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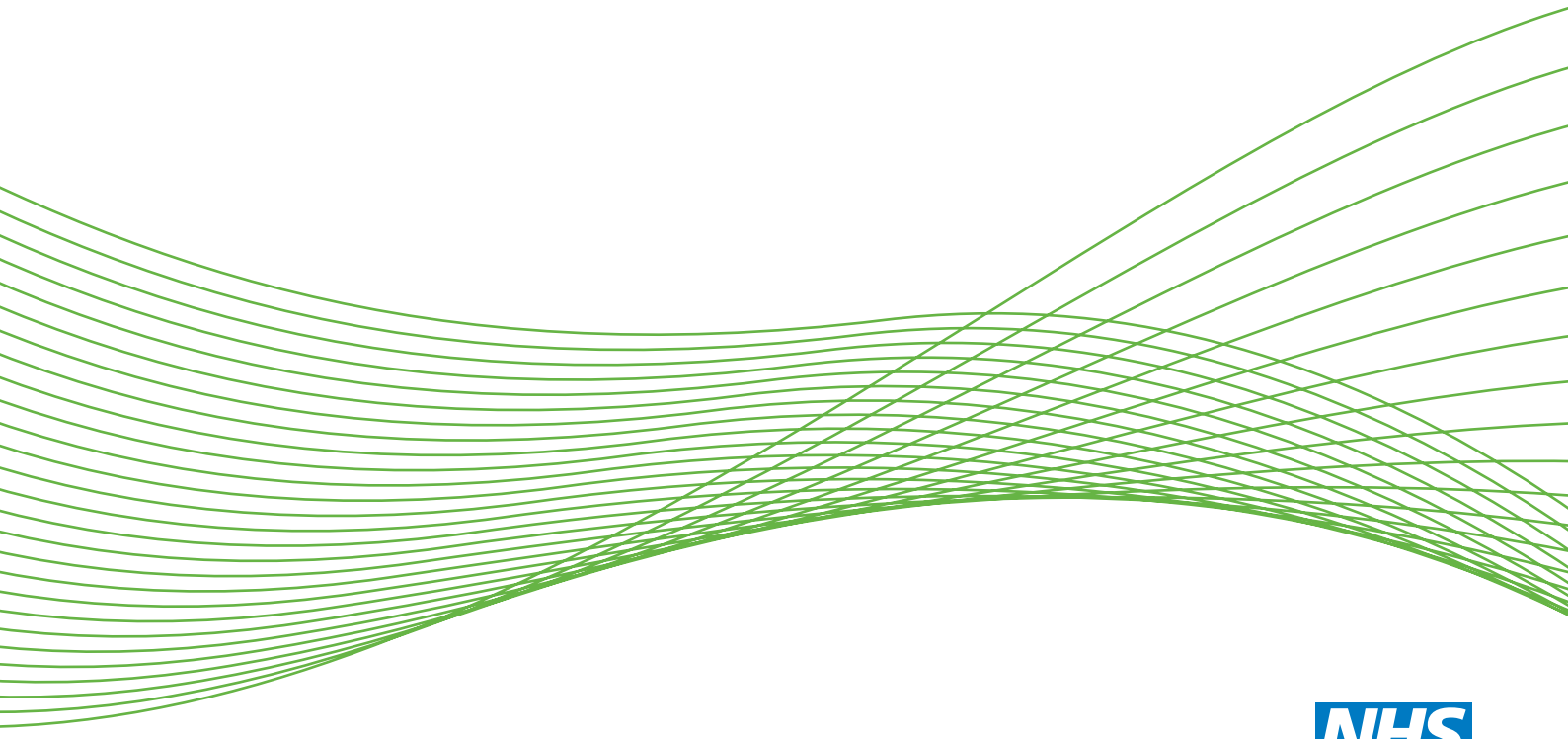

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Specialist rehabilitation for people with Parkinson's disease in the community: a randomised controlled trial

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Abstract

Specialist rehabilitation for people with Parkinson's disease in the community: a randomised controlled trial

Heather Gage,[1]* Linda Grainger,[1] Sharlene Ting,[1] Peter Williams,[2] Christina Chorley,[1] Gillian Carey,[1] Neville Borg,[1] Karen Bryan,[3] Beverly Castleton,[4] Patrick Trend,[5] Julie Kaye,[3] Jake Jordan[1] and Derick Wade[6]

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Background: Multidisciplinary rehabilitation is recommended for Parkinson's disease, but evidence suggests that benefit is not sustained.

Objectives: (1) Implement a specialist domiciliary rehabilitation service for people with Parkinson's and carers. (2) Provide continuing support from trained care assistants to half receiving the rehabilitation. (3) Evaluate the clinical effectiveness of the service, and the value added by the care assistants, compared with usual care. (4) Assess the costs of the interventions. (5) Investigate the acceptability of the service. (6) Deliver guidance for commissioners.

Design: Pragmatic three-parallel group randomised controlled trial.

Setting: Community, county of Surrey, England, 2010–11.

Participants: People with Parkinson's, at all stages of the disease, and live-in carers.

Interventions: Groups A and B received specialist rehabilitation from a multidisciplinary team (MDT) – comprising Parkinson's nurse specialists, physiotherapists, occupational therapists, and speech and language therapists – delivered at home, tailored to individual needs, over 6 weeks (about 9 hours' individual therapy per patient). In addition to the MDT, participants in group B received ongoing support for a further 4 months from a care assistant trained in Parkinson's (PCA), embedded in the MDT (1 hour per week per patient). Participants in control group (C) received care as usual (no co-ordinated MDT or ongoing support).

Main outcome measures: Follow-up assessments were conducted in participants' homes at 6, 24 and 36 weeks after baseline. Primary outcomes: Self-Assessment Parkinson's Disease Disability Scale (patients); the Modified Caregiver Strain Index (carers). Secondary outcomes included: for patients, disease-specific and generic health-related quality of life, psychological well-being, self-efficacy, mobility, falls and speech; for carers, strain, stress, health-related quality of life, psychological well-being and functioning.

Results: A total of 306 people with Parkinson's (and 182 live-in carers) were randomised [group A, $n = 102$ ($n = 61$); group B, $n = 101$ ($n = 60$); group C, $n = 103$ ($n = 61$)], of whom 269 (155) were analysed at baseline, pilot cohort excluded. Attrition occurred at all stages. A per-protocol analysis [people with Parkinson's, $n = 227$ (live-in carers, $n = 125$)] [group A, $n = 75$ ($n = 45$); group B, $n = 69$ ($n = 37$); group C, $n = 83$ ($n = 43$)] showed that, at the end of the MDT intervention, people with Parkinson's in groups A and B, compared with group C, had reduced anxiety ($p = 0.02$); their carers had improved psychological well-being ($p = 0.02$). People with Parkinson's in groups A and B also had marginally reduced disability (primary outcome, $p = 0.09$), and improved non-motor symptoms ($p = 0.06$) and health-related quality of life ($p = 0.07$), compared with C. There were significant differences in change scores between week 6 (end of MDT) and week 24 (end of PCA for group B) in favour of group B, owing to worsening in group A (no PCA support) in posture ($p = 0.001$); non-motor symptoms ($p = 0.05$); health-related quality of life ($p = 0.07$); and self-efficacy ($p = 0.09$). Carers in group B (vs. group A) reported a tendency for reduced strain ($p = 0.06$). At 36 weeks post recruitment, 3 months after the end of PCA support for group B, there were few differences between the groups. Participants reported learning about Parkinson's, and valued individual attention. The MDT cost £833; PCA support was £600 extra, per patient (2011 Great British pounds).

Conclusions: Further research is needed into ways of sustaining benefits from rehabilitation including the use of care assistants.

Study registration: Current Controlled Trials: ISRCTN44577970.

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Contents

List of tables

List of figures

List of boxes

List of abbreviations

A&E	accident and emergency
ADL	activities of daily living
ANOVA	analysis of variance
APPGPD	All Party Parliamentary Group inquiry on Parkinson's Disease
BMI	body mass index
COMT	catechol-*O*-methyltransferase
CONSORT	Consolidated Standards of Reporting Trials
CRF	client record form
DeNDRoN	Dementias and Neurodegenerative Disease Research Network
EQ-5D	European Quality of Life-5 Dimensions
GBP	Great British pounds
GP	general practitioner
HADS	Hospital Anxiety and Depression Scale
ITT	intention to treat
MAO-B	monoamine oxidase type B
MCS	mental component summary
MDS	Movement Disorder Society
MDT	multidisciplinary team
MMSE	Mini Mental State Examination
NICE	National Institute for Health and Care Excellence
OT	occupational therapist
PCA	Parkinson's care assistant
PCRN	primary care research network
PCS	physical component summary
PNS	Parkinson's nurse specialist
PPA	per-protocol analysis
PPI	patient and public involvement
PT	physiotherapist
RCT	randomised controlled trial
SD	standard deviation
SF-36	Short Form questionnaire-36 items
SLT	speech and language therapist
SPIRiTT	Specialist Parkinson's Integrated Rehabilitation Team Trial
UPDRS	Unified Parkinson's Disease Rating Scale
VAS	visual analogue scale

Plain English summary

Parkinson's disease (or 'Parkinson's') is caused by the deterioration of brain cells. Most people with Parkinson's are older. The condition makes it difficult for them to move, and many experience uncontrollable trembling. As the disease progresses, they require help with everyday activities such as eating, dressing and washing. There is currently no cure, and management of symptoms relies on medicines and rehabilitative therapies (physiotherapy, occupational therapy and speech and language therapy). A collaborative multidisciplinary team (MDT) approach to rehabilitation is recommended, but its effectiveness has not been widely researched. The Specialist Parkinson's Integrated Rehabilitation Team Trial (SPIRiTT) sought to address this gap in evidence.

People with Parkinson's received a 6-week MDT intervention in their own homes, and the impact on their functioning and well-being was measured. Family carers were included in the trial (if they wished) to see if the intervention reduced their strain and stress. Some participants additionally received telephone calls and visits from a care assistant trained in Parkinson's for 4 months after the MDT intervention ended to see if ongoing support maintained improvements.

A total of 227 people with Parkinson's (plus 125 live-in carers) completed the 6-month study. The MDT intervention resulted in the improved psychological well-being of people with Parkinson's and carers, and a small reduction in Parkinson's disability. Ongoing care assistant support helped to maintain some benefits from the MDT, and to slightly reduce carer strain. Participants reported that they valued the information and advice from the MDT professionals. More research is needed to identify effective management strategies.

Scientific summary

Background

Parkinson's disease (sometimes referred to as Parkinson's) is a degenerative neurological condition that affects mainly older people, but there are also significant numbers with young onset. Although frequently designated as a movement disorder, it additionally inflicts a range of distressing non-motor symptoms, (problems with pain, sleep, speech, swallowing, constipation, incontinence, sexual dysfunction, communication and social isolation). There is currently no known cure for Parkinson's disease, and treatment revolves around maintaining quality of life through symptom relief. The mainstay of management is a pharmacological regimen, which gradually becomes less effective and more complicated as the disease progresses. This is supported by rehabilitative therapies, assistive technologies and, occasionally, surgery. Given the range of symptoms and the complexity of managing Parkinson's disease, a collaborative multidisciplinary team (MDT) approach to rehabilitation is recommended. However, the effectiveness of the MDT approach has not been widely researched.

The Specialist Parkinson's Integrated Rehabilitation Team Trial (SPIRiTT) builds on the findings of a previous multidisciplinary rehabilitation programme, co-ordinated by a Parkinson's nurse specialist (PNS) in a day-hospital setting. This intervention resulted in significant immediate gains for patients in mobility, independence, well-being and health-related quality of life, but, in the absence of continuing input, these benefits had largely dissipated 4 months after the intervention ended. SPIRiTT delivers rehabilitation to people in their own homes, and evaluates whether or not the fading of benefit when specialist input is withdrawn can be avoided by providing continuing support from trained care assistants. Participants in SPIRiTT received an equivalent package of specialist rehabilitation to that used in the day-hospital study so that comparisons can be drawn between the models of domiciliary and day-hospital provision.

The SPIRiTT model of service delivery is based on recent NHS policy which promotes the provision of services closer to patients' homes, co-ordination of care by specialist nurses, supported self-management, personalised care planning, rehabilitation and carer support. The use of trained assistants is consistent with workforce policy which advocates the integration of non-registered health and social care workers with enhanced roles in MDTs, to implement and deliver therapy and monitor and support patients.

Objectives

1. Implement a specialist neurological rehabilitation service for people with Parkinson's and their family carers, delivered in their own homes, comprising MDT assessment, care planning and treatment (following the protocol previously evaluated in a day hospital).
2. Provide ongoing support from trained care assistants to those receiving the rehabilitation.
3. Evaluate the clinical effectiveness of the specialist rehabilitation service, and the value added by ongoing support from trained care assistants embedded in the MDT, compared with usual care, (largely non-specialist and non-team based).
4. Assess the costs of the specialist rehabilitation intervention, and of the ongoing care assistant support, and calculate relative cost-effectiveness, including consideration of savings from service use offsets.
5. Investigate the acceptability of the new service delivery models from the perspectives of all stakeholders (commissioners, MDT members, care assistants, managers, patients and family carers).
6. Deliver guidance for commissioners, providers and policy-makers.

Methods

Design
Pragmatic three-parallel group randomised controlled trial.

Setting
Contiguous communities around three district general hospitals in the county of Surrey, England, containing urban, suburban and rural localities and a broad mix of socioeconomic and ethnic groups.

Participants
People with Parkinson's, at all stages of the disease, and their live-in carers (where applicable).

Recruitment
People with Parkinson's were identified through hospital clinic lists; general practitioners; Parkinson's UK contacts; PNSs; community-based therapists; and word of mouth. Research nurses from the Primary Care Research Network and the Dementias and Neurodegenerative Diseases Research Network (DeNDRoN) assisted with recruitment. The interventions were delivered over 18 months, commencing September 2010.

Inclusion criteria
People with Parkinson's were included if they were 18 years of age or over; had a clinical diagnosis of Parkinson's disease; lived in the community (own home or minimally sheltered accommodation); lived in the catchment areas of three district hospitals in the county of Surrey; were able to read and write English in order to complete the self-report questionnaires; had not received a multidisciplinary package of care over the last 6 months; and had not taken part in rehabilitation research in the last 6 months. Live-in carers were included if they were 18 years of age or over and were able to read and write English in order to complete the self-report questionnaires. If a live-in carer did not want to take part in the research, the person with Parkinson's could still join the trial. However, carers were not accepted if the person with Parkinson's did not want to participate. Carers who did not take part in the research were included in the intervention.

Baseline data collection
Volunteers were entered into the trial in blocks (cohorts) of 30 (10 per group). They were visited at home by a research nurse. Consent was received and baseline data collection was completed (background demographic and health information and baseline outcome measures). Baseline data were checked to confirm participant eligibility.

Exclusion criteria
People with Parkinson's were excluded if they scored at the most favourable end of all outcome scales (as the trial would not be able to demonstrate improvement, and, in 6 months, had little likelihood of demonstrating reduction in any expected decline); and scored < 24 out of 30 on the Mini Mental State Examination (to ensure that those recruited could follow instructions associated with the rehabilitation intervention). Live-in carers were excluded if they scored at the most favourable end of all outcome scales (i.e. had no limitations).

Randomisation
Eligible volunteers were randomised to either group A (received MDT assessment and management for 6 weeks), group B (same MDT package and additionally received ongoing support for 4 months from a trained care assistant) or group C [received usual care: no co-ordinated MDT assessment and care, no ongoing support from a care assistant trained in Parkinson's (Parkinson's care assistant: PCA)]. A separate randomisation sequence was prepared for people with Parkinson's with and without live-in carers. In each instance, blocked randomisation was used to keep the group sizes even at 10 people with Parkinson's per group, that is to say a cohort of 30 people.

Specialist rehabilitation intervention (groups A and B)

A MDT comprising a PNS, a physiotherapist (PT), an occupational therapist (OT), and a speech and language therapist (SLT) visited the homes of participants to deliver a specialist rehabilitation package, tailored to individual needs, over 6 weeks (about 9 hours of individual therapy per patient). Educational materials were provided on aspects of Parkinson's disease. A client record form was left in the participant's home for the duration of the intervention, and was completed by each professional at each visit.
There were two team meetings per cohort to discuss patient care plans and progress. Referrals to other professionals were made when indicated, including to a neurologist, a community mental health team and a Parkinson's UK support worker.

Ongoing support (group B)

In addition to the programme of specialist MDT rehabilitation, participants in group B received ongoing support for 4 months from a PCA, starting at the end of the 6-week MDT intervention. The PCAs received training in Parkinson's disease, were embedded in the MDT and worked under the supervision of the PNS. Contact was via home visits and telephone (about 1 hour per week per patient of support), through which the PCA monitored progress in implementation of the agreed care plan and reported back to the MDT.

Usual care/control (group C)

Participants in the control group continued to receive care as usual (no co-ordinated MDT care or ongoing support). They were sent generic information (available from Parkinson's UK) about Parkinson's disease (which was also given to people in groups A and B by the MDT). At the end of the trial, people in the control group were offered an assessment by a member of the MDT (of their choice), and advice and referrals were provided, as indicated.

Outcome assessments

Research nurses visited participants in their homes to conduct follow-up assessments at three points (6 weeks, 24 weeks and 36 weeks) over 6 months.

Outcome measures

Measures of relevance to daily functioning were chosen as the primary outcomes: the Self Assessment Parkinson's Disease Disability Scale (patients report ease or difficulty of doing 25 general activities on a five-point scale) and the Modified Caregiver Strain Index. Secondary outcomes included: for patients, disease-specific and generic health-related quality of life, psychological well-being, self-efficacy, mobility, falls, speech and voice; and for carers, strain, stress, health-related quality of life, psychological well-being, and functioning.

Sample size calculations

Two hundred and seventy people with Parkinson's (90 per group) were required in order to detect a difference between groups in the change in the disability score of 1.25, after allowance for loss to follow-up. We expected to recruit 71 carers per group (because 79% of people with Parkinson's in the day-hospital study had carers).

Statistical analysis

Groups were compared at baseline. All outcomes were analysed at each follow-up assessment point. The null hypotheses tested were that there were no differences between the groups with respect to changes in each primary and secondary outcome measure from baseline (week 0) to each follow-up point (weeks 6, 24 and 36), and between each sequential follow-up point (weeks 6–24 and weeks 24–36). Within-group changes were also analysed.

Acceptability of the intervention

Feedback from participants was obtained using semistructured questionnaires. All members of the MDT and the PCAs were asked to provide reflective feedback (open comments) at three points during the trial, and through 'exit' interviews. Data were analysed descriptively and using thematic analysis.

Economic evaluation

A NHS perspective was adopted. The costs of the intervention were calculated in 2011 Great British pounds. The use of health and social care services were collected by self-report at baseline, 24- and 36-week assessments by recall for the previous 3 months, to explore cost offsets arising from the interventions. Outcomes were evaluated with reference to costs.

Results

A total of 306 people with Parkinson's (182 live-in carers) were randomised [group A, $n = 102$ ($n = 61$); group B, $n = 101$ ($n = 60$); group C, $n = 103$ ($n = 61$)]. Of these, 269 (155) were analysed at baseline. The first (pilot) cohort was not included in the analysis as the MDT processes were under development. There were some differences between groups at baseline. People with Parkinson's in group B scored worse on the Frenchay Activities Index ($p = 0.01$) and tended to display higher disability (Barthel Activities of Daily Living, $p = 0.08$) than those in groups A and C. Higher proportions in C screened positive for depression (Yale Depression Screen, $p = 0.01$); groups A and B scored worse than C on some speech items ($p = 0.03$ to $p = 0.08$).

Attrition occurred at all stages, and a per-protocol analysis is reported for 227 people with Parkinson's (125 live-in carers) [group A, $n = 75$ ($n = 45$); group B, $n = 69$ ($n = 37$); group C, $n = 83$ ($n = 43$)]. An intention-to-treat analysis was also conducted. The results and conclusions from each analysis are similar.

Effects of the multidisciplinary team

Compared with group C (control), people with Parkinson's receiving the 6-week MDT intervention (groups A and B) experienced an immediate reduction in anxiety ($p = 0.02$); their carers recorded improved psychological well-being [Short Form questionnaire-36 items (SF-36) mental component summary (MCS), $p = 0.02$]. People with Parkinson's also had marginally improved disability (primary outcome, $p = 0.09$), non-motor symptoms ($p = 0.06$) and health-related quality of life [European Quality of Life-5 Dimensions (EQ-5D) Index, $p = 0.07$].

Effects of ongoing support from Parkinson's care assistants

There were significant differences in change scores between week 6 (end of MDT) and week 24 (end of PCA for group B) in favour of group B due to worsening in group A (no PCA support) in posture ($p = 0.001$), non-motor symptoms ($p = 0.05$), health-related quality of life (EQ-5D Index, $p = 0.07$), and self-efficacy ($p = 0.09$). Carers in group B (vs. group A) reported a tendency for reduced strain (primary outcome, $p = 0.06$).

Long-term follow-up

At 36 weeks post recruitment (3 months after PCA support for group B ended), there were few differences between the groups. There were significant differences between changes in people with Parkinson's in group B and in groups A and C in psychological well-being (SF-36 MCS, both $p = 0.05$) and Speech Self Report ($p = 0.02$, 0.03) due to significant deteriorations in A and C. Gait of people with Parkinson's improved in group B versus group A ($p = 0.09$); mobility (Timed Up and Go) improved in group A versus group C ($p = 0.06$). The psychological well-being of carers in group A declined versus group B (SF-36 MCS, $p = 0.04$).

Acceptability

People with Parkinson's who received the MDT intervention reported that they had learnt a lot about the condition, and how to manage it; they valued the tailored advice and the opportunity to discuss their problems with knowledgeable professionals.

Costs of the intervention

The total cost per patient was £833 for the 6-week MDT, and an additional £600 for the 4 months of ongoing PCA support. There were no differences between groups in the cost of other service use. As no statistically significant differences in change scores between groups for either the patient or the carer primary outcome measures, or EQ-5D Index scores (for quality-adjusted life-years), at the final end point (6 months) were found, a full cost-effectiveness analysis was not undertaken.

