine, University Hospitals Bristol and Weston
Dr Amanda Mobley	Consultant Clinical Neuropsychologist, Leicester General Hospital
Susan Mitchell	Head of Influencing, Richmond Group of Charities
Sam Mountney	Head of Policy and External Affairs, Neurological Alliance
Nick Thayer and Emily James	Head of Policy and Senior Policy and Programmes Manager, Company Chemists' Association

In addition, the parliamentary roundtable held at Portcullis House in June 2026, chaired by Graeme Downie MP, brought together parliamentarians, clinicians, patient representatives and charities, and its discussion informed the definitional approach and the recommendations.

Annex D: The definitional landscape and the origins of the 5-2-1 criteria

THE INSTRUMENTS IN USE

The table sets out the main instruments used to mark the point at which Parkinson's becomes advanced, what each measures and from whose point of view, how the threshold is set, and the share of people with Parkinson's each identifies where that has been measured. The shares are not comparable with one another: they come from different populations, most of them people attending clinic, who are more likely to have advanced disease than people with Parkinson's as a whole.

INSTRUMENT	WHAT IT MEASURES AND WHOSE VIEW	HOW 'ADVANCED' IS MARKED	SHARE IDENTIFIED (POPULATION)
5-2-1 criteria[188]	Current treatment burden: five or more daily levodopa doses, two or more hours OFF, one or more hour of troublesome dyskinesia. Clinician-observed, from information available in a routine consultation.	Any one criterion as published; this report requires two or more. Thresholds were set by expert vote and were never tested in combination.	33% any one; approximately 10% to 14% two or more (G7 consulting population)[189]
Physician judgement[190]	The treating clinician's overall impression, drawing on history, examination, treatment response and the patient's account. Implicit and unstandardised.	Classified as advanced by the clinician. Used as the reference standard against which other instruments are validated.	Approximately 15% (general neurology, 14.7% in a UK sample); approximately 51% (movement disorder centres). The gap reflects setting rather than definition: specialist centres receive the patients referred to them because their condition has become complex or they are being considered for device-aided therapy, so a far larger share of their caseload is advanced[191]
Hoehn and Yahr staging[192]	Disease progression as motor disability and postural instability, from unilateral signs (stage 1) to wheelchair or bed-bound (stage 5). Clinician-rated.	Commonly stage 3 and above. Stage 3 patients remain physically independent; stage 4 marks severe disability. The independence tipping point sits between the two.	33.5% stage 3 to 5; 13.7% stage 4 to 5 (same consulting population as the 5-2-1 figures)[193]
MDS-UPDRS[194]	Four-part rating scale: non-motor and motor experiences of daily living (patient-completed), motor examination (clinician-rated) and motor complications.	No advanced threshold in the scale. Published severity cut-offs: motor examination mild up to 32, moderate 33 to 58, severe 59 and above.	16% severe, 30% moderate (international specialist clinics, dementia excluded)
Activities of daily living[195]	Basic self-care: washing, dressing, feeding, mobility. Rated by clinician, patient or both.	Needing help with daily activities at least some of the time; reached unanimous consensus in the 2018 Delphi as an indicator of suspected advanced disease.	24% of 5-2-1-positive patients independent in daily activities, against 56% of screen-negative[196]

INSTRUMENT	WHAT IT MEASURES AND WHOSE VIEW	HOW 'ADVANCED' IS MARKED	SHARE IDENTIFIED (POPULATION)
Instrumental activities of daily living[197]	Higher-order function: managing money and correspondence, preparing sequential meals, shopping, transport, medication. Patient or carer report.	No Parkinson's-specific threshold. The nearest published indicator is inability to perform complex tasks at least some of the time (94% consensus in the 2018 Delphi).	No published share
Patient-reported outcome measures[198]	The person's own account of impact across mobility, daily activities, emotional wellbeing, stigma, cognition and communication (PDQ-39 and others).	No accepted threshold. Describe impact; do not classify stage.	No share; PDQ-39 summary index 33.6 in 5-2-1-positive patients against 23.1[199]
UK four-stage care model[200]	The stage of care management rather than of disease: the complex phase is when regimens become complicated and multidisciplinary input is needed.	Entry to the complex phase, recorded by the treating team without a standard definition.	39.5% complex and 2.9% palliative (UK Parkinson's Audit 2025, 7,088 outpatients)[201]
Markers of advanced disease in routine records[202]	Proxies in prescribing and clinical records: high levodopa-equivalent dose, dyskinesia, falls, dementia, psychosis, admission or care home entry. No clinical assessment.	Any marker present. Thresholds vary by study.	56% developed a marker within ten years of diagnosis (UK, population-based); 22.9% had dementia, frailty, swallowing or nursing-care markers recorded (UK Parkinson's Audit 2025)[203]
Composite screening questionnaires[204]	Screens that add non-motor and functional items to treatment-burden measures (CDEPA; MANAGE-PD, whose first section adds unpredictable fluctuations and daily-activity limitation to the three 5-2-1 items).	Questionnaire cut-offs for suspected advanced or inadequately controlled disease.	Both identify more patients than clinician judgement; shares not comparable

WHERE THE 5-2-1 CRITERIA COME FROM

The 5-2-1 criteria trace to a modified Delphi consensus of seventeen European movement disorder specialists, including from the UK, that ran between February 2014 and January 2015 and was published in 2018. The study was designed, conducted and funded by AbbVie, which also took part in interpreting the results and writing the paper.[205] The panel reached consensus on fifteen indicators of suspected advanced disease: six motor, five non-motor (including mild dementia, hallucinations and psychosis) and four functional (including repeated falls, needing help with daily activities and inability to perform complex tasks). The three items that became 5-2-1 are three of the six motor indicators. The panel's own top-ranked motor indicator, a moderate level of troublesome motor fluctuations, is not among them.[206]

The thresholds are consensus votes rather than derived cut-points: two hours of OFF time reached 86% agreement, one hour of troublesome dyskinesia 84% and five daily doses 79%. The panel ranked five daily doses last of the six motor indicators for clinical importance, and recorded that it was premature to determine which combinations of indicators need to be present, listing the absence of any assessment of combinations as a limitation.[207] The any-one-of-three logic that later became the 5-2-1 screen was therefore never tested by the consensus that produced its items. The largest validation study, which supplies the resource-use data used in Chapter 3, found the three criteria far from equal: against clinician judgement, two or more hours of OFF time and one or more hour of dyskinesia were strong predictors of advanced disease, while five daily doses was markedly weaker.[208]

The purpose of the criteria is debated within the specialist literature. The 2018 study linked its indicators to the timing of device-aided therapy, and early applications followed that reading. A Dutch group later assessed the criteria against expert-judged eligibility for referral for advanced therapy and challenged the validation study in correspondence.[209] In their 2024 response, the criteria's authors stated that 5-2-1 was not developed to screen for device-aided therapy eligibility and is not an indication to refer for it: it is a screening aid to identify people inadequately controlled on oral medication who may warrant further evaluation, which may include specialist input. They acknowledge that it does not encompass cognition or autonomic function.[210] That is the use this report makes of it. The primary literature consistently describes 5-2-1 as criteria or screening criteria; the phrase "5-2-1 rule", which appears in some educational and charity material, overstates what the tool is, and this report does not use it.

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