Conclusions

Information on alternative specialist community rehabilitation models, such as that provided by the SPIRiTT trial, is important to enable evidence-based decisions to be made by service planners and commissioners. The SPIRiTT intervention incorporates key elements of interprofessional working (shared goal setting and care planning, effective communication channels and appropriate referrals to other specialities), and a client-centred approach that invites participants to prioritise their concerns. It also provides support for carers, which is a high policy priority, because it protects their health and improves their ability to cope.

The results showed that people with Parkinson's experienced reduced anxiety and a tendency for reduced disability and improved symptom control and health-related quality of life after the MDT intervention. There is also evidence that continuing PCA input provided some benefits [in symptom control, posture and (marginally) health-related quality of life] to people with Parkinson's while it lasted. Similarly, carers recorded improved psychological well-being at the end of the MDT intervention, and tendency to report reduced strain after the PCA support. Feedback from participants suggested that the MDT intervention was effective at increasing their understanding of the condition and signposting to other services.

Further research on the relative benefits and costs of alternative models of specialist multidisciplinary rehabilitation for people with Parkinson's in the community is required, including the means by which improvements gained from specialist MDT rehabilitation can be sustained. The potential of PCA support for people with Parkinson's and carers deserves further attention. A relatively small amount of PCA input in SPIRiTT helped to maintain patient functioning on some indicators, and to reduce carer strain, while it was provided, but more research is required on how the nature and 'dose' might affect longer-term outcomes.

Study registration

This trial is registered as ISRCTN44577970.

Funding

Funding for this study was provided by the Health Services and Delivery Research programme of the National Institute for Health Research, the South East Coast Dementias and Neurodegenerative Disease Research Network (DeNDRoN), and the NHS South East Coast.

Chapter 1 Introduction

Parkinson's disease

Parkinson's disease (sometimes referred to as Parkinson's) is a degenerative neurological condition that affects mainly older people, but there are also significant numbers with young onset.[1] Globally, it is the second most common neurological condition.[2] Within the UK, it is estimated that 1% of people over the age of 65 years have Parkinson's, with the prevalence rising to 2% among those over 85 years.[1] Parkinson's disease is caused by the destruction of cells in the substantia nigra of the brain, resulting in a lack of the neurotransmitter dopamine, and hence difficulties with movement. The main motor symptoms are bradykinesia (slowness of movement) and muscle rigidity. Tremor is also experienced in about 70% of people with Parkinson's. Although frequently designated a movement disorder, Parkinson's disease additionally inflicts a range of distressing non-motor symptoms, including pain, sleep disturbance, postural instability (leading to falls), and problems with speech, swallowing, constipation, incontinence and sexual dysfunction.[3–5] Difficulties with communication and impaired cognitive function can result in social isolation, and many people with Parkinson's suffer depression. About 25% will develop dementia.[6]

There is currently no known cure for Parkinson's disease. Symptoms usually appear gradually on one side of the body first and worsen over time. As the disease progresses, people with Parkinson's become increasingly dependent, and a considerable burden is carried by family carers. Treatment revolves around maintaining quality of life through symptom relief, and may involve a large number of different professionals and services (specialist neurology, primary care, nursing, physiotherapy, occupational therapy, speech and language therapy, pharmacy, dietetics, continence, psychiatry, mental health and social care).[7]

Four stages in the development of Parkinson's disease have been identified, each requiring different types and levels of care. Around the time of diagnosis, when the symptoms are mild, patients and carers need information and support to help them understand the nature of the condition and services available. As symptoms gradually worsen, patients enter a maintenance stage, when minor disability is managed effectively by a drug regimen and input from a range of therapists. In the complex stage, when medications are less effective, symptoms become difficult to manage and a variety of complications arise, new medicines have to be added and carefully adjusted to control for side effects, and additional non-pharmacological treatment input is required. At the palliative stage, when drugs may no longer be effective, relieving distress, pain and other symptoms and providing support for the patient and family are the sole remaining options.[8]

The mainstay of management of Parkinson's disease is a pharmacological regimen, which gradually becomes less effective and more complicated as the disease progresses. This is supported by rehabilitative therapies, assistive technologies and, occasionally, surgery. The range of pharmacological options has increased over time, and centres around levodopa (which acts through replacing depleted dopamine stores in the brain), dopamine agonists, (typically used early in the disease to stimulate the production of dopamine) and monoamine oxidase type B (MAO-B) inhibitors and catechol-*O*-methyltransferase (COMT) inhibitors (to prolong the effect of levodopa).[9]

Parkinson's is a complex condition and affects people differently, so individual assessment, and treatments tailored to specific needs, are required.[9] In particular, Parkinson's medications need to be titrated to balance symptom relief with significant side effects, including nausea, daytime sleepiness, vivid dreams and hallucinations, increased libido and compulsive behaviours (gambling, shopping and other repetitive activities).[2] When drugs are working, the patient is said to be 'on', but as the effect of a dose wears off, symptoms return (the patient is 'off'), and the prevention of large and rapid swings in functioning requires careful adjustment of the timing and size of doses. Over time, the efficacy of medications diminishes, and

increases in the dosage need to be managed carefully to reduce the risk of dyskinesia (large uncontrollable limb movements). Rehabilitative therapies have a role in primary and secondary prevention, and to optimise health, functioning and quality of life, at all stages of the disease.[10]

Rationale for Specialist Parkinson's Integrated Rehabilitation Team Trial

Given the range of symptoms and the complexity of managing Parkinson's disease, a collaborative multidisciplinary team (MDT) approach to rehabilitation is recommended in order to provide a co-ordinated and seamless package of care to people with Parkinson's, and is accepted best practice.[3,10–13] However, the effectiveness of the MDT approach has not been widely researched.[3,13–18] Active management within a co-ordinated multidisciplinary Parkinson's disease centre had a positive impact on functioning over 12 months,[19] and two community-based studies have identified short-term benefits of treatment.[20,21] One self-management programme has been found to have positive effects on health-related quality of life at 6 months,[22] but another study found that short-term effects were not sustained.[23] A need has been expressed for studies that identify cost-effective service delivery models that reduce disability and dependency and prevent admission to long-term care.[12–16,24,25] The Specialist Parkinson's Integrated Rehabilitation Team Trial (SPIRiTT) investigates the effectiveness and cost-effectiveness of two alternative models of specialist rehabilitation for people with Parkinson's in a community setting.

SPIRiTT builds on the findings of a previous multidisciplinary rehabilitation programme, co-ordinated by a Parkinson's nurse specialist (PNS) in a day-hospital setting.[26] This intervention resulted in significant immediate gains for patients in mobility, independence, well-being and health-related quality of life,[21] but, in the absence of continuing input, these benefits had largely dissipated 4 months after the intervention ended.[26] Some patients were excluded because they could not get to the day hospital. Moreover, the accompanying economic evaluation showed that day-hospital treatment incurred facility overhead costs and involved the use of expensive hospital transport for patients with more advanced disease.[27]

SPIRiTT specifically addresses the issue of patient transport raised by the day-hospital model by delivering rehabilitation to people in their own homes. Moreover, it evaluated whether or not the fading of benefit when specialist input is withdrawn (a common feature of time-limited rehabilitation interventions)[27] can be avoided in a cost-effective way by providing continuing support from specially trained care assistants. Participants in SPIRiTT received an equivalent package of specialist rehabilitation to that used in the day-hospital study so that valid comparisons could be drawn between the models of domiciliary and day-hospital provision.

Policy context

The SPIRiTT model of service delivery is grounded in the recommendations of several recent policy documents of the English NHS. These promote the integration of health and social care services,[28] provision of services closer to patients' homes,[28] co-ordination of care for particular patient groups by specialist disease-specific nurses,[29] supported self-management[29] and personalised care planning, rehabilitation and carer support in order to reduce costly unplanned hospital admissions.[30] Moreover, guidelines from the National Institute for Health and Care Excellence (NICE) for the management of Parkinson's disease[12] recommend regular patient review, comprehensive care plans, a central role for PNSs and regular access to physiotherapy, occupational therapy, and speech and language therapy. PNSs are deployed in many parts of the NHS, supporting specialist neurology teams in acute settings, or as part of community services. Evaluations of PNS roles suggest that they do not improve outcomes, compared with doctors, but that their input is highly valued by patients and carers because they are accessible, and for the information and support that they provide.[31,32] PNSs are key to the organisation of a MDT, being pivotal to the co-ordination of care around the patient.

Many people with Parkinson's do not routinely see PNSs or individual therapists, and even fewer receive co-ordinated MDT input.[33,34] Inequalities in care, shortages of specialist nurses and therapists, poorly integrated services, and inadequate information provision and signposting are key features of the gap between established standards of care and the care received, that have recently been identified.[33,35–38]

SPIRiTT investigates the impact of implementing a proactive approach to Parkinson's management, in line with recent recommendations. Other research has shown routine assessment and support for older people living in the community, with a variety of conditions, can have positive effects on mortality and admission to long-term care.[39] Evaluations have been conducted in a range of countries, including the USA,[40–43] Canada,[44] Australia,[45,46] Denmark,[47,48] Italy[49] and Switzerland,[50] but overall evidence on outcomes (such as physical functioning and health-related quality of life), service use and costs is inconsistent.[46,51,52] Through a focus on outcomes for people with Parkinson's, SPIRiTT seeks to extend the current evidence base.

Workforce issues

Capacity constraints in the form of high PNS caseloads and shortages of therapists were identified by NICE as barriers to the delivery of their guidance for management of Parkinson's disease,[12] and these have been confirmed by a recent survey of PNSs.[53] While NICE recommends a caseload of 300 patients, over half of PNSs have lists in excess of 500, with adverse effects on the amount of routine support that they can provide to patients. In common with other advanced practice nurses in the community, PNSs report undertaking a variety of tasks (some of which do not require advanced skills), and that time pressures create a need to risk stratify patients. Their focus is on 'crisis' management rather than ongoing advice and support.[54,55] The use of care assistants, trained in the special features and management of Parkinson's, working with PNSs and MDTs of health-care professionals in the community on assigned tasks appropriate to their skill level and knowledge, is one way in which resources for delivering care and support to people with Parkinson's can be increased.

Competency-based training enables non-registered staff to properly complement the activities of professionals,[28,56] and professionals to appropriately meet supervision, delegation and accountability challenges.[57] Trained care assistants have been shown to be effective at underpinning professional working and to have a positive impact on nurses' ability to provide high-quality care, their work experiences, and the cost-effectiveness of service delivery.[58] The use of trained assistants is consistent with NHS policy for the health and social care workforce which advocates the integration of non-registered health and social care workers with enhanced roles in MDTs, to implement and deliver therapy and monitor and support patients,[30,59] as a means of increasing the flexibility, efficiency and responsiveness of services.[60,61]

Aims, objectives and hypotheses

The **aims** of the SPIRiTT study were to evaluate two models of specialist MDT rehabilitation for people with Parkinson's in the community, to add to the existing evidence base, to inform future service development and commissioning, and ultimately to improve the quality of care and outcomes for patients and live-in carers (i.e. family, friends and paid carers living in the same household). The specialist rehabilitation was based on a multidisciplinary service that works with the patient and family to resolve problems, through a process of goal setting, care planning, intervention and evaluation, to achieve outcomes that maximise functioning and social participation with minimum distress to patient or family carer.[62] The research set out to explore not just the multidisciplinary professional input, but also budgetary and management arrangements, and barriers and facilitators to cross-sector working, that may impact on future implementation of the model.

The specific **objectives** were to:

1. implement a specialist neurological rehabilitation service for people with Parkinson's and their live-in carers, delivered in their own homes, comprising MDT assessment, care planning and treatment (following the protocol previously evaluated in a day-hospital setting)
2. provide ongoing support from specially trained care assistants to half (randomly selected) of those receiving the specialist rehabilitation
3. evaluate the clinical effectiveness of the specialist rehabilitation service, and the value added by ongoing support from trained care assistants embedded in the MDT, compared with usual care (which is largely non-specialist and non-team based), across a range of patient and carer outcomes
4. assess the costs of the specialist rehabilitation intervention and of the ongoing care assistant support, and calculate relative cost-effectiveness, including the consideration of savings from service use offsets
5. investigate the acceptability of the new service delivery models (specialist domiciliary rehabilitation with and without ongoing support from trained care assistants) from the perspectives of all stakeholders including commissioners, MDT members, care assistants, service managers, patients and live-in carers and
6. deliver guidance for commissioners, providers and policy-makers about the acceptability, clinical effectiveness and cost-effectiveness of different models of specialist neurological rehabilitation.

The **hypotheses** were that:

1. a package of domiciliary multidisciplinary specialist rehabilitation would benefit:
   i. people with Parkinson's in terms of maintaining mobility and independence (primary outcome for patients) and improving well-being and health-related quality of life
   ii. live-in carers in terms of reduced strain (primary outcome for carers) and improved health-related quality of life and
   iii. society through reduced use of other health and social care services, including hospitalisations and admissions to long-term care
2. the addition of 4 months of ongoing support from trained care assistants would help to maintain the benefits of the specialist team rehabilitation, and avoid the fading of effects that typically accompanies the withdrawal of input
3. the intervention would be acceptable to major stakeholders, and barriers and facilitators to wider implementation would be identified.

Chapter 2 Methods

Design

The study consisted of a pragmatic three-parallel group randomised controlled trial (RCT). People with Parkinson's in group A were assessed and managed by a specialist MDT for 6 weeks according to a care plan that was agreed among the professionals and with the patient and carer. Group B had the same MDT assessment and management, and additionally received ongoing support for 4 months from a trained care assistant. Group C received normal care (i.e. no co-ordinated MDT assessment and care planning, and no ongoing support). Follow-up was conducted at three points (6, 24 and 36 weeks) over 6 months to determine the impact and relative cost-effectiveness of the two interventions. Qualitative interviews were undertaken with providers (MDT members, care assistants), and patients and carers in groups A and B, to gain feedback about the acceptability of the interventions. The Consolidated Standards of Reporting Trials (CONSORT) flow diagram[63] summarises the study design (*Figure 1*).

Setting

Contiguous communities around three district general hospitals in the county of Surrey, England. The study area contains urban, suburban and rural localities and a broad mix of socioeconomic and ethnic groups.

Participants

The project sought to recruit people with Parkinson's, at all stages of the disease, and their live-in carers (where applicable). People with Parkinson's were identified by a variety of means, including hospital clinic lists; general practitioners (GPs); Parkinson's UK contacts; PNSs; community-based therapists; and word of mouth. Research nurses from the Primary Care Research Network (PCRN) and the Dementias and Neurodegenerative Diseases Research Network (DeNDRoN) assisted with the identification of people with Parkinson's through general practices and specialist Parkinson's hospital clinics, respectively. Any interested person with Parkinson's was given a leaflet which included a brief description of the study and the contact details of the research team (see *Appendix 1*). Posters (see *Appendix 2*) were sent to relevant organisations with a request that they be displayed in areas visible to people with Parkinson's.

People with Parkinson's could volunteer to take part in the study by contacting the research team by telephone, post or e-mail. An initial eligibility screen was undertaken by a researcher by telephone (see *Appendix 3*). Volunteers who met the inclusion criteria (*Box 1*) were sent full information about the trial, and a consent form. A separate information sheet and consent form was provided for people with Parkinson's and live-in carers (family, friends, and paid carers living in the same household), where appropriate (see *Appendix 4*).

Recruitment

Following telephone screening, a pool of eligible volunteers was built up. The MDT intervention was started once this pool contained 180 people with Parkinson's, a process that took about 3 months (June to August 2010). The establishment of this pool of patients ensured that the 6-week intervention could be delivered continuously to six cohorts of 30 patients, without any delays. Volunteers were informed during the telephone screening that it could be a few months before their turn for starting the trial came around. While the early volunteers were receiving treatment, recruitment of further people with Parkinson's

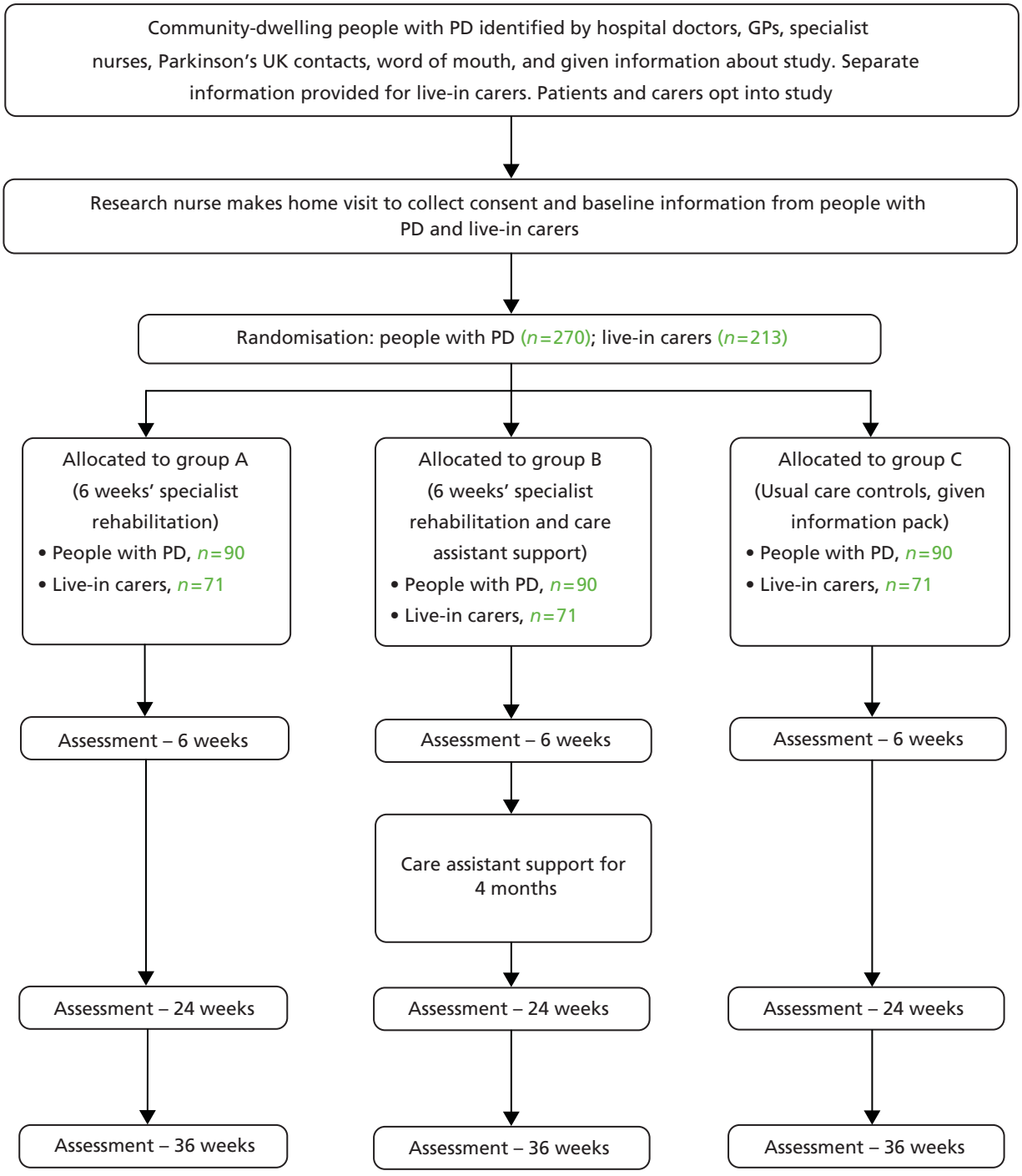

FIGURE 1 Consolidated Standards of Reporting Trials flow chart for SPIRiTT. GP, general practitioner; PD, Parkinson's disease.

BOX 1 Inclusion criteria

People with Parkinson's (any stage of the disease) were included if they:

- were 18 years of age, or over
- had a clinical diagnosis of Parkinson's disease
- lived in the community (own home or minimally sheltered accommodation) with their own living areas
- lived in the catchment areas of three district hospitals in the county of Surrey
- were able to read and write English in order to complete the self-report questionnaires
- had not received a multidisciplinary package of care over the last 6 months
- had not taken part in rehabilitation research in the last 6 months.

Live-in carers were included if they were:

- 18 years of age, or over
- able to read and write English in order to complete the self-report questionnaires.

continued until the study target sample size of 270 (see sample size calculations below) was achieved. In this way, the research team ensured that the next cohort of patients was assembled for the MDT in a timely manner, and that the MDT professionals had no idle periods pending recruitment of participants.

Treatment of the first cohort started in September 2010. An ex post decision was made to consider the first cohort as a pilot, and recruitment was increased to 306 people with Parkinson's so that an additional cohort could be treated and any volunteers found ineligible at baseline could be replaced. The MDT rehabilitation programme for the final cohort ended December 2011, with PCA support for that cohort finishing in April 2012, and final assessments completed in July 2012.

Consent and baseline data collection

Volunteers were entered into the trial in blocks (cohorts) of 30. These blocks were initially defined on the basis of participants' home addresses, in order to reduce the time and costs of travel to participants' homes for the delivery of the intervention and collection of the research data. In the later cohorts, geographical grouping was no longer possible as the last volunteers were spread around the whole catchment area.

When a volunteer was assigned to a cohort, an appointment was made for a research nurse to make a home visit to answer further questions, receive consent (person with Parkinson's and carer separately), and collect baseline information (see *Appendix 4*). If a live-in carer did not want to take part in the research, the person with Parkinson's could still join the trial. However, carers were not accepted if the person with Parkinson's did not want to participate. When live-in carers opted out of taking part in the research, they were still invited to be part of the MDT treatment programme. The baseline visit was arranged as close as possible to the start of the intervention for any cohort. However, with 30 volunteers (and live-in carers) in each cohort to be assessed, the visits had to be spread over a period of 4 to 6 weeks.

Baseline information

People with Parkinson's self-reported details of their age, sex, ethnicity, education, housing tenure, living situation (alone or with others), caring arrangements, employment status, income, benefits, smoking, height and weight [for body mass index (BMI)], and comorbidities (see *Appendix 5*). The abbreviated Lubben Social Network Scale was used to screen for social isolation.[64] This asks respondents to report on frequency of contacts with friends (three items) and relatives (three items), each scored on a scale of 0 to 5, and summed; total scores of ≤ 12 deem the respondent to be at risk of social isolation. The research nurse assessed time since Parkinson's diagnosis, MDT service use, falls, disease stage [using the six-category modified Hoehn and Yahr scale (0, no sign of disease to 5, wheelchair bound/bedridden without help, but not using the 0.5 increments that are not clinimetrically tested)][65] and cognitive function [using the 30-item Mini Mental State Examination (MMSE),[66] which includes simple tests of arithmetic, memory and orientation (see *Appendix 5*)]. Background information requested from live-in carers included age, sex, ethnicity, education, employment status, smoking, height and weight (for BMI), comorbidities (see *Appendix 5*), and relationship to, and time spent caring for, the person with Parkinson's. The baseline assessment included the outcome measures selected for the trial (see *Table 2*). If participants found the baseline data collection process tiring, some items suitable for self-completion were left with them, and the research nurse made a second visit a few days later to collect the remaining questionnaires.

Exclusion

Baseline data were examined at the research office to confirm eligibility for the trial, and some volunteers were excluded at this stage (*Box 2*). Specifically, people with Parkinson's with a MMSE score of < 24 were excluded because it was judged that they would not be able to follow instructions associated with the rehabilitation intervention. People with Parkinson's and live-in carers were excluded if they scored at the most favourable end of all outcome scales as the trial would not be able to demonstrate improvement, and, in 6 months, had little likelihood of demonstrating reduction in any expected decline; provided that they scored under the maximum on at least one measure, they were included. They were informed of the decision by letter (see *Appendix 6*), and were replaced by another volunteer, whenever possible, in order to keep the cohort sizes at 30 people with Parkinson's.

BOX 2 Exclusion criteria

People with Parkinson's were excluded if they:

- scored at the most favourable end of all outcome scales (i.e. had no limitations)
- scored < 24 out of 30 on the MMSE,[66] to ensure that those recruited could follow instructions associated with the rehabilitation intervention.

Live-in carers were excluded if they:

- scored at the most favourable end of all outcome scales (i.e. had no limitations).

Registration and randomisation

After consent and baseline data had been collected, volunteers were given a unique registration number by the project administrator. Those that were eligible were randomised to either group A – specialist rehabilitation; group B – specialist rehabilitation and ongoing care assistant support; or group C – usual care, control group. A separate randomisation sequence was prepared by the study statistician prior to the commencement of the study for patients without live-in carers and for patients with live-in carers. In each instance, blocked randomisation was used to formulate the sequence involving the three comparison groups. With three groups in the study, there are six possible sequences (ABC, ACB, BAC, BCA, CAB, CBC). A die was thrown to determine the group order within any block of three. Hence, any of the six possible group sequences in a block were equally possible, and group sizes were kept even (10 people with Parkinson's per group, provided that the cohort had the full complement of 30 people). Only the project administrator and the study statistician had access to each randomisation sequence.

The project administrator informed all participants of the group to which they were randomised, and provided a schedule of dates indicating when they might expect the treatment visits (groups A and B only) and research visits (all groups) (see *Appendix 7*). Contact details of the participants randomised to either of the treatment arms were passed to the MDT. The GPs of all participants were informed of their involvement in the trial and the group to which they had been randomised (see *Appendix 8*).

Interventions

Specialist rehabilitation intervention (groups A and B)

A MDT comprising two PNSs, two physiotherapists (PTs), one occupational therapist (OT) and two speech and language therapists (SLTs) was assembled from local professionals. They worked part-time for the trial from a base in the University of Surrey, and were employed by other health-care providers for the rest of the week. Friday was assigned (for the convenience of all concerned) for the delivery of the intervention, and for team meetings. Some team members also conducted treatment visits on Thursdays as the workload required. An administrative assistant in the research office provided support, to confirm MDT schedules and appointments with participants (by mail and telephone), organise team meetings, keep records and arrange travel expenses.

Team members visited the homes of participants to deliver a specialist rehabilitation package, tailored to individual needs. In order to make the outcome from the trial comparable with that of the previous study set in a day hospital,[21,23,26] a similar programme of specialist rehabilitation was provided comprising an initial assessment and the formation of an agreed care plan reflecting the needs, wishes and expectations of the person with Parkinson's and carers. A group education and relaxation component in the day-hospital trial could not be replicated in the domiciliary setting. As a substitute, the MDT provided participants with a folder containing 11 fact sheets produced by Parkinson's UK and the research team, and discussed these with participants according to individual needs. Topics included various aspects of living with Parkinson's, such as medications, physiotherapy exercises, foot care, diet and nutrition, speech and language, sleep and fatigue, continence and bowel care, welfare rights and benefits, advice for carers, and relaxation techniques (see *Appendix 9*).

The rehabilitation intervention was co-ordinated by the PNSs, and involved specialist input from each professional, over a period of 6 weeks. Most patients received one visit from one of the professionals each week. The team met face to face twice in each 6-week cycle to discuss patient plans and progress, and communicated by e-mail and telephone at other times. Two hospital consultants (a neurologist and a gerontologist), both with a special interest in movement disorders, were available to the MDT, and provided patient-specific advice as required. Referrals to other professionals were made when indicated, including to a neurologist, a community mental health team and a Parkinson's UK support worker. Further treatment for people with ongoing needs beyond the end of the 6-week intervention was

arranged through referrals to local community services. The MDT input was expected to be about 9–12 hours of individualised patient-facing nursing and therapy input, which was largely equivalent to that delivered in the previous day-hospital trial, so that findings could be compared. However, it was recognised that some people may need more, and others less, time than this. Including patient-related non-patient-facing time spent in travel, writing case notes, meetings, etc., 3 days of professional time was allowed for each person with Parkinson's in the trial.

Ongoing support (group B)

In addition to the programme of specialist MDT rehabilitation, participants randomised to group B received ongoing support for 4 months from a care assistant trained in Parkinson's [Parkinson's care assistant (PCA)], starting at the end of the 6-week MDT intervention. Three PCAs were employed over the period of the trial (*Table 1*). The main one had sole responsibility for five cohorts, and shared three other cohorts with another PCA. The other PCAs had sole responsibility each for one other cohort. The PCAs were embedded in the MDT and worked under the supervision of the PNS. About 1 hour per week per patient was allowed for ongoing support, and contact was via a mix of home visits and telephone contacts, through which the PCA monitored progress in the implementation of the agreed care plan and reported back to the MDT. If required, MDT members continued to provide input. Care assistants were recruited to the project from local health and social care employers.

Usual care/control (group C)

Participants in the control group continued to receive care as usual (no co-ordinated MDT care planning or ongoing support). When informed of their group allocation, people with Parkinson's and their live-in carers (as appropriate) were sent generic information (available from Parkinson's UK) about Parkinson's disease (see *Appendix 10*). This was a small enhancement on the service they were likely to be receiving. In order to measure the impact of the interventions, this information was also given to the participants in groups A and B by the MDT (additional to the educational fact sheets that they received). At the end of the trial, people in the control group were offered an assessment by a member of the MDT (of their choice), and the educational fact sheets provided to groups A and B were provided for them at that time. The assessment was the same as that provided by the MDT to the intervention groups, and advice and referrals were provided as indicated.

Cross-contamination between groups was minimised through recruiting people with Parkinson's individually, and giving treatments tailored to their specific needs. Moreover, the intervention and research assessments took place in participants' homes, which were geographically dispersed over the catchment areas of three large district general hospitals.

The MDT treatment started for the first cohort in September 2010 and ran continuously for 10 cohorts (cohort 1 was a pilot) until December 2011, with the PCA input to the last cohort ending in April 2012. On completion of the intervention, or the assessment for the control group, a detailed report was written about each participant and sent to their GP. All participants continued to receive care as usual during their time in the trial, attending for routine outpatient appointments or contacting their GPs, as required.

TABLE 1 Group B PCA allocation

	Cohort									
PCA	1	2	3	4	5	6	7	8	9	10
PCA 1	■			■						
PCA 2		■	■	■	■		■	■	■	■
PCA 3			■	■		■	■			

Shaded cells indicate support provided.

Multidisciplinary team processes and monitoring

Members of the MDT met prior to the trial to discuss and agree the details of the intervention, including the roles and protocol to be followed by individual therapists (see *Appendix 11*). A client record form (CRF) was designed comprising sections for (1) general information about the patient [age, sex, contact details, GP's name and telephone number, description of home (e.g. steps), services received, driving status, date of Parkinson's diagnosis, falling history, other health problems]; (2) PNS assessment, based on the Movement Disorder Society (MDS) Unified Parkinson's Disease Rating Scale (UPDRS),[67] and review of non-motor symptoms, medication and side effects; (3) PT assessments of balance, posture, gait and mobility; (4) OT assessment of activities; and (5) SLT subjective and objective assessment of speech, voice and swallowing. Each professional had space to record problems, actions and recommendations for the patient (see *Appendix 12*). The goals of the agreed care plan were reviewed and ratified at team meetings and summarised in the CRF, which also contained instructions for the care assistant (group B only). The start and end time of each contact (visit and telephone call), all referrals and recommendations made were recorded in summary form on the front cover.

The CRF was left in the participant's home for the duration of the 6-week intervention, and was completed by each professional at each visit. At the end of each visit, each professional sent a brief report by e-mail to the MDT administrator, who compiled a master document for team meeting discussions which took place in the third and sixth week of each cohort, in a meeting room at the university (team base). The purpose of the meeting in week 3 was to review the professionals' assessments for each patient and agree on the subsequent treatment plan. The meeting at the end of the cohort was to confirm individualised future recommendations, to provide guidance for the care assistants who would take over supporting participants in group B, and to plan the schedule of visits in the first 3 weeks of the next cohort. In addition to patient-related business, team meetings were used to further interdisciplinary understanding and working. Early in the project, each professional provided training insights for team members from the other disciplines. These presentations were often based around case studies of individual patients in the trial, and served to improve knowledge and interprofessional co-ordination.

Training

A one-day MDT training event was held before the launch of the intervention. Led by the PNS, the team focused on the UPDRS,[67] using a training video from the MDS. Two people with Parkinson's [members of the patient and public involvement (PPI) group] attended the session and each professional was able to test out and refine their component of the CRF. Each PCA was individually trained by the PNS using the training pack previously developed by the research team,[68] fact sheets and a training video published by Parkinson's UK. They then shadowed each individual therapist. The PNSs accompanied the PCAs on the early visits made by the PCAs.

Intervention pilot

The finally agreed CRF and MDT processes reflect some minor changes that were implemented, in the light of experience, at the end of the first cohort. In particular, the original plan for three team meetings per cohort (weeks 3, 5 and 6) was revised, and the meeting in week 5 was dropped because it was found to be time-consuming and unnecessary. A decision was made to leave the CRF in participants' homes and send summary reports of each contact to the MDT administrator, because the original plan to transfer the CRF between professionals proved impractical. It was also agreed that only the PNS would assess the patient using the UPDRS, whereas the original idea had been that this would be undertaken by whichever

professional met the patient first. Owing to these changes, and because the recruitment of professionals was still under way and the team was under-resourced during the treatment of the first cohort, it was decided to extend the trial to include a tenth cohort (a total of 300 people with Parkinson's, instead of 270), and to consider the first cohort to be a pilot.

Outcome measures

Instruments which reflect the needs of people with Parkinson's (functional outcomes, disease-specific and generic health-related quality of life, psychological well-being, self-efficacy, mobility, falls and speech) and carers (strain, stress, health-related quality of life, psychological well-being, and functioning), and which had been found sensitive in previous rehabilitation studies undertaken by the research team,[21,23,26,27] were included in the list of outcomes selected for the study. All instruments are widely used and well validated for use with older people and in intervention studies (*Table 2*). Measures of relevance to daily functioning were chosen as the primary outcomes: the Self-Assessment Parkinson's Disease Disability Scale (patients report ease or difficulty of doing 25 general activities on a five-point scale)[69,70] and the Modified Caregiver Strain Index.[71] Information on use of other health and social services was also collected as part of the economic evaluation (see below) to explore whether or not expenditure on the intervention was offset by reductions in the use of other health and social services. The instrument battery was developed and piloted in collaboration with patient and carer representatives in the PPI group. It took about 1 hour to complete.

TABLE 2 Trial outcome measures and instruments: baseline, 6, 24 and 36 weeks

Category	Instrument	Description and scoring	Range
Participant: people with Parkinson's[a]			
Disability (primary outcome)	Self-Assessment Parkinson's Disease Disability Scale[69,70]	Self-reported ease of or difficulty in doing 25 activities in general (e.g. getting out of bed, getting dressed, cutting food, writing a letter), scored on five-point scale: 1 (able to do it alone) to 5 (unable to do it at all). Original scale contained 24 items and suggested two factors – gross mobility and fine co-ordination[69] – but a later paper concludes that the items form a unidimensional hierarchy[70]	25–125 (highest disability)
Parkinson's specific	PDQ-8[72,73]	Summary index reflecting overall impact of Parkinson's disease on patients for use in trials. Eight items related to self-perceived health (getting around in public, getting dressed, feeling depressed, embarrassed in public, problems with close personal relationships, concentration, communication and muscle cramps) over the last month are each scored on five-point scale: 0 (never) to 4 (always). The total score is summed and transposed to a scale of 0 to 100 (worst). PDQ-8 is derived from the more extensive PDQ-39 and was selected to reduce participant burden	0–100 (worst perceived health)
	Non-Motor Symptoms Questionnaire[74,75]	Self-report of 30 non-motor symptoms (e.g. bowel, pain, concentration, falling, sleep, dreams, sweating, dribbling) in the last month (scored yes = 1, no = 0)	0–30 (worst symptoms)

TABLE 2 Trial outcome measures and instruments: baseline, 6, 24 and 36 weeks (*continued*)

Category	Instrument	Description and scoring	Range
Participant: people with Parkinson's[a]			
Activities	Barthel ADL[76]	Widely used instrument to establish the degree of independence in 10 activities (e.g. mobility, bathing, dressing, toilet, feeding), scored 0 for unable or totally dependent. Some items are binary while others have three or four points on the scale; maximum score 20 (totally independent)	0 (dependent) to 20 (independent)
	Frenchay Activities Index[77–79]	The Frenchay Activities Index is a short questionnaire that is widely used to measure lifestyle after stroke. The first of two parts was used – frequency of 10 everyday activities in the last 3 months; each scored 0 (never) to 3 (most days) (for meal preparation and washing-up) or at least weekly (for other items such as washing clothes, housework and hobbies). The third part of the index was not used as it relied on 6-month recall and this was not suitable for more frequent assessments	0 (no social activity) to 30 (best)
HRQoL (generic)	EQ-5D Thermometer[80,81] EQ-5D Index[80,81]	EQ-5D is a simple standard measure, designed for self-completion and applicable to a wide range of health conditions. It provides a descriptive profile [five dimensions – mobility, self-care, usual activities, pain/discomfort and anxiety/depression – each measured on a three-point scale (no, some and extreme problems)], transformed to a single index for use in economic evaluations. There is also a VAS (thermometer) recording the respondent's self-rated health on a vertical scale (end points – best and worst imaginable health state, 0–100)	0 (worst) to 100 (best health state) –0.57 (worst) to 1.0 (perfect health)
	SF-36 PCS[82] SF-36 MCS[82]	SF-36 is a widely used scale assessing eight health domains (limitations in physical activities, usual activities, roles and social activities, bodily pain, mental well-being, vitality and general health). The instrument was constructed for self-report or use by interview. Scoring is by algorithm, range 0 (worst) – 100 (best) and set to US population norm, mean of 50, SD of 10. The eight subscales form two distinct higher-order clusters: the PCS and the MCS	0 (worst) to 100 (best) 0 (worst) to 100 (best)
Psychological well-being	HADS – anxiety[83] HADS – depression[83]	HADS is a self-assessment scale developed to detect states of depression and anxiety in a hospital outpatient setting. It contains 14 questions (seven each for depression and anxiety), scored 0–3: total range 0 (no anxiety/depression) to 21 (high anxiety/depression). Cut-offs: 0–7 = normal; 8–10 = borderline; 11–21 = abnormal	0 (no anxiety) to 21 (worst) 0 (no depression) to 21 (worst)
	Yale Depression Screen[84,85]	This is a single-item tool with reasonable reliability and validity that can be administered by non-registered staff to screen for depression in the community: *In the past 4 weeks, have you often felt sad or depressed?* (Yes = 1, no = 2)	Yes = 1, no = 0

continued

TABLE 2 Trial outcome measures and instruments: baseline, 6, 24 and 36 weeks (*continued*)

Category	Instrument	Description and scoring	Range
Participant: people with Parkinson's[a]			
Self-efficacy	Self-Efficacy Scale[86]	Self-efficacy for managing chronic diseases six-item scale measures confidence in doing certain activities such as managing pain, fatigue and medications, each scored from 1 (not confident at all) to 10 (totally confident) and summed, and the mean calculated	1 (no self-efficacy) to 10 (high self-efficacy)
Mobility	Timed Up and Go[87,88]	Quick and simple nurse-measured indicator of ability to perform sequential locomotor tasks that incorporate walking and turning. Subject stands from a standard armchair, walks (a measured) 3 metres, turns, walks back and sits. The same chair should be used in repeated tests. Timed with stopwatch. Recorded mean, SD 'off' ('on'): 17.2, 7.3 (13.7, 3.9)	Seconds (low number good)
	Falls (self-report)	*In last 3 months, have you fallen*? Yes = 1, no = 0. If yes, asked how many times; if hurt themselves; if able to get up off the floor/ground; if saw doctor; if falls related to freezing	Yes = 1, no = 0
Mobility	UPDRS[b] – posture item from motor examination part of the scale[89]	0: normal erect 1: not quite erect, slightly stooped posture; could be normal for older person 2: moderately stooped posture, definitely abnormal; can be slightly leaning to one side 3: severely stooped posture with kyphosis; can be moderately leaning to one side 4: marked flexion with extreme abnormality of posture	0 (normal) to 4 (extreme, abnormal)
	UPDRS[b] – gait item from motor examination part of the scale[89]	0: normal 1: walks slowly, may shuffle with short steps, but no festination or propulsion 2: walks with difficulty, with little/no assistance; may have some festination, short steps, or propulsion 3: severe disturbance of gait, requiring assistance 4: cannot walk at all even with assistance	0 (normal) to 4 (cannot walk at all)
Pain	VAS, in 'on' and 'off' states[90–93]	Unidimensional measure of pain intensity, with low respondent burden, and widely used in diverse adult populations. The VAS is shown as a continuous 10 cm horizontal line anchored by verbal descriptors: 0 (no pain at all) to 10 (worst pain imaginable). Participants were asked to mark two VAS scales, one to show pain in the 'on' state and one for the 'off' state when pain ratings are typically higher. Measured by ruler in millimetres	0 (no pain) to 100 (worst pain imaginable)

TABLE 2 Trial outcome measures and instruments: baseline, 6, 24 and 36 weeks (*continued*)

Category	Instrument	Description and scoring	Range
Participant: people with Parkinson's[a]			
Speech	Speech Self Report Questionnaire (reproduced in *Appendix 13*; available from authors)	Non-validated patient-centred questionnaire used successfully in previous trial.[21,23,26,27] Used in clinical practice by SLT to identify problems encountered by patients, and comprises 11 statements about speech problems (e.g. voice is weak, husky, hesitant), and 15 statements about situations avoided (e.g. making telephone calls, ordering in a café, participating in a meeting), each scored 0 (never) to 5 (always) and summed, giving total score range of 0 (no speaking problems) to 130 (extreme speaking problems)	0 (no speaking problems) to 130 (extreme speaking problems)
	UPDRS[b] – speech item in the ADL section[89]	0: normal 1: mildly affected, no difficulty being understood 2: moderately affected, sometimes asked to repeat statements 3: severely affected, frequently asked to repeat statements 4: unintelligible most of the time	0 (normal) to 4 (unintelligible)
Speech	Abridged Emerson and Enderby Screening Assessment Rating Scale – voice[94]	1: no impairment, voice normal for age and sex 2: slight impairment, slight abnormal nasality, quality or volume 3: moderate impairment, abnormal nasality, quality or volume 4: severe impairment, severely abnormal nasality, quality or volume	1 (normal) to 4 (severe abnormality of voice)
	Abridged Emerson and Enderby Screening Assessment Rating Scale – articulation[94]	1: no impairment, normal 2: slight impairment, a few articulatory substitutions, not usually affecting intelligibility 3: moderate impairment; abnormal articulation noticeable, sometimes affects intelligibility 4: severe impairment, many sounds articulated abnormally, intelligibility markedly affected	1 (normal) to 4 (severe abnormality of articulation)

continued

TABLE 2 Trial outcome measures and instruments: baseline, 6, 24 and 36 weeks (*continued*)

Category	Instrument	Description and scoring	Range
Participant: live-in carers[a]			
Strain (primary outcome)	Modified Caregiver Strain Index[71]	Fifteen items that caregivers can find difficult (e.g. disturbed sleep, financial strain, work adjustments), each rated on a three-point scale: 0 = no; 1 = yes, sometimes; 2 = yes, on a regular basis	0 (no strain) to 26 (worst)
General health	General Health Questionnaire –12[95]	Widely used questionnaire to assess stress in carers, with 12 questions about their emotional state over the last 4 weeks (e.g. ability to concentrate, enjoyment of day-to-day activities, feeling happy, under strain, lost sleep), scored on four-point scale: 0 = better than usual/no problem; 1 = as usual; 2 = worse than usual; 3 = much worse than usual, and summed to give total 0 (no stress) to 36 (worst)	0 (no stress) to 36 (worst)
Activities	Barthel ADL[76]	As in people with Parkinson's (above)	
	Frenchay Activities Index[77–79]	As in people with Parkinson's (above)	
HRQoL (generic)	EQ-5D Thermometer[80,81]	As in people with Parkinson's (above)	
	EQ-5D Index[80,81]	As in people with Parkinson's (above)	
	SF-36 PCS[82]	As in people with Parkinson's (above)	
HRQoL (generic)	SF-36 MCS[82]	As in people with Parkinson's (above)	
Psychological well-being	HADS – anxiety[83]	As in people with Parkinson's (above)	
	HADS – depression[83]	As in people with Parkinson's (above)	
	Yale Depression Screen[84,85]	As in people with Parkinson's (above)	

ADL, Activities of Daily Living; EQ-5D, European Quality of Life-5 Dimensions; HADS, Hospital Anxiety and Depression Scale; HRQoL, health-related quality of life; MCS, mental component summary; PCS, physical component summary; PDQ-8, Parkinson's Disease Questionnaire-8 items; PDQ-39, Parkinson's Disease Questionnaire-39 items; SD, standard deviation; SF-36, Short Form questionnaire-36 items; VAS, visual analogue scale.

a The nurse assessed the UPDRS, Abridged Emerson and Enderby Screening Assessment Rating Scale voice and articulation scales, and Timed Up and Go. The rest of the patient measures were completed by self-report, but with nurse assistance as required. If the nurse read out the questions in an interview situation, respondents had a copy of the questionnaire to refer to or were provided with laminated sheets showing response options in large print (for Parkinson's Disability Scale, PDQ-8, Frenchay Activity Index, Self-Efficacy Scale, SF-36, Speech Self Report Questionnaire). Live-in carers were asked to self-complete all questionnaires, although a small number found this problematic and were assisted by the research nurse.

b UPDRS has been the most widely used clinical rating scale for Parkinson's disease. Parts I–III (mentation, behaviour and mood; activities of daily living; motor examination) contain 44 questions, each measured on a five-point scale.[89,96,97]

Outcome assessments

Participants in all groups were assessed in their homes by a research nurse, at baseline, week 6 (at the end of the 6-week rehabilitation intervention), week 24 [4 months (18 weeks) after the end of rehabilitation, coinciding with the end of ongoing support for group B], and week 36 (for final follow-up). For each cohort of 30 people with Parkinson's (and live-in carers), baseline assessments took place in the 6-week period prior to the start of the treatment phase. Assessments after the end of the 6-week treatment phase took place during the subsequent 6 weeks. The assessments at 24 and 36 weeks after baseline were arranged as close as possible to those stages for individual participants. In the event that participants were unavailable owing to holidays, illness or other reasons, visits would be arranged up to 6 weeks beyond the stipulated time. Beyond that, the assessment was deemed missed. Those unavailable at 24 weeks were contacted for their final 36-week follow-up assessment. The time between assessments was analysed on a per-patient basis.

When follow-up research assessments were due (cohort by cohort), participants were telephoned by the research office to make an appointment at a time convenient to them. A letter confirming the day and time of the visit was mailed, together with some of the outcome measures that were suitable for self-completion. To save time during the research nurse visits, participants (people with Parkinson's and carers) were asked to complete these questionnaires in advance (see *Appendix 13*). At the visit, the research nurse checked or assisted with the self-completion questionnaires (which included the reporting of service use for the economic evaluation) and undertook the remaining assessments of the people with Parkinson's: single-item depression screen; measures requiring clinical judgement (Timed Up and Go,[87,88] posture, gait and speech items); and falls reporting (also for trial safety monitoring) (see *Appendix 14*). All questionnaires were checked for completeness before the research nurse left the participant's home, and again in the research office. Any missing or unclear data were checked with participants as soon as possible after each assessment.

Inter-rater reliability

One full-time research nurse conducted assessments throughout the trial. Prior to starting data collection, visits to the home of members of the PPI group were arranged (a person with Parkinson's and a live-in carer) so that the battery of assessments could be practised. The research nurse was accompanied on these visits by the research manager, so that any problems could be addressed. In particular, this enabled guidance for the safe conduct of the Timed Up and Go test to be established. It also served to identify the need for laminated sheets to be prepared with response options (in large print) for different questionnaires for use when participants could not self-complete and that data needed to be collected from them in an interview.

During the middle period of the trial, when several cohorts were at different stages of assessment, two part-time research nurses were employed to assist with the data collection. To ensure consistency of processes, the assistants were trained by the main research nurse through shared assessment visits. The first assessments undertaken by the assistant nurses were observed by the senior research nurse and followed by a debriefing discussion after it was completed.

Blinding

Group allocation was not known at baseline assessment, which took place prior to randomisation. Databases showing group allocations were not available to the research nurses. Moreover, the research nurses did not answer the office telephone because participants often called in to alter MDT appointments, and this would have compromised the nurses' blinding. Participants were asked not to discuss aspects of the trial and treatments with the research nurses, and were reminded of this at each assessment visit.

Despite this, some participants did disclose that they had been treated by mentioning MDT members or the care assistant during the second and third research assessment visits.

Blinding was broken at the end of the third (24-week) assessment, when research nurses collected feedback on the acceptability of the interventions (from groups A and B only). It was not possible to collect data on acceptability separately. Thus, the acceptability questionnaires were placed at the back of the pack of self-completion instruments that were mailed in advance to participants for the 24-week visit. Nurses collected and checked completeness of these packs prior to leaving the participant's home, and were thus made aware of whether or not the participant had received the MDT intervention by the presence or absence of acceptability questionnaires. Research nurses might have remembered patients' groups when they returned for the final 36-week assessment. However, they reported poor recall of group allocations because there were over 300 participants in the trial, they were undertaking contemporaneous assessments of several cohorts at any point in time, and there was a gap of 3 or 4 months between the follow-up assessments.

Acceptability of the intervention

Participants

Semistructured questionnaires were designed to gather feedback on the acceptability of the interventions from group A and B participants at the end of the 24-week research assessment (separate forms for people with Parkinson's and live-in carers) (see *Appendix 15*). This part of the study sought to capture the patient and carer voice and experience of the rehabilitation interventions relative to perceived needs and priorities. The questionnaires contained rating scales and open-text fields regarding how helpful, or how successful, participants found different aspects of the programme or the programme as a whole, and how they thought it could be improved. Items on value for money were included.

However, the research nurse found that many participants were having problems recalling the MDT phase, which had been completed 4 months earlier. As a result, a decision was taken to send the questionnaire (with questions relating to the PCA component removed) to participants by mail (to protect blinding) at the 6-week assessment point. Participants were sent a stamped addressed envelope for the return of the questionnaires. The research office reminded participants by telephone to ensure a good response rate. This change was implemented from the fourth cohort onwards (i.e. it did not apply to the pilot cohort or the first two cohorts that are included in the analysis). The acceptability questionnaires continued to be distributed at the 24-week assessment point to collect feedback on ongoing benefit and the PCA input.

Multidisciplinary team professionals and Parkinson's care assistants

All members of the MDT and the PCAs were asked to provide reflective feedback (in the form of open comments) on integrated team working, team functioning and their individual role, and the delivery of the intervention at the end of cohorts 2, 6, and 8 (see *Appendix 16*). In addition, a structured feedback form was circulated at the end of the intervention, asking for Likert scale ratings and comments on communication and support within the team, delegation of responsibilities, involvement of patients and carers in care planning, and examples of good practice and challenging situations that they had encountered (see *Appendix 16*).

'Exit' interviews were also conducted with all team members, and PCAs, to learn about their views and experiences of MDT working. The interviews were conducted by an experienced qualitative researcher, who was a member of the project team but who had minimal contact with the day-to-day working of the MDT. The interview took the form of a conversation, guided by a list of topics (see *Appendix 17*). The main points were noted by hand. In addition, during the analysis phase of the study, the lead PNS wrote a report on the intervention, including observations on team working and illustrative participant case studies.

Stakeholder interviews

It was originally intended that service providers and a selection of commissioners would be asked for their views about the intervention, to identify strengths and weaknesses, and barriers and facilitators to its wider implementation. However, during the project period, significant organisational changes were put in place within the NHS (replacement of primary care trusts with local commissioning groups) to take effect shortly after the project ended. This made it difficult to identify the relevant stakeholders. Following discussion with the external advisory group, it was decided that this part of the project would be integrated into dissemination activities.

Sample size calculations

Patient sample size calculations were based on detecting clinically meaningful differences in the primary patient outcome measure. Carer sample sizes reflected the findings of previous work that suggest that 79% of people with Parkinson's have a carer.[21]

It was planned to recruit 270 people with Parkinson's over a 12-month period across the three areas, with 90 randomly allocated to each of the three groups. This calculation was based on the numbers of people with Parkinson's needed to detect differences between groups in changes in the primary outcome: Self-Assessment Parkinson's Disease Disability Scale.[69,70] Assuming a similar level of variation as in the day-hospital trial,[23] in order to detect a difference in the changes in the disability score of 1.25 [with standard deviation (SD) = 2.5, size = 5%, power = 80% and a two-sided test], 64 subjects with Parkinson's disease were needed in each of the three groups.

Assuming a similar level of variation in the primary outcome – Modified Caregiver Strain Index[71] – as in the day-hospital trial,[23] in order to detect a difference between groups in the changes in the Modified Caregiver Strain Index of 0.535 (with SD = 1.07, size = 5%, power = 80% and a two-sided test), 64 carers were needed in each of the three groups. In the previous study, 79% of community-dwelling people with Parkinson's had a live-in carer.[21] Thus, if there were 64 carers per group, this necessitated 246 [(64 × 3)/0.79 = 243.04] Parkinson's subjects, i.e. 82 per group.

In the previous day-hospital trial, the loss to follow-up/non-completion/missing data rate between recruitment and the 6-month assessments was 26%. However, in that trial, participants attended the day hospital for treatment (six visits) and research assessments (four visits), and difficulties with transport and intercurrent illness accounted for missing data and drop-out. We expected less attrition in the SPIRiTT trial because participants would receive both treatment and the research assessments in their own homes, at times convenient to them.

Allowing for 10% loss to follow-up/non-completion/missing data rates for people with Parkinson's, 243.04/0.90 = 270.04 patients were required = 90 per group. With 90 patients per group, we expected to recruit 71 carers per group. These group sizes would also ensure that the samples for patients and carers would both remain above the critical values of 64 if there was a loss of 5% of carers (and associated patients) and an independent loss of 5% of people with Parkinson's.

Withdrawals

Participants could withdraw from the study due to illness or personal reasons. They were made aware (via the information sheet and consent form) that withdrawal from the study would not affect their future care, and that data collected to date would still be used in the final analysis. Volunteers who were not randomised because they failed eligibility criteria at baseline were replaced, but participants who withdrew from the trial for any other reason were not replaced.

Data management

Data were entered into IBM SPSS Statistics version 19 (IBM Corporation, Armonk, NY, USA) databases using the trial unique patient identification number. Separate databases were constructed for:

- information collected at baseline and on outcomes (all four assessments), by cohort, and combined for the analysis at the end of the trial
- the data from the patient and live-in carer acceptability questionnaires
- items from the CRF that were needed (a) for the calculation of the costs of the treatment programme (number and duration of therapist visits and telephone calls) for the economic evaluation, and (b) to illustrate MDT activity (quantifiable variables only, i.e. referrals made, medication changes recommended, recommendations made by the OT for aids and adaptations).

Contact details and GP details of participants were kept in an administrative database separate from the research information. All paper data were stored in locked cabinets, and all computer data were stored on a secure server.

Data were entered by one person and checked by a second, with random checking (using random numbers and ID numbers) of five persons with Parkinson's and five carers in each cohort. If errors were found, the rate of checking was increased. The statistician, who was blinded to group allocation until all databases were completed, undertook further data cleaning.

Statistical analysis

Data relating to people with Parkinson's and carers were analysed separately.

The analysis started with an intention-to-treat (ITT) approach, based on group assignment (excluding the pilot cohort), and including participants who had provided information at baseline assessment but had subsequently withdrawn, had not been available for assessments or were lost to follow-up. Some participants completing a baseline assessment had dropped out prior to treatment. A per-protocol analysis (PPA) was, therefore, also conducted, restricted to participants who fulfilled the protocol in terms of eligibility, interventions and all outcome assessments.

Baseline data (week 0) were analysed to describe the characteristics of the participants and to check for significant imbalance between the three groups with respect to background characteristics and outcomes, using appropriate statistical tests. The characteristics of the participants who were lost in the PPA were compared with those of the full ITT sample.

All outcomes were analysed at each follow-up assessment point [6 (post MDT treatment), 24 (post PCA) and 36 weeks (final end point)]. A series of null hypotheses were set out a priori for testing. Groups were compared with respect to changes in outcome measures between assessment points.

In order to identify short-term effects arising from the MDT intervention, change scores (week 6 minus week 0) of each participant in the specialist rehabilitation groups (A and B) were compared with those of participants in the control group (group C). The null hypotheses tested were that there were no differences between the groups (A + B vs. C) with respect to change in any outcome.

The impact of the PCA support for group B from week 6 to week 24 was assessed by comparing changes in outcomes for group A versus group B between week 6 (end of MDT intervention for both groups) and week 24 (end of PCA intervention for group B). The null hypotheses tested were that there were no differences between the groups (A vs. B) with respect to change in any outcome (week 24 minus week 6).

This analysis was designed to show loss or maintenance of effects arising from the PCA support after the MDT input ceased.

Medium-term effects were further investigated through a comparison of all groups at 24 weeks (A vs. B, A vs. C, and B vs. C) using participants' change scores from baseline (week 24 minus week 0). The null hypotheses tested were that there were no differences between the groups with respect to change in any outcome.

In order to identify long-term effects, groups were compared at 36 weeks (A vs. B, A vs. C, and B vs. C) using participants' change scores from baseline (week 36 minus week 0). The null hypotheses tested were that there were no differences between the groups with respect to change in any outcome.

An additional exploratory analysis was performed using each participant's change score for all outcomes between week 24 and week 36 (36 minus 24). This analysis provides evidence of trends in each group, and differences between groups, over the follow-up period after all interventions ceased in week 24.

Although multiple statistical tests were undertaken, adjustments for multiple testing were not made because a priori hypotheses were specified. Results are presented in full and selective reporting of significant results has been avoided. Furthermore, most outcomes are independent.

For all of the above analyses of changes, distributions were inspected to identify major aberrations from normality which could preclude the use of parametric tests. In most cases, raw data failed normality tests, but change scores were close to normal and parametric tests were used. One-way analysis of variance (ANOVA) tests were used for comparisons between all three groups, and unpaired *t*-tests were used for comparisons between pairs of groups. Within-group changes between assessment points were also explored using paired *t*-tests. In each case, a two-sided test was used.

Missing data

Stringent attempts were made to minimise missing data through checking questionnaires as they were completed, and returning to participants to retrieve missing items. If more than two responses were missing from an instrument, the whole instrument was disregarded for that individual. As a result, remaining missing responses within instruments were minimal, averaging 0.40% for people with Parkinson's and 0.06% for live-in carers (see *Appendix 18*). These missing items were filled using the established procedures for that scale (if available), or else setting the value of the missing item to zero (or normal), i.e. the most favourable value. Some participants found it difficult to complete some outcome measures [e.g. the pain visual analogue scales (VASs)], and this resulted in non-response for that instrument and a smaller sample size in the analysis. The research nurses did not carry out the Timed Up and Go test if the participant was in an 'off' state during the assessment or was immobile due to injury or surgery.

Loss to follow-up

Collection of research data from participants in their own homes minimised the loss to follow-up. If participants could not be reached, or were away from home, or hospitalised at one follow-up point, they were contacted and asked to complete later assessments.

Analysis of the acceptability questionnaires

Responses from people with Parkinson's and live-in carers were analysed separately and mainly focused on those sent by mail at 6 weeks (at the completion of the MDT intervention) from cohort 4 onwards.

Questionnaires completed at 24 weeks were not fully analysed due to concerns about participant recall. Research nurses reported that by 24 weeks (4 months after the end of the MDT intervention), some participants found it difficult to remember the input of different professionals, sometimes confusing trial therapists with regular health and social care professionals who they had seen in the meantime. Two issues from the acceptability questionnaire distributed at 24 weeks were analysed: a question asking about continuing benefit beyond the end of the MDT intervention (at 6 weeks); and two items that specifically gave participants in group B an opportunity to comment on the PCA input over weeks 7–24.

Quantitative items (rating scales) were analysed descriptively and results were presented as proportions, means and SDs, depending on the nature of the questions. Text responses were transferred to a Microsoft Excel database (Microsoft Corporation, Redmond, WA, USA) for analysis. These questions asked, at the 6-week assessment, how helpful participants found the treatment; the most successful aspects of the programme; the least successful aspects of the programme; ways in which the programme could be improved; and for other comments about the treatment and the study overall. For each of these questions, the written responses were printed out and read several times by a researcher. Irrelevant comments that did not address the question were removed, including comments that were illegible and those relating to the research process (e.g. that there were too many forms to fill in). Main themes in the responses were then identified. The question from the 24-week assessment about continuing benefit from the MDT intervention was analysed in the same way. The process was independently checked by a second researcher.

Analysis of feedback from the multidisciplinary team and Parkinson's care assistants

Notes taken during the 'exit' interviews were combined with reflections provided by team members during the trial and subjected to thematic analysis[98] by the researcher who undertook the interviews. The analysis was checked by a second researcher.

Economic evaluation

The economic evaluation adopted a NHS perspective. Participants were treated in their own homes and incurred no costs in accessing treatment.

The resources used in the delivery of the intervention (both MDT and PCA components) were recorded in the individual participant CRFs. Information relating to patient contact [number and duration (in minutes) of visits and telephone calls to participants by individual therapists] was transferred to a patient-level SPSS database, and descriptive statistics were calculated. Time spent with individual professionals was summed to determine total minutes of contact with the MDT and with the PCA (group B). Data on total contact time were checked for normality (using histograms) and for variance. Variation was explored between groups A and B, and within cohorts, with respect to total MDT contact duration and PCA input (group B only), using appropriate statistical tests.

The costs of the intervention were calculated in Great British pounds (GBP) for 2011, at the level of individual patients, as the sum of the costs of (1) patient contact time (home visits and telephone calls) with all members of the MDT and with the PCA (group B), including an allowance for non-patient-facing follow-up tasks arising from visits or telephone calls, such as writing notes, arranging referrals, and discussion at MDT meetings; (2) travel expenditures and time spent in travel for home visits; and (3) a fixed 1 hour spent by the PNS in writing a letter to the GP of each participant to report on what care had been given to their patient.

Costs of staff time were obtained from validated national sources[99] (see *Appendix 19*). The hourly rates used are inclusive of all on-costs, and management office/administrative support and facilities overheads. Following discussion with the professionals, an extra 30 minutes per home visit and 15 minutes per telephone call were added for time spent in non-patient-facing follow-up. The distances from the MDT base to the home postcodes of all participants in the study were obtained, and the median distance taken as the basis for calculating the travel costs for all home visits, and the NHS mileage reimbursement rate was applied. Professional time spent in travel was costed on the basis of an assumed 20 miles per hour (which was judged appropriate for the suburban/rural nature of the catchment area). Unit costs used in the calculations are shown in *Appendix 19*. Costs of the MDT intervention were compared between groups A and B, and between cohorts, to confirm uniformity of delivery.

The use of health and social care services [hospital in- and outpatient, accident and emergency (A&E), GP and a range of other community health and social services, respite care in residential settings, personal social services] were collected by self-report at baseline, 24- and 36-week assessments by recall for the previous 3 months. Participants were also asked about informal (unpaid care from family and friends). Service use was analysed descriptively at group level. The costs of health services were calculated at each assessment point using unit costs obtained from national sources[99] (see *Appendix 20*), multiplied by the number of units used. Weekly day-care use was multiplied by 12 to give the cost over 3 months. Contacts with GPs at home and in the surgery were combined as one category, but the appropriate unit cost was applied to each component. Where participants reported self-paying for services, the costs were excluded from the calculations. Costs of service utilisation in the intervention groups (A and B) were compared with each other and with the usual-care group (C) to assess the extent to which the costs of the interventions may be offset by savings elsewhere in the health and social care system. The costs of tests, social and informal care reported by participants were not calculated due to insufficient details about the type and frequency of the service.

Clinical results were inspected to assess the value of conducting a cost-effectiveness analysis. If statistically significant differences in change scores between groups were found for either the patient or carer primary outcome measures, or European Quality of Life-5 Dimensions (EQ-5D) Index scores (for quality-adjusted life-years), at the final end point (6 months), a full cost-effectiveness/cost–utility analysis would be conducted. Otherwise, the costs of the intervention would be evaluated in relation to the broader range of patient and carer consequences/outcomes.[100]

Risks and adverse events

Risks to participants from the trial were considered small, and no higher than those of usual care. The MDT intervention was delivered by experienced professionals and was based on standard practices that aim to improve self-awareness and management. It included assessment of home safety and aids and adaptations, and recommendations made to participants were intended to result in overall improvements in safety. The care assistants were fully trained, and worked under the instruction of team professionals, in the support of patients and carers and the implementation of the agreed care plan. However, it is possible that encouragement to exercise could result in falls that might not otherwise have occurred. Accordingly, falls were closely monitored and analysed on an ongoing basis. Fall rates reported during the trial were compared between groups and with baseline falls data. The external advisory group reviewed falls data at each meeting to ensure that the incidence of falls in intervention groups had not increased significantly since baseline, or in comparison with the control group. Other potential harms to the experimental groups included depression if raised expectations were not met, distress when additional input was stopped, and loss of support from family and friends if the additional care was perceived to reduce the need for informal support.

All adverse events (any unfavourable or unintended sign, symptom, syndrome or illness that developed or worsened during the period of the trial) and serious adverse events (life-threatening or resulting in hospitalisation, disability or death) were recorded. The information was gathered from various sources, including report by MDT, research nurses, telephone messages from participants, obituary notices, and information from doctors. All reported events were reviewed by the project manager, and assessed for seriousness, expectedness and causality by clinical members of the research team. Any serious adverse event deemed to be directly related to, or suspected to be related to, the intervention, and unexpected, was to be reported to the study external advisory group and the ethics committee.

Management and governance

The research team was run on a day-to-day basis by a full-time manager, with help from an administrative assistant. All aspects of data collection and management were under the supervision of the research manager, and analysis was undertaken by a statistician. The research team was supported in the delivery of the trial by an external steering committee, which met twice per year to review progress and ensure timely completion of milestones. Membership included clinical experts, experienced researchers, representatives from Parkinson's UK and the European Parkinson's Disease Association, local service providers and commissioners, and people with Parkinson's and carers.

A PPI group, co-ordinated by an independent PNS, helped the research team at all stages of the project, from planning to dissemination. It met separately and in conjunction with the research team and advised on the development of study documents, processes and procedures for recruitment, treatment and research assessments. The PPI group worked with the research team on the production of newsletters to participants to keep them updated on the progress of the trial.

Ethical and organisational review

A favourable ethical opinion was obtained from Surrey Research Ethics Committee (application number 10/H1109/1), and the University of Surrey Ethics Committee. NHS research and development approval was granted by four participant identification centres (Ashford and St. Peter's Hospitals NHS Foundation Trust, Frimley Park Hospital NHS Foundation Trust, Royal Surrey County NHS Foundation Trust, and Surrey Primary Care Trust).

Protocol

The protocol was published.[101]

Chapter 3 Recruitment and trial processes

Flow of participants through the trial: Consolidated Standards of Reporting Trials diagram

A total of 464 people with Parkinson's expressed an interest in participating in the trial and were contacted by telephone by members of the research team. Of these, 151 did not proceed further: 44 were found not to meet the inclusion criteria; 88 declined to take part after learning more about the study; 15 were sent information about the trial but did not respond to subsequent telephone messages left by the research team; and four expressed interest in participating after recruitment had been closed.

Baseline visits took place to 313 people with Parkinson's. Among these people, there were 188 live-in carers who were interested in participating. Following consent and baseline assessment, seven people with Parkinson's (with six live-in carers) were found to be ineligible and were excluded because their MMSE score was < 24, hence 306 people with Parkinson's and 182 live-in carers were randomised. The group allocation of people with Parkinson's (and live-in carers) was as follows: group A, $n = 102$ ($n = 61$); group B, $n = 101$ ($n = 60$); group C, $n = 103$ ($n = 61$).

Baseline comparisons were conducted on 269 people with Parkinson's and 155 live-in carers (the ITT analysis sample). There were 37 people with Parkinson's and 27 live-in carers who were randomised but excluded from the analysis. Exclusions arose for various reasons. During the treatment and research phase, five patients were identified whose diagnosis of Parkinson's was in doubt, even though they had previously been clinically diagnosed and were receiving treatment for that condition. These patients were further investigated by the consultant neurologists and found not to have Parkinson's disease, and were therefore removed from the analysis. In addition, there were two protocol violations – a person with Parkinson's who was too ill to participate in the trial (live-in carer also excluded from study) and a live-in carer who scored at the most favourable end of all outcome scales. Data relating to people recruited into the first (pilot) cohort were also not included in the analysis because the MDT was not at full strength and its processes were under development ($n = 31$, of whom one was a wrong Parkinson's diagnosis).

Randomisation and completion of the trial

The group assignment of 269 people with Parkinson's (155 live-in carers) included in the analysis was 88 (52) to receive the 6-week MDT intervention only (group A); 88 (50) to receive the MDT intervention plus PCA support for a further 4 months (group B); and 93 (53) in the usual-care control (group C). Not all of these participants completed the trial. Attrition occurred at all stages, as indicated on the CONSORT diagram (*Figure 2*), including eight people with Parkinson's who did not receive treatment (two in group A and six in group B). Some participants who were not available for assessment at 24 weeks were reached at 36 weeks.

Trial processes

Intervention fidelity

Although the decision to exclude the first cohort from the analysis and to recruit an extra cohort of participants was taken early in the trial (because MDT staffing increased and processes were consolidated after the initial cohort had been completed), this course of action is confirmed by an analysis of intervention delivery. Comparison of the duration of MDT contact time with participants (patient-facing minutes on home visits plus time on telephone calls) in each cohort showed that people treated in the first cohort had significantly less MDT input than those in the subsequent nine cohorts. No significant difference was found in MDT input across the subsequent nine cohorts, or in comparisons of the MDT

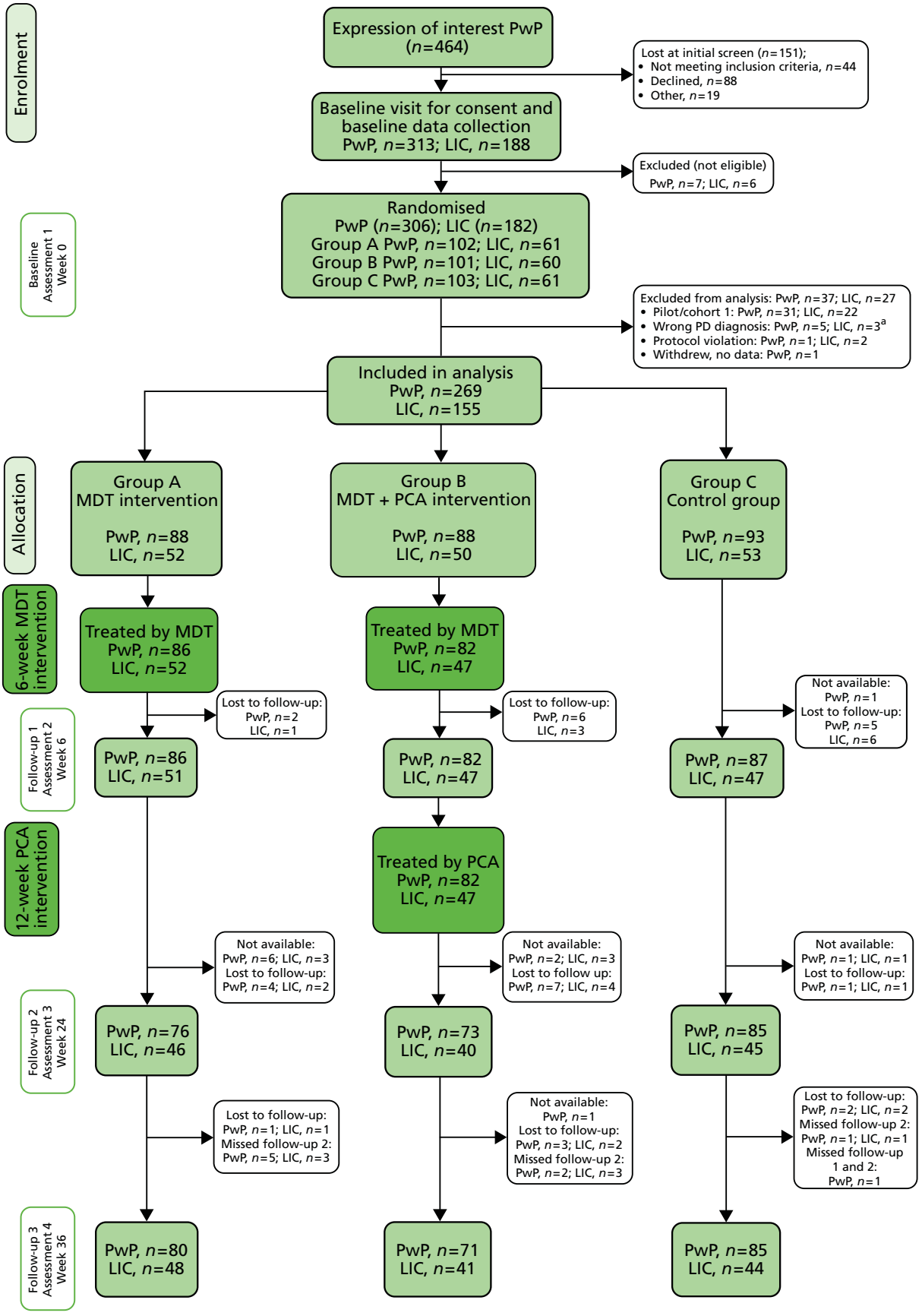

FIGURE 2 Flow of participants throughout the trial: CONSORT diagram. LIC, live-in carers; PD, Parkinson's disease; PwP, people with Parkinson's. a, 1 PwP with wrong diagnosis and also in pilot. Dark green shading indicates an intervention; light green shading indicates participants in study; and no shading indicates people lost to the study.

input between group A (received MDT only) and group B (received MDT + PCA). There was more variability in the PCA input between cohorts, but differences were still not significant (*Table 3*). Analysis of the intervention costs is reported in the economic evaluation section in *Chapter 4*.

Distribution of follow-up assessments

The main research nurse undertook 757 (76.2%) of the 994 assessments that were conducted. Help was required in the middle of the trial when several cohorts were being followed up concurrently, and for holiday cover. The remainder of the assessments were conducted by two assistants. Owing to difficulties recruiting a suitable assessor on a part-time and temporary basis, a PNS from within the project team and a PCA (with nursing qualifications) fulfilled the role. The PCA mostly conducted the 24-week assessments, and the PNS mostly undertook baseline assessments (*Table 4*). The PCA was masked to the group allocation of the participants that she assessed, and she was not allocated participants in group B unless they were in a cohort treated by the other PCA in the trial. The PNS mostly conducted baseline assessments before group allocation was determined.

Timing of follow-up assessments

Gaps between assessments

For over 90% of participants, there was < 12 weeks (84 days) between the first and second assessment, indicating that most baseline assessments took place within 4 weeks of the start of the 6-week treatment period for any cohort, and that most post-MDT treatment assessments took place within 4 weeks of the end of that 6-week treatment phase. The mean gap between assessments 1 and 2 was 72.0 days (*Table 5*). The third assessment [due 24 weeks after baseline/18 weeks (126 days) after the end of treatment] took place, on average, 136.4 days after the post-treatment assessment. The fourth assessment [due 36 weeks after baseline and 12 weeks (84 days) after assessment 3], took place, on average, 78 days after assessment 3.

Assessments in relation to treatment

Assessment 2 took place within a mean of 12 days after completion of the MDT (groups A and B only). A small number ($n = 11$) of people had assessment 2 prior to the completion of the MDT input, usually because sickness or holidays of the participant or professional had delayed the MDT delivery. Assessment 3 took place within a mean of 20 days from the end of the PCA input (group B only).

Adverse events

During the trial, a large number of falls were recorded in the adverse events log, and analysed by assessment time point and group. Many people reported multiple falls. Data on falls were presented and discussed with the external advisory group on an ongoing basis. The data revealed no statistically significant differences in fall rates (number of fallers and number of falls) between groups at each assessment point (*Table 6*). Other adverse events that were reported (39 in A, 44 in B and 25 in C) included infections (chest, gastric, urinary), worsening symptoms and minor surgery (but not requiring hospital admission overnight).

There were 69 serious adverse events (involving hospital stays or death) recorded for people with Parkinson's (24 in A, 26 in B and 19 in C), and two for carers (*Table 7*). No serious adverse events were judged to be unexpected by clinical members of the research team. Many adverse events came to the notice of the research team through the MDT and PCA visits to treatment groups, and this may account for the lower number of adverse events recorded for the control group (C).

TABLE 3 Comparison of input across cohorts

Cohort	Group A: MDT (*N* = 87)						Group B: MDT + PCA (*N* = 83)					
	Patients, *n*	Mean contact duration (minutes)[a]	SD	Median duration (minutes)	IQR	Within-group A comparison of cohorts; *p*-value	Patients, *n*	Mean contact duration (minutes)[a]	SD	Median duration (minutes)	IQR	Within-group B comparison of cohorts; *p*-value
Comparison of duration of MDT input across cohorts (minutes of patient contact)												
2	11	450.64	91.26	450.00	150.00	Multiple comparisons ANOVA, between cohorts 0.29	10	493.80	93.65	500.00	150.00	Multiple comparisons ANOVA, between cohorts 0.84
3	10	474.50	50.41	465.00	40.00		10	483.50	88.73	457.50	165.00	
4	10	502.50	48.61	510.00	60.00		10	506.50	66.75	509.50	110.00	
5	9	508.89	103.37	535.00	130.00		10	480.50	98.08	472.50	80.00	
6	10	504.50	57.27	510.00	55.00		10	501.30	81.04	500.00	140.00	
7	10	476.50	52.12	467.50	90.00		9	489.44	46.26	470.00	40.00	
8	8	520.63	75.00	500.00	80.00		8	523.13	43.83	530.00	50.00	
9	11	532.73	67.39	525.00	30.00		10	503.00	67.01	502.50	100.00	
10	8	553.13	192.87	480.00	122.50		6	545.83	90.36	535.00	170.00	
Comparison of duration of MDT input (minutes of patient contact), cohorts 2–10 vs. pilot (cohort 1)[b]												
2–10 mean	87	500.80	89.50	495.00	87.50	0.002[c]	83	500.60	75.90	490.00	102.50	0.001[c]
1 (pilot)	10	375.50	93.41	372.50	87.50		10	391.50	58.64	380.00	60.00	

Cohort	Group A: MDT ($N = 87$) Patients, *n*	Mean contact duration (minutes)[a]	SD	Median duration (minutes)	IQR	Within-group A comparison of cohorts; *p*-value	Group B: MDT + PCA ($N = 83$) Patients, *n*	Mean contact duration (minutes)[a]	SD	Median duration (minutes)	IQR	Within-group B comparison of cohorts; *p*-value
Comparison of duration of PCA input across cohorts (minutes of patient contact)												
2							10	512.60	128.43	505.50	219.00	Multiple comparisons ANOVA, between cohorts; 0.12
3							10	336.40	103.19	334.00	182.00	
4							10	417.10	180.84	438.50	223.00	
5							10	474.80	93.02	489.00	159.00	
6							10	411.60	219.03	426.00	148.00	
7							9	400.56	193.59	450.00	159.00	
8							8	503.75	149.28	547.50	265.00	
9							10	358.30	129.03	372.50	145.00	
10							6	328.33	196.99	295.00	340.00	

IQR, interquartile range.
a Contacts calculated as the sum of the number of home visits and number of telephone calls made by the PNS, PT, OT and SLT.
b Group A vs. B comparisons: unequal variance two-sided *t*-test, mean duration, pilot group 1, $p = 0.932$, cohorts 2–10, $p = 0.990$.
c Unequal variance two-sided *t*-test, mean duration of cohort 1 vs. cohorts 2–10.
Shading indicates that these results are not applicable to group A.

TABLE 4 Distribution of 994 assessments conducted by research nurses

Assessment	Research nurse	Group A: MDT [*n* (%)]	Group B: MDT + PCA [*n* (%)]	Group C: control [*n* (%)]	Total assessments [*n* (%)] by		
					Lead nurse	Assistant 1 (PCA)	Assistant 2 (PNS)
1: baseline	Main research nurse	69 (78)	65 (74)	66 (71)	200 (74)		
	Assistant 1 (PCA)	5 (6)	5 (6)	3 (3)		13 (5)	
	Assistant 2 (PNS)	14 (16)	18 (20)	24 (26)			56 (21)
2: post treatment	Main research nurse	78 (91)	79 (96)	71 (82)	228 (89)		
	Assistant 1 (PCA)	6 (7)	0 (0)	11 (13)		17 (7)	
	Assistant 2 (PNS)	2 (2)	3 (4)	5 (6)			10 (4)
3: 24 weeks	Main research nurse	9 (12)	64 (88)	25 (30)	98 (42)		
	Assistant 1 (PCA)	67 (88)	9 (12)	59 (70)		135 (58)	
	Assistant 2 (PNS)	0 (0)	0 (0)	0 (0)			0 (0)
4: 36 weeks	Main research nurse	80 (100)	72 (100)	79 (93)	231 (97)		
	Assistant 1 (PCA)	0 (0)	0 (0)	6 (7)		6 (3)	
	Assistant 2 (PNS)	0 (0)	0 (0)	0 (0)			0 (0)
Total		330	315	349	757 (76)	171 (17)	66 (7)

TABLE 5 Timing between treatments and assessments (days)

Time between	Number of assessments	Missing	Mean (SD)	Minimum	Maximum	10th percentile	25th percentile	50th percentile (median)	75th percentile	90th percentile
Assessments 1 (baseline) and 2 (post 6-week treatment)	254	15	72.0 (10.9)	34	128	59	65	70	79	85
Assessments 2 and 3 (24 weeks)	232	37	136.4 (13.9)	90	188	123	129.25	134	142	153.7
Assessments 3 and 4 (36 weeks)	224	45	77.7 (20.5)	23	181	61	68	77	84	92
End of MDT treatment and assessment 2	163	106	11.9 (12.4)	–21	82	2.4	5	10	18	26
End of PCA treatment and assessment 3	72	197	19.9 (17.8)	4	132	5.3	8.5	17	25	38

TABLE 6 Analysis of falls data from adverse events logs: number of falls and number of people with Parkinson's who fell

	MDT		MDT + PCA		Control		
Assessment time point	Number of falls	Number of people	Number of falls	Number of people	Number of falls	Number of people	Significance[a]
Baseline (304 people)	318	42	273	44	168	38	$p = 0.251$ (Kruskal–Wallis) $p = 0.215$ (chi-squared test)
6 weeks (286 people)	130	29	146	34	159	31	$p = 0.377$ (Kruskal–Wallis) $p = 0.640$ (chi-squared test)
24 weeks (253 people)	108	39	313	36	98	32	$p = 0.464$ (Kruskal–Wallis) $p = 0.444$ (chi-squared test)
36 weeks (173 people)	571	19	70	22	99	21	$p = 0.483$ (Kruskal–Wallis) $p = 0.494$ (chi-squared test)

a Comparison of number of falls: Kruskal–Wallis. Comparison of people with Parkinson's who repeated any falls: chi-squared test.

TABLE 7 Serious adverse events (hospitalisations and death) reported regarding people with Parkinson's[a]

Cohort	Group A	Group B	Group C
1 (pilot)	Fall, taken to A&E	One fall and fractured neck of femur	Severe stroke
		Seizure	Chest infection
			Extreme depression (suicidal thoughts)
			MI
2	Two falls and pneumonia	Vomiting blood	
	One fall, contracted MRSA in hospital	Poor mobility and UTI	
	One death (pneumonia)	Stroke (unconfirmed)	
		TIA	
		Endoscopy and stent	
3	Condition deteriorated, hospitalised with UTI	One fall and fractured shoulder	GI problems
	One fall and fractured cheekbone		Colostomy
	One fall and TIA		
4	Weight loss, swallowing problems	One fall and UTI	One fall, discharged with care package
	Pneumonia	Pneumonia	
	Pulmonary fibrosis		
	Stroke		
	MI		
5	One death (bowel surgery, heart failure)	Prolonged hospital stay, transfer to care home, UTI	One fall and shoulder damage
	One fall and hip replacement	Kidney failure/infection	Two fractured vertebrae, three fractured ribs
		One fall and UTI	
		UTI, hallucinations	
6	One fall and cracked ribs	Chest infection	Pneumonia
	One fall; collapsed and PD medication overdose	TIA	One death (cause not known)
	Cracked neck of femur	Loss of consciousness (hypotension, heart rate)	Epistaxis
7	One fall		Vomiting blood
	Loss of consciousness/hypotension		Viral infection
			RTI
			Angina
8	Chest pain	Chest infection	Dizziness
		One fall and fractured kneecap	

TABLE 7 Serious adverse events (hospitalisations and death) reported regarding people with Parkinson's[a] (*continued*)

Cohort	Group A	Group B	Group C
9	Chest infection and urinary retention	'Unwell'	
		Hypertension	
	Lewy Body dementia and infection		
		One fall and loss of consciousness	
10	One fall and fractured arm, pelvis	One fall and hypertension	Breathless, weak, fluid in lungs
	Pneumonia	Arrhythmia	MI
		Collapse (hypotension)	
		Severe pain and infection	
Total	24	26	19

GI, gastrointestinal; MI, myocardial infarction; MRSA, methicillin-resistant *Staphylococcus aureus*; PD, Parkinson's disease; RTI, respiratory tract infection; TIA, transient ischaemic attack; UTI, urinary tract infection.
a Two serious adverse events were reported for live-in carers: transfer to care home following falls and hip replacement.

Baseline characteristics of participants, and comparison of groups

Baseline characteristics were analysed for 269 people with Parkinson's and 155 live-in carers.

People with Parkinson's

Significantly more of the people with Parkinson's in group A (MDT only) were men. Although few participants were current smokers, there was a tendency for more people with Parkinson's in group C (control) than in the other groups to have reported smoking in the past. People with Parkinson's in group B (MDT + PCA) had a (just) significantly lower BMI. There were no differences between the groups with respect to other baseline descriptors including age; with a carer in the study; education; income group; comorbidities; medication use; time since Parkinson's diagnosis; disease stage; proportions living alone; and at risk of social isolation (*Table 8*).

Regarding previous Parkinson's care (*Table 9*), over 80% of people with Parkinson's reported that they had a PNS, and over 60% of these had seen the nurse within the last 6 months. A total of 53 (19.7%) either did not have a PNS or reported that they had not seen a PNS within 2 years. There was no difference between groups in outpatient hospital appointments for Parkinson's, with most participants having two appointments per year. Of the 231 people with Parkinson's (across all groups) diagnosed more than 2 years previously, 72 (31.2%) had seen a PT within 6 months, but 97 (42.0%) stated that they had not seen a PT for 2 years or had never/did not know if they had seen one. In comparison with consultations with PNSs and PTs, the proportions who had seen OTs and SLTs within 6 months were much lower (11.7% and 9.1%, respectively), and the proportions without contact with these therapists in the previous 2 years/never/did not know were much higher (74.0% and 77.5%, respectively).

Participants reported having a wide range of aids and adaptations, many of which they had purchased themselves (see *Appendix 21*). The profile of medications taken for Parkinson's, and for the management of non-motor symptoms and medication side effects, is shown in *Appendix 22*. The only significant difference found between treatment groups was in the use of glutamate antagonists (which was higher in group B).

TABLE 8 Baseline characteristics of 269 people with Parkinson's, cohorts 2–10 (the ITT sample)

Characteristic	Group A: MDT (*N* = 88) *n* (%)		Group B: MDT + PCA (*N* = 88) *n* (%)		Group C: usual care, control (*N* = 93) *n* (%)		Significance	Test
Categorical variables								
Sex								
Male	65 (73.9)		50 (56.8)		49 (52.7)		0.009	Chi-squared
Female	23 (26.1)		38 (43.2)		44 (47.3)			
Carer status								
No carer	19 (21.6)		18 (20.5)		25 (26.9)		0.546[a]	Chi-squared
Carer (in study)	52 (59.1)		50 (56.8)		53 (57.0)			
Of which carer is spouse/ partner [vs. family member or friend]	49 [3] (94.2)		48 [2] (96.0)		49 [4] (92.5)			
Carer (not in study)	17 (19.3)		20 (22.7)		15 (16.1)			
Ethnicity								
White	88 (100)		88 (100)		93 (100)		N/A	N/A
Warden-assisted or sheltered accommodation								
Yes	6 (7.1)	*n* = 85	8 (9.2)	*n* = 87	5 (5.5)	*n* = 91	0.633	Chi-squared
No	79 (92.9)		79 (90.8)		86 (94.5)			
Accommodation type								
Owner-occupied flat/house	82 (94.3)	*n* = 87	84 (96.6)	*n* = 87	89 (96.7)	*n* = 92	N/A	N/A
Rented flat or housing association	5 (5.7)		2 (2.3)		2 (2.2)			
Other	0 (0)		1 (1.1)		1 (1.1)			
Education level								
Primary to 12 years	1 (1.2)	*n* = 83	2 (2.3)	*n* = 82	1 (1.1)	*n* = 91	0.347	Kruskal–Wallis
Secondary to 16 years	33 (38.4)		36 (41.9)		49 (53.3)			
Secondary to 18 years	9 (10.5)		9 (10.5)		6 (6.5)			
Vocational/further education	18 (20.9)		17 (19.8)		14 (15.2)			
University	22 (25.6)		18 (20.9)		21 (22.8)			
Employment status								
Full/part time	8 (9.1)		5 (5.7)	*n* = 87	4 (4.3)	*n* = 92	0.411	Chi-squared
Not employed	80 (90.9)		82 (94.3)		88 (95.7)			

TABLE 8 Baseline characteristics of 269 people with Parkinson's, cohorts 2–10 (the ITT sample) (*continued*)

Characteristic	Group A: MDT ($N = 88$) *n* (%)		Group B: MDT + PCA ($N = 88$) *n* (%)		Group C: usual care, control ($N = 93$) *n* (%)		Significance	Test
Household income per year								
< £12,000	12 (15.8)	$n = 76$	11 (15.5)	$n = 71$	8 (11.0)	$n = 73$	0.984	Kruskal–Wallis
£12,000–20,000	23 (30.3)		22 (31.0)		25 (34.2)			
£20,001–30,000	20 (26.3)		18 (25.4)		22 (30.1)			
£30,001–45,000	12 (15.8)		9 (12.7)		9 (12.3)			
> £45,000	9 (11.8)		11 (15.5)		9 (12.3)			
Do you receive benefits?								
Yes	54 (62.1)	$n = 87$	49 (57.6)	$n = 85$	49 (53.3)	$n = 92$	0.492	Chi-squared
No	33 (37.9)		36 (42.4)		43 (46.7)			
Number reporting								
Direct payment of personal budget	2 (2.3)		1 (1.1)		0 (0)		N/A	N/A
Attendance allowance	30 (53.6)		36 (66.7)		29 (59.2)		0.374	Chi-squared
Council tax benefit	10 (17.9)		11 (20.8)		4 (8.2)		0.192	Chi-squared
Disability Living Allowance	18 (32.1)		13 (24.5)		20 (40.8)		0.213	Chi-squared
Housing benefit	3 (5.4)		2 (3.8)		1 (2.0)		N/A	N/A
How long ago were you diagnosed with PD?								
< 2 years	13 (14.8)		10 (11.4)		15 (16.1)		0.290	Kruskal–Wallis
2–4.99 years	28 (31.8)		27 (30.7)		29 (31.2)			
5–9.99 years	29 (33.0)		23 (26.1)		27 (29.0)			
10–14.99 years	14 (15.9)		16 (18.2)		16 (17.2)			
≥ 15 years	4 (4.5)		12 (13.6)		6 (6.5)			
Modified Hoehn and Yahr disease stage[65]								
0. No sign of disease	0 (0)		2 (2.3)		4 (4.3)		0.152	Kruskal–Wallis
1. Unilateral disease (mild symptoms)	21 (23.9)		21 (23.9)		26 (28.0)			
2. Bilateral disease, minimal disability	21 (23.9)		19 (21.6)		22 (23.7)			
3. Bilateral disease, moderate disability, some postural instability	38 (43.2)		34 (38.6)		38 (40.9)			

continued

TABLE 8 Baseline characteristics of 269 people with Parkinson's, cohorts 2–10 (the ITT sample) (*continued*)

Characteristic	Group A: MDT (*N* = 88) *n* (%)		Group B: MDT + PCA (*N* = 88) *n* (%)		Group C: usual care, control (*N* = 93) *n* (%)		Significance	Test
4. Severe symptoms and disability	8 (9.1)		11 (12.5)		3 (3.2)			
5. Wheelchair/ bedridden without help	0 (0)		1 (1.1)		0 (0)			
Have you ever smoked?								
Yes	38 (43.2)		36 (41.4)	*n* = 87	52 (56.5)	*n* = 92	0.084	Chi-squared
No	50 (56.8)		51 (58.6)		40 (43.5)			
If yes: are you a current or ex-smoker?[b]								
Current smoker	3 (7.9)		4 (11.1)		4 (7.7)		0.835	Chi-squared
Ex-smoker	35 (92.1)		32 (88.9)		48 (92.3)			
LSNS-6[64] *(range 0–30)*								
≤ 12, at risk of social isolation	21 (24.1)	*n* = 87	18 (20.9)	*n* = 86	13 (14.1)	*n* = 92	0.226	Chi-squared
> 12, not at risk of social isolation	66 (75.9)		68 (79.1)		79 (85.9)			

Characteristic	Group A: MDT (*N* = 88) Mean (SD)		Group B: MDT + PCA (*N* = 88) Mean (SD)		Group C: usual care, control (*N* = 93) Mean (SD)		Significance	Test
Continuous variable								
Age, years	72.94 (8.63)		74.02 (8.19)	*n* = 87	71.57 (7.88)		0.137	One-way ANOVA
Comorbidities, number	3.16 (1.976)		3.00 (1.75)	*n* = 86	3.12 (1.86)	*n* = 92	0.842	
Total medications, number per day	6.32 (4.04)	*n* = 87	6.43 (3.77)	*n* = 87	6.84 (4.29)		0.661	One-way ANOVA
Parkinson's medications, number per day	2.53 (1.29)	*n* = 87	2.60 (1.48)		2.70 (1.77)		0.757	One-way ANOVA
MMSE score (range 0–30)[66]	28.53 (1.76)		28.52 (1.74)		28.62 (1.73)		0.912	One-way ANOVA
LSNS-6[64] (range 0 isolated–30)	16.98 (6.36)	*n* = 87	17.43 (5.92)	*n* = 86	17.55 (5.87)	*n* = 92	0.800	One-way ANOVA
BMI	25.04 (4.26)	*n* = 84	24.41 (4.12)	*n* = 84	25.97 (4.22)	*n* = 91	0.050	One-way ANOVA

LSNS-6, Lubben Social Network Scale-6; N/A, not applicable; PD, Parkinson's disease.
a No carer vs. carer.
b No significant difference between groups in length of time smoked in years, mean (SD): A 16.86 (14.06); B 25.11 (19.44); C 20.88 (14.55); $p = 0.095$, one-way ANOVA.

TABLE 9 Prior Parkinson's care reported at baseline by 269 people with Parkinson's, cohorts 2–10 (the ITT sample)

Characteristic	Group A: MDT ($N = 88$) *n* (%)		Group B: MDT + PCA ($N = 88$) *n* (%)		Group C: control ($N = 93$) *n* (%)		Significance	Test
Have PNS								
Yes	73 (83.0)		77 (87.5)		79 (84.9)		0.697	Chi-squared
No	15 (17.0)		11 (12.5)		14 (15.1)			
If yes: last time saw PNS								
< 6 months ago	44 (61.1)	$n = 72$	54 (72.0)	$n = 75$	43 (54.4)	$n = 79$	0.131	Kruskal–Wallis
Between 6 months and 1 year ago	15 (20.8)		12 (16.0)		24 (30.4)			
1–2 years ago	7 (9.7)		5 (6.7)		9 (11.4)			
> 2 years ago	6 (8.3)		4 (5.3)		3 (3.8)			
Last time saw PT **(only those diagnosed for ≥ 2 years)**								
< 6 months ago	20 (26.7)	$n = 75$	28 (35.9)	$n = 78$	24 (30.8)	$n = 78$	0.025	Kruskal–Wallis
Between 6 months and 1 year ago	8 (10.7)		10 (12.8)		4 (5.1)			
1–2 years ago	9 (12.0)		15 (19.2)		16 (20.5)			
> 2 years ago	12 (16.0)		7 (9.0)		13 (16.7)			
Never	19 (25.3)		12 (15.4)		17 (21.8)			
Don't know	7 (9.3)		6 (7.7)		4 (5.1)			
Last time saw OT **(only those diagnosed for ≥ 2 years)**								
< 6 months ago	8 (10.7)	$n = 75$	13 (16.7)	$n = 78$	6 (7.7)	$n = 78$	0.142	Kruskal–Wallis
Between 6 months and 1 year ago	3 (4.0)		8 (10.3)		3 (3.8)			
1–2 years ago	5 (6.7)		5 (6.4)		9 (11.5)			
> 2 years ago	9 (12.0)		10 (12.8)		8 (10.3)			
Never	46 (61.3)		39 (50.0)		48 (61.5)			
Don't know	4 (5.3)		3 (3.8)		4 (5.1)			
Last time saw SLT **(only those diagnosed for ≥ 2 years)**								
< 6 months ago	9 (12.0)	$n = 75$	8 (10.3)	$n = 78$	4 (5.1)	$n = 78$	0.395	Kruskal–Wallis
Between 6 months and 1 year ago	4 (5.3)		4 (5.1)		4 (5.1)			
1–2 years ago	5 (6.7)		7 (9.0)		7 (9.0)			
> 2 years ago	7 (9.3)		7 (9.0)		5 (6.4)			
Never	46 (61.3)		51 (65.4)		58 (74.4)			
Don't know	4 (5.3)		1 (1.3)		0 (0.0)			

continued

TABLE 9 Prior Parkinson's care reported at baseline by 269 people with Parkinson's, cohorts 2–10 (the ITT sample) (*continued*)

Characteristic	Group A: MDT (*N* = 88) *n* (%)		Group B: MDT + PCA (*N* = 88) *n* (%)		Group C: control (*N* = 93) *n* (%)		Significance	Test
Number of times per year that usually visit hospital as outpatient to see doctor about Parkinson's								
Never	6 (6.8)	*n* = 81	3 (3.4)	*n* = 81	3 (3.2)	*n* = 81	0.722	Kruskal–Wallis
< once per year	3 (3.4)		4 (4.5)		20 (21.5)			
About once per year	20 (22.7)		25 (28.4)		45 (46.8)			
About 2 times per year	43 (48.9)		38 (43.2)		22 (23.7)			
About 3–4 times per year	11 (12.5)		14 (15.9)		3 (3.2)			
More than 4 times per year	5 (5.7)		4 (4.5)		0 (0)			

Live-in carers

A higher proportion of carers in group A than in groups B and C were female. Consistent with the people with Parkinson's, the live-in carers in the control group were more likely to report previous smoking behaviours. On average, compared with the live-in carers in groups A and C, those in group B (MDT + PCA) reported that they could leave the person with Parkinson's alone for less time during the day ($p = 0.048$) (*Table 10*).

Baseline outcome measures: comparison of groups

People with Parkinson's

Participants in group B (MDT + PCA) scored significantly worse on the Frenchay Activities Index ($p = 0.012$),[77–79] and tended to display higher dependency on the Barthel Activities of Daily Living (ADL) measure ($p = 0.079$)[76] than those in groups A and C. People with Parkinson's in group B also reported more disability on the primary outcome measure, but this difference was not significant (*Table 11*). There was a significant difference between groups in the proportions screening positive on the Yale single-item Depression Screen (highest in C, lowest in A, $p = 0.09$).[84,85] Groups also differed on some speech items (C better than A and B, $p = 0.026$–0.083). There were no significant differences between groups at baseline in the other outcome measures [including Hospital Anxiety and Depression Scale (HADS),[83] self-efficacy, self-report speech problems, disease-specific and generic health-related quality of life, pain and mobility] (see *Table 11*).

Generally, low average levels of disability and functional impairment were observed among the people with Parkinson's in the study, with many scoring towards the most favourable end of most of the outcome scales. Distributions were non-normal, with small numbers of participants reporting significant limitations.

Live-in carers

As with the people with Parkinson's, the live-in carers in group B scored worse than those in the other two groups on the Frenchay Activities Index ($p = 0.056$).[77–79] There was no difference between the groups on any other carer outcome at baseline, including carer strain and stress, ADL, health-related quality of life, and anxiety and depression. Generally, the carers in the study reported almost no functional limitations (*Table 12*).

TABLE 10 Baseline characteristics of 155 live-in carers, cohorts 2–10 (the ITT sample)

Characteristic	Group A: MDT ($N = 88$)		Group B: MDT + PCA ($N = 88$)		Group C: control ($N = 93$)		Significance	Test
Categorical variables *Sex*	**n *(%)***		**n *(%)***		**n *(%)***			
Male	9 (17.3)		19 (38.0)		15 (28.3)		0.065	Chi-squared
Female	43 (82.7)		31 (62.0)		38 (71.7)			
Live with person with Parkinson's								
Yes, all the time	50 (96.2)		50 (100.0)		51 (96.2)		Not applicable	Not applicable
Yes, some of the time	1 (1.9)		0 (0.0)		0 (0.0)			
No	1 (1.9)		0 (0.0)		2 (3.8)			
Education level								
Primary to 12 years	0 (0.0)	$n = 49$	2 (4.3)	$n = 47$	1 (1.9)	$n = 51$	0.809	Kruskal–Wallis
Secondary to 16 years	19 (38.8)		17 (36.2)		22 (42.3)			
Secondary to 18 years	6 (12.2)		6 (12.8)		6 (11.5)			
Vocational/further education	12 (24.5)		13 (27.7)		10 (19.2)			
University	12 (24.5)		9 (19.1)		12 (23.1)			
Employment status								
Full/part time	6 (11.5)		5 (10.0)		10 (18.9)		0.368	Chi-squared
Not employed	46 (88.5)		45 (90.0)		43 (81.1)			
Do you receive Carer's Allowance?								
Yes	7 (36.8)	$n = 19$	4 (30.8)	$n = 13$	3 (20)	$n = 15$	0.564	Chi-squared
No	12 (63.2)		9 (69.2)		12 (80)			
Have you given up or cut down on work to provide care?								
No	41 (78.8)		35 (72.9)	$n = 48$	41 (80.4)	$n = 51$	0.703	Kruskal–Wallis
Yes, cut down	5 (9.6)		7 (14.6)		4 (7.8)			
Yes, given up	6 (11.5)		6 (11.8)		6 (11.8)			
On a typical day, how much of the time can you leave the person with Parkinson's at home alone?								
< 25%	11 (21.2)		18 (36.7)	$n = 49$	11 (21.2)	$n = 52$	0.048	Kruskal–Wallis
25% to 49%	9 (17.3)		9 (18.4)		7 (13.5)			
50% to 74%	11 (21.2)		7 (14.3)		6 (11.5)			
75% to 100%	21 (40.4)		15 (30.6)		28 (53.8)			
Have you ever smoked?								
Yes	14 (27.5)	$n = 51$	19 (38.0)		31 (58.5)		0.005	Chi-squared
No	37 (72.5)		31 (62.0)		22 (41.5)			
If yes: are you a current or an ex-smoker?								
Current smoker	1 (7.7)	$n = 13$	2 (10.5)	$n = 19$	6 (20.0)	$n = 30$	0.482	Chi-squared
Ex-smoker	12 (92.3)		17 (89.5)		24 (80)			
Continuous variables	***Mean (SD)***		***Mean (SD)***		***Mean (SD)***			
Age, years	70.01 (7.28)	$n = 51$	72.46 (8.22)		68.73 (7.19)		0.043	One-way ANOVA
Time spent caring in an average week, hours	52.07 (60.10)	$n = 51$	59.13 (63.07)	$n = 48$	39.61 (51.49)	$n = 49$	0.252	

TABLE 11 Baseline outcome measures of 269 people with Parkinson's, cohorts 2–10 (the ITT sample)

Category	Outcomes	Values	Group A: MDT ($N = 88$)		Group B: MDT + PCA ($N = 88$)		Group C: usual care, control ($N = 93$)		Difference between groups	
									p-value	Test
Continuous variables			***Mean (SD)***		***Mean (SD)***		***Mean (SD)***			
Disability	Self-Assessment Parkinson's Disability Scale (primary outcome)[69,70]	25 to 125 (worst disability)	48.78 (32.05)		53.36 (44.91)		49.07 (42.78)		0.178	One-way ANOVA
Parkinson's specific	PDQ-8[72,73]	0 to 100 (worst)	23.37 (17.95)		25.65 (16.64)	$n = 87$	25.34 (19.33)	$n = 92$	0.661	
	Non-Motor Symptoms Questionnaire[74,75]	0 to 30 (worst)	10.67 (4.96)		10.80 (4.98)		10.29 (5.44)		0.787	
Activities	Barthel ADL[76]	0 to 20 (independent)	18.40 (2.13)	$n = 87$	17.58 (3.43)	$n = 86$	18.47 (2.68)		0.079	
	Frenchay Activities Index[77–79]	0 to 30 (best)	18.86 (7.02)	$n = 87$	17.51 (8.38)	$n = 87$	18.47 (2.68)		0.012	
HRQoL	EQ-5D Thermometer[80,81]	0 to 100 (best)	66.57 (18.39)		64.19 (18.03)	$n = 87$	64.70 (20.23)	$n = 92$	0.679	
	EQ-5D Index[80,81]	–0.57 to 1.0 (best)	0.59 (0.26)		0.52 (0.28)	$n = 87$	0.54 (0.28)	$n = 92$	0.216	
	[a]SF-36 PCS[82]	0 to 100 (best)	33.59 (10.63)	$n = 87$	33.21 (9.87)	$n = 86$	34.98 (10.72)	$n = 92$	0.489	
	[a]SF-36 MCS[82]	0 to 100 (best)	52.80 (10.18)	$n = 87$	51.26 (9.83)	$n = 86$	52.21 (10.60)	$n = 92$	0.610	
Psychological well-being	HADS – anxiety total[83]	0 to 21 (worst)	5.86 (3.80)	$n = 87$	6.06 (3.60)	$n = 86$	6.47 (4.34)	$n = 93$	0.567	
	HADS – depression total[83]	0 to 21 (worst)	5.24 (3.41)	$n = 87$	5.55 (3.10)	$n = 86$	5.49 (3.04)		0.795	
Self-efficacy	Self-Efficacy Scale[86]	1 to 10 (best)	6.98 (2.05)	$n = 87$	6.84 (1.90)	$n = 86$	6.89 (2.01)	$n = 92$	0.902	
Mobility	Timed Up and Go (minutes)[87,88]	Low good	18.70 (12.39)	$n = 85$	20.76 (16.45)	$n = 84$	19.07 (18.90)		0.677	
Pain	VAS – on[90–93]	0 to 100 (worst)	25.93 (27.05)	$n = 76$	25.47 (25.43)	$n = 80$	26.02 (24.70)	$n = 86$	0.989	
	VAS – off[90–93]	0 to 100 (worst)	33.31 (28.53)	$n = 66$	33.57 (32.27)	$n = 78$	33.90 (31.17)	$n = 79$	0.993	
Speech	Speech Self Report Questionnaire	0 to 130 (worst)	28.38 (22.30)		28.60 (23.26)		25.00 (23.78)		0.502	

Category	Outcomes	Values	Group A: MDT ($N = 88$)		Group B: MDT + PCA ($N = 88$)		Group C: usual care, control ($N = 93$)	Difference between groups	
								p-value	Test
Categorical variables			**n *(%)***		**n *(%)***		**n *(%)***		
Posture	UPDRS[89]	0: normal erect	20 (23)	$n = 87$	26 (30.6)	$n = 85$	26 (28)	0.924	Kruskal–Wallis
		1: not quite erect, slightly stooped	49 (56.3)		38 (44.7)		46 (49.5)		
		2: moderately stooped	15 (17.2)		17 (20)		18 (19.4)		
		3: severely stooped with kyphosis	1 (1.1)		3 (3.5)		3 (3.2)		
		4: marked flexion, extreme abnormality	2 (2.3)		1 (1.2)		0 (0.0)		
Gait	UPDRS[89]	0: normal	16 (18.4)	$n = 87$	16 (18.8)	$n = 85$	23 (24.7)	0.516	Kruskal–Wallis
		1: walks slowly, may shuffle	42 (48.3)		35 (41.2)		40 (43.0)		
		2: walks with difficulty, may festinate	23 (26.4)		30 (35.3)		25 (26.9)		
		3: severe disturbance, needs assistance	6 (6.9)		4 (4.7)		5 (5.4)		
		4: cannot walk at all even if assisted	0 (0.0)		0 (0.0)		0 (0.0)		

continued

TABLE 11 Baseline outcome measures of 269 people with Parkinson's, cohorts 2–10 (the ITT sample) (*continued*)

Category	Outcomes	Values	Group A: MDT ($N = 88$)	Group B: MDT + PCA ($N = 88$)	Group C: usual care, control ($N = 93$)	Difference between groups	
						p-value	Test
Categorical variables			**n *(%)***	**n *(%)***	**n *(%)***		
Speech	UPDRS[89]	0: normal	33 (37.5)	38 (43.2)	51 (54.8)	0.083	Kruskal–Wallis
		1: mildly affected	39 (44.3)	28 (31.8)	28 (30.1)		
		2: moderately affected	13 (14.8)	19 (21.6)	12 (12.9)		
		3: severely affected	3 (3.4)	3 (3.4)	2 (2.2)		
		4: unintelligible most of the time	0 (0.0)	0 (0.0)	0 (0.0)		
	Abridged Emerson and Enderby Screening Assessment Rating Scale – voice	1: no impairment, voice normal	16 (18.2)	21 (23.9)	32 (34.4)	0.026	Kruskal–Wallis
		2: slight impairment in quality/volume	36 (40.9)	32 (36.4)	35 (37.6)		
		3: moderate impairment	31 (35.2)	29 (33.0)	24 (25.8)		
		4: severe impairment in quality/volume	5 (5.7)	6 (6.8)	2 (2.2)		
	Abridged Emerson and Enderby Screening Assessment Rating Scale – articulation	1: no impairment, normal	39 (44.3)	43 (48.9)	54 (58.1)	0.066	Kruskal–Wallis
		2: slight impairment	31 (35.2)	29 (33.0)	31 (33.3)		
		3: moderate impairment	16 (18.2)	13 (14.8)	8 (8.6)		
		4: severe impairment affects intelligibility	2 (2.3)	3 (3.4)	0 (0.0)		

Category	Outcomes	Values	Group A: MDT ($N = 88$)	Group B: MDT + PCA ($N = 88$)	Group C: usual care, control ($N = 93$)	Difference between groups	
						p-value	Test
Categorical variables			**n *(%)***	**n *(%)***	**n *(%)***		
Fallen in last 3 months (self-report)		Yes = 1	37 (42.0)	37 (42.0)	35 (37.6)	0.782	Chi-squared
		No = 0	51 (58.0)	51 (58.0)	58 (62.4)		
Do you frequently feel sad or depressed? (Yale Depression Screen[84,85])		Yes = 1	17 (19.3)	24 (27.3)	37 (39.8)	0.009	Chi-squared
		No = 0	71 (80.7)	64 (72.7)	56 (60.2)		

HADS, Hospital Anxiety and Depression Scale; HRQoL, health-related quality of life; PCS, physical component summary; PDQ-8, Parkinson's Disease Questionnaire-8 items; SF-36, Short Form questionnaire-36 items.
a SF-36, US population norms: mean = 50; SD = 10.

TABLE 12 Baseline outcome measures of 155 live-in carers, cohorts 2–10 (the ITT sample)

Category	Outcomes	Values	Group A: MDT ($N = 52$)		Group B: MDT + PCA ($N = 50$)	Group C: usual care, control ($N = 53$)	Difference between groups	
							p-value	Test
Continuous variables			***Mean (SD)***		***Mean (SD)***	***Mean (SD)***		
Strain	Modified Caregiver Strain Index (primary outcome)[71]	0 to 30 (worst)	6.79 (4.82)		7.50 (6.10)	7.53 (6.63)	0.770	One-way ANOVA
General health	General Health Questionnaire-12[95]	0 to 36 (worst)	10.65 (4.25)	$n = 51$	11.04 (4.97)	10.75 (4.58)	0.907	One-way ANOVA
Activities	Barthel ADL[76]	0 to 20 (independent)	20.0 (0.20)	$n = 51$	19.82 (0.66)	19.75 (0.73)	0.187	One-way ANOVA
	Frenchay Activities Index[77–79]	0 to 30 (best)	28.02 (2.55)		26.22 (4.32)	27.28 (4.18)	0.056	One-way ANOVA
HRQoL	EQ-5D Thermometer[80,81]	0 to 100 (best)	78.80 (15.88)	$n = 51$	78.24 (17.32)	78.30 (20.98)	0.985	One-way ANOVA
	EQ-5D Index[80,81]	–0.57 to 1.0 (best)	0.81 (0.22)	$n = 51$	0.78 (0.23)	0.80 (0.26)	0.758	One-way ANOVA
	[a]SF-36 PCS[82]	0 to 100 (best)	43.75 (11.89)	$n = 51$	45.11 (9.89)	46.69 (9.23)	0.354	One-way ANOVA
	[a]SF-36 MCS[82]	0 to 100 (best)	52.97 (8.30)	$n = 51$	50.34 (10.09)	51.70 (10.00)	0.385	One-way ANOVA
Psychological well-being	HADS – anxiety total[83]	0 to 21 (worst)	5.31 (3.59)	$n = 51$	5.54 (4.02)	5.64 (3.86)	0.905	One-way ANOVA
	HADS – depression total[83]	0 to 21 (worst)	3.59 (2.76)	$n = 51$	3.56 (2.77)	3.53 (3.54)	0.995	One-way ANOVA
Categorical variables			**n *(%)***		**n *(%)***	**n *(%)***		
Do you frequently feel sad or depressed? (Yale Depression Screen[84,85])		Yes = 1	14 (26.9)		16 (32.0)	19 (35.8)	0.615	Chi-squared
		No = 0	38 (73.1)		34 (68.0)	34 (64.2)		

HRQoL, health-related quality of life; MCS, mental component summary; PCS, physical component summary; SF-36, Short Form questionnaire 36-items.
a SF-36, US population norms: mean = 50; SD = 10.

Chapter 4 Outcomes and costs

Clinical outcomes

An ITT analysis was conducted for 269 people with Parkinson's (155 live-in carers), i.e. 306 people with Parkinson's randomised, less five people who were later found not to have Parkinson's, one protocol violation, one person who withdrew data, and 31 in the pilot group (one with a wrong diagnosis) who received a reduced version of the intervention. However, eight people (two in group A and six in group B) did not receive the MDT intervention, and further attrition occurred at every assessment point. Hence the post-treatment outcomes reported in the text are based on the analysis of participants who fulfilled the protocol requirements in terms of eligibility, treatment and completion of all four assessments (i.e. a PPA). This included 227 people with Parkinson's (and 125 live-in carers) [group A, 75 (45); group B, 69 (37), group C, 83 (43)], although the sample size was reduced below these numbers for any instrument when participants failed to complete all four assessments. Comparisons of the results of the PPA and ITT, as shown in *Appendix 23*, revealed no differences in the conclusions that could be drawn from the data.

Comparison of people included in intention-to-treat but omitted in per-protocol analysis

Comparing the 269 people with Parkinson's included in the ITT analysis with the 226 who completed all assessments for the primary outcome measure (Self-Assessment Parkinson's Disease Disability Scale[69,70]), those lost to follow-up had been diagnosed earlier and had a higher Hoehn and Yahr (disease stage) score (Mann–Whitney *U* test: $p = 0.007$ and 0.001, respectively), were older, took more medications and Parkinson's medications, and had a lower BMI (unpaired *t*-tests: $p = 0.014$, < 0.0005, < 0.0005 and 0.002, respectively). People who lived alone were less likely to complete the trial than those who lived with a carer (chi-squared $p = 0.016$). There was no significant difference between those completing and those dropping out with respect to sex, education, smoking, and social support.

Comparing the 155 live-in carers included in the ITT analysis with the 125 who completed all assessments for the primary outcome measure (Modified Carer Strain Index[71]), those lost to follow-up were significantly older (unpaired *t*-test $p = 0.011$). There was no significant difference between those completing and those dropping out with respect to sex, education, smoking and how long they stated that they spent looking after the person with Parkinson's on a typical day.

Graphical representation of findings

To gain an understanding of trends, the mean values from the PPA for each group were plotted for each outcome across all assessment points (see *Appendix 23* for people with Parkinson's and for live-in carers). For instruments which measure disability (such that an improvement is a reduction), the scales on the graphs have been reversed. This is to assist with visual interpretation, i.e. in all cases where the trend lines are upwards, this represents an improvement in the average condition of participants. However, Parkinson's is a degenerative disease, and a reduction in the rate of deterioration (one group compared with another) may also be a positive outcome.

The graphs of PPA outcomes in *Appendix 23* are supported by tables that show baseline (week 0) means by treatment group, and changes in group means: baseline to week 6 (post treatment) for the effect of the MDT in groups A and B; week 6–week 24 (end of PCA support for group B) for the effect of the PCA intervention; baseline to week 24; week 24–36 (final assessment/end point) for trends after both

interventions had stopped; and baseline to week 36 for the overall intervention effectiveness. The tables also show the results of tests of significance (p-values) for differences between group means at baseline; differences between group change scores from baseline (week 0) to week 6, week 6–24, week 0–24, week 24–36 and week 0–36; and within-group changes for the same periods between assessments. Tables with the results from the ITT analysis are also shown in *Appendix 23*, but these results are not plotted on graphs as the differences from the PPA analysis are small.

The results of the PPA are reported by follow-up period in *Tables 13–22* and are summarised in *Table 23*, and by outcome measure in *Table 24* (people with Parkinson's) and *Table 25* (live-in carers). Outcomes where there are significant ($p < 0.05$) and marginally significant ($p < 0.10$) differences in change scores between groups are discussed in the text. Information on the within-group changes that account for the observed differences in the between-group change scores is also provided. Results are not discussed where change scores between groups are not significantly different, but are shown in the tables.

Short-term effects of the 6-week multidisciplinary team intervention: groups A and B combined versus group C

Change scores were significantly different, and in favour of intervention groups A + B, compared with group C (control), in measures of psychological well-being (*Table 13*). Participants in the intervention groups experienced a reduction in anxiety (HADS,[83] $p = 0.02$), while depression (HADS,[83] $p = 0.05$) and the mental component summary (MCS $p = 0.04$) score of Short Form Questionnaire-36 items (SF-36)[82] worsened significantly in the control group. There was a tendency for those receiving the MDT to show improvements, compared with those who did not, in the primary outcome (Parkinson's disability $p = 0.09$), the Parkinson's Non-Motor Symptoms Questionnaire[74,75] ($p = 0.06$) and the EQ-5D health-related quality-of-life index[80,81] ($p = 0.07$); self-reported speech tended to worsen in the control group relative to the intervention groups ($p = 0.07$).

Live-in carers in groups A + B reported significantly improved psychological well-being (SF-36 MCS $p = 0.02$), compared with those in group C. There were no differences in changes between groups from baseline to end of MDT treatment on any other outcome measure (*Table 14*).

Medium-term effects of the Parkinson's care assistant intervention (weeks 6 to 24): group B (Parkinson's care assistant support) versus group A (no Parkinson's care assistant support)

The impact of the PCA intervention was assessed by comparing changes in outcomes for group A versus group B between week 6 (end of the MDT intervention for both groups) and week 24 (end of PCA support for group B) (*Table 15*). Scores recorded for group A worsened significantly, while those for group B did not change, resulting in a significant difference in change scores in favour of the intervention group B for the Parkinson's Non-Motor Symptoms Questionnaire[74,75] ($p = 0.05$) and the UPDRS posture measure[89] ($p = 0.01$), and marginally for the EQ-5D health-related quality-of-life index[80,81] ($p = 0.07$) and self-efficacy[86] ($p = 0.09$). There was a significant difference in change scores on the Emerson and Enderby voice measure[94] that was in favour of group A ($p < 0.001$).

There was a marginally significant difference in change scores on the live-in carer primary outcome measure (carer strain[71]) due to a non-significant increase in strain in group A and a similar non-significant reduction in strain in group B ($p = 0.06$) (*Table 16*).

TABLE 13 Primary and secondary clinical outcomes, within- and between-group differences at 6 weeks (post treatment): people with Parkinson's

			Group A + B: MDT			Group C: controls			Difference in changes, weeks 6 – 0: A + B vs. C	
Category	Instrument	*n*	Baseline (week 0) Yes, *n* (%)	Change week 6 – 0 (95% CI)	*p*-value[a] (df)	Baseline (week 0) Yes, *n* (%)	Change week 6 – 0 (95% CI)	*p*-value[a] (df)	Mean (95% CI)	*p*-value[a] (df)
Disability (primary outcome)	Self-Assessed Parkinson's Disability (25 to 125 worst)[69,70]	226	49.5 (17.6)	–2.8 (–4.31 to –1.37)	< 0.001 (142)	47.0 (16.3)	–0.72 (–2.67 to 1.23)	0.46 (82)	–2.12 (–4.54 to 0.31)	0.09 (224)
Parkinson's specific	PDQ-8 (0 to 100 worst)[72,73]	227	23.74 (17.26)	–0.37 (–2.03 to 1.29)	0.66 (143)	23.65 (18.30)	0.98 (–1.73 to 3.69)	0.47 (82)	–1.35 (–4.33 to 1.63)	0.37 (225)
	Non-Motor Symptoms Questionnaire (0 to 30 worst)[74,75]	227	10.43 (5.09)	–0.91 (–1.43 to –0.39)	< 0.001 (143)	10.01 (5.32)	–0.08 (–0.79 to 0.62)	0.81 (82)	–0.83 (–1.69 to 0.04)	0.06 (225)
Activities	Barthel ADL (0 to 20 independent)[76]	227	18.19 (2.61)	–0.06 (–0.35 to 0.22)	0.66 (142)	18.53 (2.18)	–0.27 (–0.60 to 0.07)	0.12 (82)	0.20 (–0.25 to 0.65)	0.37 (225)
	Frenchay Activities Index (0–30 best)[77–79]	226	18.59 (7.74)	–0.32 (–0.98 to 0.34)	0.34 (142)	21.31 (6.83)	–1.00 (–1.91 to –0.09)	0.31 (82)	0.678 (–0.42 to 1.78)	0.23 (224)
HRQoL (generic)	EQ-5D Thermometer (0 to 100 best)[80,81]	226	66.57 (18.32)	–0.23 (–3.29 to 2.83)	0.88 (143)	65.68 (20.62)	0.38 (–4.31 to 5.08)	0.87 (81)	–0.72 (–6.05 to 4.62)	0.79 (224)
	EQ-5D Index (–0.57 to 1.0 best)[80,81]	227	0.57 (0.27)	0.06 (0.03 to 0.09)	< 0.001 (143)	0.58 (0.26)	0.01 (–0.03 to 0.06)	0.56 (82)	0.05 (0.00 to 0.10)	0.07 (225)
	SF-36 PCS (0 to 100 best)[82]	225	33.93 (10.18)	–0.74 (–2.19 to –0.50)	0.23 (142)	35.23 (11.10)	–0.88 (–2.82 to 1.05)	0.37 (81)	0.13 (–2.52 to 2.78)	0.92 (148)
	SF-36 MCS (0 to 100 best)[82]	226	52.76 (9.65)	0.14 (–1.32 to 1.60)	0.85 (143)	53.02 (10.03)	–2.31 (–4.05 to –0.58)	0.01 (81)	2.45 (0.13 to 4.78)	0.04 (224)

continued

TABLE 13 Primary and secondary clinical outcomes, within- and between-group differences at 6 weeks (post treatment): people with Parkinson's (*continued*)

			Group A + B: MDT			Group C: controls			Difference in changes, weeks 6 – 0: A + B vs. C	
Category	Instrument	*n*	Baseline (week 0) Yes, *n* (%)	Change week 6 – 0 (95% CI)	*p*-value[a] (df)	Baseline (week 0) Yes, *n* (%)	Change week 6 – 0 (95% CI)	*p*-value[a] (df)	Mean (95% CI)	*p*-value[a] (df)
Psychological well-being (Yale Depression Screen, see below)	HADS – anxiety (0 to 21 worst)[83]	226	5.81 (3.68)	–0.58 (–0.99 to –0.17)	0.01 (143)	6.10 (4.25)	0.23 (–0.37 to 0.84)	0.45 (81)	–0.82 (–1.52 to – 0.11)	0.02 (224)
	HADS – depression (0 to 21 worst)[83]	226	5.24 (3.31)	–0.04 (–0.44 to 0.35)	0.84 (143)	5.20 (2.94)	0.61 (0.09 to 1.13)	0.02 (81)	–0.65 (–1.30 to 0.00)	0.05 (224)
Self-efficacy	Self-Efficacy Scale (1 to 10 high)[86]	226	7.21 (1.82)	–0.04 (–0.32 to 0.24)	0.75 (143)	7.03 (2.13)	–0.16 (–0.53 to 0.21)	0.40 (81)	0.12 (–0.34 to 0.58)	0.62 (224)
Mobility (falls, see below)	Timed Up and Go (seconds, low good)[87,88]	210	19.55 (13.81)	0.26 (–1.68 to 2.19)	0.79 (131)	16.08 (12.68)	–1.35 (–3.25 to 0.55)	0.16 (77)	1.61 (–1.29 to 4.51)	0.28 (208)
	UPDRS posture item (0 to 4 worst)[89]	212	0.98 (0.85)	–0.25 (–0.36 to –0.14)	0.00 (133)	0.88 (0.72)	–0.15 (–0.34 to 0.03)	0.10 (77)	–0.10 (–0.30 to 0.10)	0.33 (210)
	UPDRS gait item (0 to 4 worst)[89]	212	1.20 (0.83)	–0.28 (–0.10 to –0.16)	0.00 (133)	1.00 (0.79)	–0.17 (–0.33 to –0.01)	0.04 (77)	–0.12 (–0.32 to 0.09)	0.26 (210)
Pain 'on'	VAS (0 to 100 worst)[90–93]	164	25.87 (25.79)	5.53 (–0.07 to 11.12)	0.053 (102)	29.27 (25.10)	10.81 (3.75 to 17.87)	0.003 (60)	–5.28 (–14.29 to 3.73)	0.25 (162)
Speech	Speech Self Report Questionnaire (0 to 130 worst)	227	27.41 (22.87)	0.43 (–1.77 to 2.64)	0.70 (143)	22.84 (22.49)	3.99 (0.67 to 7.31)	0.02 (82)	–3.35 (–7.38 – 0.27)	0.07 (225)
	UPDRS item (0 to 4 worst)[89]	226	0.77 (0.80)	–0.13 (–0.23 to –0.03)	0.01 (143)	0.59 (0.78)	–0.07 (–0.23 to 0.08)	0.36 (81)	–0.06 (–0.23 to 0.11)	0.49 (224)
	Emerson and Enderby – voice (0 to 4 worst)[94]	226	2.18 (0.85)	0.04 (–0.08 to 0.15)	0.56 (143)	1.94 (0.85)	–0.02 (–0.17 to 0.12)	0.74 (81)	0.06 (–0.13 to 0.25)	0.54 (224)
	Emerson and Enderby – articulation (0 to 4 worst)[94]	226	1.69 (0.79)	–0.13 (–0.23 to –0.02)	0.02 (143)	1.47 (0.63)	–0.04 (–0.18 to 0.11)	0.62 (81)	–0.09 (–0.27 to 0.09)	0.32 (224)

			Group A + B: MDT			Group C: controls			Difference in changes, weeks 6–0: A + B vs. C	
Category	Instrument	*n*	Baseline (week 0) Yes, *n* (%)	Change week 6–0 (95% CI)	*p*-value[a] (df)	Baseline (week 0) Yes, *n* (%)	Change week 6–0 (95% CI)	*p*-value[a] (df)	Mean (95% CI)	*p*-value[a] (df)
Psychological well-being	Yale Depression Screen (yes = 1; no = 0)[84,85]	225	32 (22.4)	Improve: 16 (11.2) Same: 119 (83.27) Worse: 8 (5.6)	0.10	28 (34.10)	Improve: 14 (17.1) Same: 66 (80.5) Worse: 2 (2.4)	< 0.001	Not applicable	0.12
Mobility	Falls (yes = 1; no = 0)	226	59 (41.3)	Improve: 26 (18.2) Same: 105 (73.4) Worse: 12 (8.4)	0.02	31 (37.3)	Improve: 13 (15.7) Same: 61 (73.5) Worse: 9 (10.8)	0.39	Not applicable	0.48

df, degrees of freedom; HRQoL, health-related quality of life; PCS, physical component summary; PDQ-8, Parkinson's Disease Questionnaire-8 items.

a One-way ANOVA tests were used for comparisons between all three groups, and unpaired *t*-tests were used for comparisons between pairs of groups. Within-group changes between assessment points were also explored using paired *t*-tests. In each case, a two-sided test was used.

TABLE 14 Primary and secondary clinical outcomes, within- and between-group differences at 6 weeks (post treatment): live-in carers

			Group A + B: MDT			Group C: controls			Difference in changes, weeks 6 – 0: A + B vs. C	
Category	Instrument	*n*	Baseline (week 0) mean (SD)	Change week 6 – 0 (95% CI)	*p*-value[a] (df)	Baseline (week 0) mean (SD)	Change week 6 – 0 (95% CI)	*p*-value[a] (df)	Mean (95% CI)	*p*-value[a] (df)
Strain (primary outcome)	Modified Caregiver Strain Index (0 to 26 worst)[71]	125	7.27 (5.31)	–0.62 (–1.25 to 0.00)	0.05 (81)	7.44 (6.92)	–0.67 (–1.54 to 0.19)	0.12 (42)	0.05 (–1.01 to 1.11)	0.92 (123)
General health	General Health Questionnaire-12 (0 to 36 worst)[95]	125	10.83 (4.49)	–0.62 (–1.28 to 0.04)	0.06 (81)	10.53 (4.61)	0.02 (–1.12 to 1.16)	0.97 (42)	–0.65 (–1.86 to 0.57)	0.30 (123)
Activities	Barthel ADL (0 to 20 independent)[76]	125	19.88 (0.53)	0.04 (–0.11 to 0.18)	0.61 (80)	19.84 (0.61)	–0.05 (–0.29 to 0.20)	0.70 (42)	0.08 (–0.17 to 0.34)	0.52 (123)
	Frenchay Activities Index (0 to 30 best)[77–79]	125	27.71 (2.70)	–0.00 (–0.41 to 0.41)	1.00 (81)	27.63 (4.05)	–0.19 (–0.82 to 0.45)	0.56 (42)	0.19 (–0.53 to 0.90)	0.61 (123)
HRQoL (generic)	EQ-5D Thermometer (0 to 100 best)[80,81]	125	80.41 (15.27)	–2.19 (–4.66 to 0.29)	0.08 (80)	78.26 (19.45)	–0.21 (–5.96 to 5.54)	0.94 (42)	–1.68 (–7.02 to 3.66)	0.53 (123)
	EQ-5D Index (–0.57 to 1.0 best)[80,81]	125	0.82 (0.20)	0.01 (–0.03 to 0.02)	0.70 (81)	0.82 (0.23)	0.00 (–0.04 to 0.05)	0.83 (42)	–0.01 (–0.06 to 0.04)	0.69 (123)
	SF-36 PCS (0 to 100 best)[82]	125	45.57 (10.25)	–1.03 (–2.51 to 0.45)	0.17 (81)	47.19 (8.92)	1.01 (–1.10 to 3.13)	0.34 (42)	–2.04 (–4.57 to 0.48)	0.11 (123)
	SF-36 MCS (0 to 100 best)[82]	125	52.15 (8.75)	1.60 (0.03 to 3.18)	0.05 (81)	51.66 (9.79)	–1.78 (–4.19 to 0.62)	0.14 (42)	3.38 (0.63 to 6.14)	0.02 (123)
Psychological well-being (Yale Depression Screen see below)	HADS – anxiety (0 to 21 worst)[83]	125	5.40 (3.72)	–0.45 (–0.98 to 0.08)	0.10 (81)	5.91 (3.95)	0.12 (–0.74 to 0.98)	0.79 (42)	–0.57 (–1.52 to 0.38)	0.24 (123)
	HADS – Depression (0 to 21 worst)[83]	125	3.43 (2.68)	–0.21 (–0.62 to 0.21)	0.32 (81)	3.65 (3.68)	0.21 (–0.55 to 0.97)	0.58 (42)	–0.42 (–1.20 to 0.36)	0.29 (123)
Category	Instrument	*n*	Baseline yes, *n* (%)	Change week 6 – 0	*p*-value[a]	Baseline yes, *n* (%)	Change week 6 – 0	*p*-value[a]	Differences in changes	*p*-value[a]
Psychological well-being	Yale Depression Screen (yes = 1; no = 0)[84,85]	125	22 (26.8)	Improve: 5 (6.1) Same: 69 (84.1) Worse: 8 (9.8)	0.41	16 (37.2)	Improve: 4 (9.3) Same: 33 (76.7) Worse: 6 (14.0)	0.53	Not applicable	0.89

df, degrees of freedom; HRQoL, health-related quality of life; PCS, physical component summary.

a One-way ANOVA tests were used for comparisons between all three groups, and unpaired *t*-tests were used for comparisons between pairs of groups. Within-group changes between assessment points were also explored using paired *t*-tests. In each case, a two-sided test was used.

TABLE 15 Primary and secondary clinical outcomes, within- and between-group differences from week 6 (end of MDT for groups A and B) to week 24 (end of PCA for group B): people with Parkinson's

			Group A: MDT			Group B: MDT + PCA			Difference in changes weeks 24 – 6: A vs. B	
Category	Instrument	*n*	Week 6 yes, *n* (%)	Change week 24 – 6 (95% CI)	*p*-value[a] (df)	Week 6 yes, *n* (%)	Change week 24 – 6 (95% CI)	*p*-value[a] (df)	Mean (95% CI)	*p*-value[a] (df)
Disability (primary outcome)	Self-Assessed Parkinson's Disability (25 to 125 worst)[69,70]	143	45.04 (17.04)	3.28 (1.35 to 5.21)	< 0.001 (74)	48.51 (18.64)	1.91 (–0.09 to 3.91)	0.06 (67)	1.37 (–1.38 to 4.12)	0.33 (141)
Parkinson's specific	PDQ-8 (0 to 100 worst)[72,73]	144	22.17 (17.38)	1.92 (–1.00 to 4.84)	0.20 (74)	24.68 (16.80)	1.27 (–1.44 to 3.98)	0.35 (68)	0.65 (–3.32 to 4.62)	0.75 (142)
	Non-Motor Symptoms Questionnaire (0 to 30 worst)[74,75]	144	9.08 (5.25)	1.00 (0.31 to 1.69)	< 0.001 (74)	10.00 (4.80)	–0.01 (–0.80 to 0.77)	0.97 (68)	1.01 (–0.01 to 2.04)	0.05 (142)
Activities	Barthel ADL (0 to 20 independent)[76]	144	18.47 (2.10)	–0.33 (–0.69 to 0.03)	0.07 (74)	17.67 (3.46)	–0.30 (–0.64 to 0.04)	0.08 (68)	–0.03 (–0.52 to 0.46)	0.91 (142)
	Frenchay Activities Index (0 to 30 best)[77–79]	143	18.55 (7.44)	–0.88 (–2.00 to 0.24)	0.12 (73)	17.96 (8.37)	–0.49 (–1.68 to 0.69)	0.41 (68)	–0.39 (–2.00 to 1.23)	0.64 (141)
HRQoL (generic)	EQ-5D Thermometer (0 to 100 best)[80,81]	144	67.61 (19.23)	–3.49 (–6.96 to –0.02)	0.05 (74)	65.09 (20.40)	–2.47 (–6.92 to 1.97)	0.27 (68)	–1.02 (–6.56 to 4.53)	0.72 (142)
	EQ-5D Index (–0.57 to 1.0 best)[80,81]	144	0.66 (0.23)	–0.06 (–0.11 to –0.01)	0.02 (74)	0.60 (0.28)	0.00 (–0.04 to 0.04)	0.95 (68)	–0.06 (–0.12 to 0.00)	0.07 (142)
	SF-36 PCS (0 to 100 best)[82]	143	33.32 (11.34)	0.68 (–1.23 to 2.59)	0.48 (74)	33.06 (10.24)	–0.45 (–2.04 to 1.13)	0.57 (67)	1.13 (–1.36 to 3.63)	0.37 (141)
	SF-36 MCS (0 to 100 best)[82]	144	53.39 (8.31)	–2.55 (–4.30 to 0.79)	< 0.001 (74)	52.37 (9.60)	–0.68 (–2.53 to 1.16)	0.46 (68)	–1.87 (–4.39 to 0.66)	0.15 (142)

continued

TABLE 15 Primary and secondary clinical outcomes, within- and between-group differences from week 6 (end of MDT for groups A and B) to week 24 (end of PCA for group B): people with Parkinson's (*continued*)

			Group A: MDT			Group B: MDT + PCA			Difference in changes weeks 24 – 6: A vs. B	
Category	Instrument	*n*	Week 6 yes, *n* (%)	Change week 24 – 6 (95% CI)	*p*-value[a] (df)	Week 6 yes, *n* (%)	Change week 24 – 6 (95% CI)	*p*-value[a] (df)	Mean (95% CI)	*p*-value[a] (df)
Psychological well-being (Yale Depression Screen see below)	HADS – anxiety (0 to 21 worst)[83]	144	5.05 (3.43)	0.71 (0.10 to 1.31)	0.02 (74)	5.42 (4.05)	0.22 (–0.40 to 0.84)	0.49 (68)	0.49 (–0.37 to 1.35)	0.26 (142)
	HADS – depression (0 to 21 worst)[83]	144	5.36 (3.59)	0.49 (–0.09 to 1.07)	0.09 (74)	5.01 (3.04)	0.17 (–0.31 to 0.66)	0.47 (68)	0.32 (–0.43 to 1.07)	0.40 (142)
Self-efficacy	Self-Efficacy Scale (1 to 10 high)[86]	144	7.34 (1.98)	–0.67 (–1.05 to –0.30)	< 0.001 (74)	7.00 (2.14)	–0.21 (–0.60 to 0.19)	0.29 (68)	–0.47 (–1.00 to 0.07)	0.09 (142)
Mobility (falls, see below)	Timed Up and Go (seconds, low good)[87,88]	132	20.15 (17.48)	2.80 (–1.81 to 7.42)	0.23 (71)	16.83 (9.09)	1.95 (–1.80 to 5.70)	0.30 (59)	0.85 (–5.20 to 6.90)	0.78 (130)
	UPDRS posture item (0 to 4 worst)[89]	134	0.75 (0.76)	0.25 (0.09 to 0.41)	< 0.001 (71)	0.61 (0.66)	–0.03 (–0.19 to 0.13)	0.69 (61)	0.28 (0.06 to 0.50)	0.01 (131)
	UPDRS gait item (0 to 4 worst)[89]	134	0.82 (0.66)	0.17 (0.01 to 0.32)	0.03 (71)	0.95 (0.86)	0.05 (–0.11 to 0.21)	0.55 (61)	0.12 (–0.10 to 0.34)	0.29 (132)
Pain 'on'	VAS (0 to 100 worst)[90–93]	103	45.04 (17.04)	1.67 (–6.31 to 9.65)	0.68 (47)	48.51 (18.64)	–2.84 (–10.25 to 4.58)	0.45 (54)	4.50 (–6.25 to 15.26)	0.41 (101)
Speech	Speech Self Report Questionnaire (0 to 130 worst)	144	22.17 (17.38)	0.63 (–2.70 to 3.96)	0.71 (74)	24.68 (16.80)	1.03 (–2.22 to 4.28)	0.53 (68)	–0.40 (–5.03 to 4.22)	0.86 (142)
	UPDRS item (0 to 4 worst)[89]	144	9.08 (5.25)	0.07 (–0.08 to 0.21)	0.36 (74)	10.00 (4.80)	0.09 (–0.07 to 0.24)	0.26 (68)	–0.02 (–0.23 to 0.19)	0.85 (142)
	Abridged Emerson and Enderby Screening Assessment Rating Scale – voice (0 to 4 worst)[94]	144	18.47 (2.10)	–0.37 (–0.55 to –0.19)	< 0.001 (74)	17.67 (3.46)	–0.01 (–0.16 to 0.13)	0.84 (68)	–0.36 (–0.59 to –0.13)	< 0.001 (138)
	Abridged Emerson and Enderby Screening Assessment Rating Scale – articulation (0 to 4 worst)[94]	144	18.55 (7.44)	0.11 (–0.05 to 0.27)	0.18 (74)	17.96 (8.37)	0.03 (–0.09 to 0.15)	0.64 (68)	0.08 (–0.12 to 0.28)	0.44 (136)

Category	Instrument	*n*	Group A: MDT			Group B: MDT + PCA			Difference in changes weeks 24–6: A vs. B	
			Week 6 yes, *n* (%)	Change week 24–6 (95% CI)	*p*-value[a] (df)	Week 6 yes, *n* (%)	Change week 24–6 (95% CI)	*p*-value[a] (df)	Mean (95% CI)	*p*-value[a] (df)
Psychological well-being	Yale Depression Screen (yes = 1; no = 0)[84,85]	143	14 (18.9)	Improve: 6 (8.1)	0.53	10 (14.5)	Improve: 3 (4.3)	0.21	Not applicable	0.18
				Same: 64 (86.5)			Same: 59 (85.5)			
				Worse: 4 (5.4)			Worse: 7 (10.1)			
Mobility	Falls (yes = 1; no = 0)	145	22 (29.3)	Improve: 5 (6.7)	0.004	24 (34.4)	Improve: 4 (15.8)	0.05	Not applicable	0.37
				Same: 51 (68)			Same: 53 (76.8)			
				Worse: 1.9 (25.3)			Worse: 12 (17.4)			

df, degrees of freedom; HRQoL, health-related quality of life; PCS, physical component summary; PDQ-8, Parkinson's Disease Questionnaire-8 items.

a One-way ANOVA tests were used for comparisons between all three groups, and unpaired *t*-tests were used for comparisons between pairs of groups. Within-group changes between assessment points were also explored using paired *t*-tests. In each case, a two-sided test was used.

TABLE 16 Primary and secondary clinical outcomes, within- and between-group differences from week 6 (end of MDT for groups A and B) to week 24 (end of PCA for group B): live-in carers

			Group A: MDT			Group B: MDT + PCA			Difference in changes weeks 24–6: A vs. B	
Category	Instrument	*n*	Week 6 mean (SD)	Change week 24–6 (95% CI)	*p*-value[a] (df)	Week 6 mean (SD)	Change week 24–6 (95% CI)	*p*-value[a] (df)	Mean (95% CI)	*p*-value[a] (df)
Strain (primary outcome)	Modified Caregiver Strain Index (0 to 26 worst)[71]	82	5.62 (4.07)	0.56 (–0.29 to 1.40)	0.19 (44)	7.89 (6.92)	–0.57 (–1.42 to 0.28)	0.18 (36)	1.12 (–0.07 to 2.32)	0.06 (80)
General health	General Health Questionnaire-12 (0 to 36 worst)[95]	82	9.62 (3.63)	0.76 (–0.35 to 1.86)	0.17 (44)	10.92 (5.04)	–0.43 (–2.07 to 1.20)	0.60 (36)	1.19 (–0.76 to 3.14)	0.23 (65)
Activities	Barthel ADL (0 to 20 independent)[76]	82	19.93 (0.45)	–0.04 (–0.27 to 0.19)	0.70 (44)	19.89 (0.31)	–0.05 (–0.21 to 0.10)	0.49 (36)	0.01 (–0.28 to 0.30)	0.95 (80)
	Frenchay Activities Index (0 to 30 best)[77–79]	82	28.44 (2.55)	0.11 (–0.46 to 0.68)	0.70 (44)	26.81 (3.22)	–0.24 (–1.25 to 0.77)	0.63 (36)	0.35 (–0.74 to 1.45)	0.52 (80)
HRQoL (generic)	EQ-5D Thermometer (0 to 100 best)[80,81]	82	78.27 (15.91)	0.99 (–3.16 to 5.14)	0.63 (44)	78.82 (20.04)	–4.35 (–10.36 to 1.66)	0.15 (36)	5.34 (–1.66 to 12.34)	0.13 (80)
	EQ-5D Index (–0.57 to 1.0 best)[80,81]	82	0.83 (0.20)	–0.01 (–0.06 to 0.03)	0.59 (44)	0.79 (0.24)	0.00 (–0.07 to 0.07)	0.90 (36)	–0.01 (–0.09 to 0.07)	0.83 (80)
	SF-36 PCS (0 to 100 best)[82]	82	45.53 (10.04)	0.22 (–2.10 to 2.53)	0.85 (44)	43.34 (12.34)	–0.06 (–3.26 to 3.15)	0.97 (36)	0.27 (–3.53 to 4.08)	0.89 (80)
	SF-36 MCS (0 to 100 best)[82]	82	54.43 (7.85)	–1.16 (–2.98 to 0.66)	0.21 (44)	52.93 (8.53)	–1.72 (–3.91 to 0.46)	0.12 (36)	0.56 (–2.21 to 3.34)	0.69 (80)
Psychological well-being (Yale Depression Screen below)	HADS – anxiety (0 to 21 worst)[83]	82	4.60 (3.58)	0.31 (–0.33 to 0.95)	0.33 (44)	5.38 (4.00)	0.32 (–0.47 to 1.12)	0.41 (36)	–0.01 (–1.01 to 0.98)	0.98 (80)
	HADS – depression (0 to 21 worst)[83]	82	2.82 (2.44)	0.33 (–0.14 to 0.81)	0.16 (44)	3.70 (2.93)	0.11 (–0.51 to 0.73)	0.72 (36)	0.23 (–0.53 to 0.98)	0.55 (80)
Category	**Instrument**	***n***	**Week 6 yes, *n* (%)**	**Change week 24–6**	***p*-value[a]**	**Week 6 yes, *n* (%)**	**Change week 24–6**	***p*-value[a]**	**Differences in changes**	***p*-value[a]**
Psychological well-being	Yale Depression Screen (yes = 1; no = 0)[84,85]	82	13 (28.9)	Improve: 3 (6.7) Same: 37 (82.2) Worse: 5 (11.1)	0.48	12 (32.4)	Improve: 3 (8.1) Same: 30 (81.1) Worse: 4 (10.8)	0.71	Not applicable	0.86

df, degrees of freedom; HRQoL, health-related quality of life; PCS, physical component summary.

a One-way ANOVA tests were used for comparisons between all three groups, and unpaired *t*-tests were used for comparisons between pairs of groups. Within-group changes between assessment points were also explored using paired *t*-tests. In each case, a two-sided test was used.

Medium-term effects (baseline to week 24): groups A versus B; A versus C; B versus C

The paired-group comparisons of changes from baseline to week 24 reveal scattered significant effects that mostly focus on the same outcomes that showed effect at 6 weeks (A + B vs. C) and over the 18-week PCA follow-up period (A vs. B). There were no significant effects on the primary outcomes of either people with Parkinson's or live-in carers (*Tables 17* and *18*).

Comparing group A (MDT) and group B (MDT + PCA), significant differences in change scores from baseline were observed for people with Parkinson's in EQ-5D health-related quality-of-life index[80,81] ($p = 0.04$) and UPDRS posture[89] ($p < 0.001$), due to significant improvements in group B; SF-36 MCS[82] ($p = 0.04$) and depression (HADS,[83] $p = 0.02$), due to significant worsening in group A; and Emerson and Enderby voice measure[94] ($p < 0.01$), due to significant improvements in group A. The change in the physical component summary (PCS) score of SF-36[82] was significantly different for live-in carers ($p = 0.01$), due to a significant worsening in group B.

The only significant difference in change scores from baseline for people with Parkinson's between groups A (MDT) and C (control) was in the Emerson and Enderby voice measure[94] ($p = 0.02$) (A significantly improved); there was a marginally significant difference in changes in Speech Self Report ($p = 0.09$) (C worsened significantly). Differences in change scores between the groups were found for live-in carers on depression (HADS,[83] $p = 0.04$), due to significant worsening in group C, and marginally in SF-36 PCS,[82] $p = 0.06$ (improvement in group A and worsening in group C, both non-significant).

Significant differences in changes were observed for people with Parkinson's between group B (MDT + PCA) and group C (control) on a larger number of measures: Parkinson's Non-Motor Symptoms Questionnaire[74,75] ($p = 0.05$) (B improved, C worsened, both non-significant); EQ-5D Index[80,81] ($p = 0.04$) and UPDRS posture[89] ($p = 0.01$) due to significant improvements in group B; Emerson and Enderby articulation scale[94] ($p = 0.04$) (trend for B to improve); and Speech Self Report ($p = 0.01$) (C worsened significantly). There were marginally significant differences in the change scores for SF-36 MCS[82] ($p = 0.06$) and anxiety ($p = 0.09$) (HADS[83]), due to worsening in group C [significant for MCS, marginal for anxiety (HADS)]. There was a significant difference in the SF-36 MCS[82] change scores of live-in carers ($p = 0.05$) due to a significant worsening in group C.

Changes during follow-up (weeks 24 to 36) when no group received treatment: groups A versus B; A versus C; B versus C

Significant differences in change scores in favour of group A, compared with group B, were found for people with Parkinson's in UPDRS posture[89] ($p < 0.001$) and the Emerson and Enderby articulation measure[94] ($p = 0.01$) (significant improvements in group A) (*Table 19*). The difference in change scores for the Emerson and Enderby voice measure[94] was in favour of group B ($p < 0.001$) (significant worsening in group A). There was a significant difference in the change scores for live-in carers on depression (HADS,[83] $p = 0.03$) (group A worsened significantly), and marginally on the EQ-5D health-related quality-of-life thermometer[80,81] ($p = 0.06$) (group A worsened, group B improved, neither change significant) (*Table 20*).

Compared with people with Parkinson's in group C, those in group A reported significantly improved mobility ($p = 0.01$) (Timed Up and Go[87,88]). However, on all of the other measures where significant differences in change scores were observed, the results favoured group C: UPDRS gait[89] ($p = 0.01$) (C improved significantly); Speech Self Report ($p = 0.03$) (A worsened significantly); Emerson and Enderby voice measure[94] ($p = 0.02$) (A and C both worsened significantly but by a larger amount in A); SF-36 PCS[82] ($p = 0.04$) (A worsened, C improved, neither change significant). There were significant differences in the change scores of live-in carers in groups A and C for EQ-5D health-related quality of life thermometer[80,81] ($p = 0.05$), SF-36 MCS,[82] $p = 0.05$ and depression, $p = 0.01$ (HADS[83]), due, in each case, to a significant deterioration in group A.

TABLE 17 Primary and secondary clinical outcomes, within- and between-group differences at 24 weeks (end of PCA for group B): people with Parkinson's

			Group A: MDT			Group B: MDT + PCA			Group C: controls			Differences in changes weeks 24–0					
												A vs. B		A vs. C		B vs. C	
Category	Instrument	*n*	Baseline (week 0) mean (SD)	Change week 24–0 (95% CI)	*p*-value[a] (df)	Baseline (week 0) mean (SD)	Change week 24–0 (95% CI)	*p*-value[a] (df)	Baseline (week 0) mean (SD)	Change week 24–0 (95% CI)	*p*-value[a] (df)	Mean (95% CI)	*p*-value[a] (df)	Mean (95% CI)	*p*-value[a] (df)	Mean (95% CI)	*p*-value[a] (df)
Disability (primary outcome)	Self-Assessed Parkinson's Disability (25 to 125 worst)[69,70]	226	48.51 (17.15)	–0.19 (–2.37 to 2.00)	0.87 (74)	50.66 (18.17)	–0.24 (–3.19 to 2.72)	0.87 (67)	46.95 (16.30)	1.01 (–1.34 to 3.36)	0.39 (82)	0.05 (–3.55 to 3.65)	0.98 (141)	–1.20 (–4.40 to 2.01)	0.46 (156)	–1.25 (–4.94 to 2.45)	0.51 (149)
Parkinson's specific	PDQ-8 (0 to 100 worst)[72,73]	227	23.04 (7.16)	1.04 (–1.61 to 3.69)	0.44 (74)	24.50 (17.46)	1.45 (–1.93 to 4.83)	0.39 (68)	23.64 (18.30)	3.69 (0.95 to 6.43)	0.01 (82)	–0.41 (–4.63 to 3.81)	0.85 (142)	–2.65 (–6.45 to 1.15)	0.17 (156)	–2.24 (–6.51 to 2.03)	0.30 (150)
	Non-Motor Symptoms Questionnaire (0 to 30 worst)[74,75]	227	10.25 (5.03)	–0.17 (–0.90 to 0.56)	0.64 (74)	10.62 (5.19)	–0.64 (–1.52 to 0.24)	0.15 (68)	10.01 (5.32)	0.46 (–0.19 to 1.11)	0.17 (82)	0.46 (–0.66 to 1.59)	0.42 (142)	–0.63 (–1.60 to 0.34)	0.20 (156)	–1.10 (–2.18 to –0.01)	0.05 (130)
Activities	Barthel ADL (0 to 20 independent)[76]	226	18.48 (2.09)	–0.35 (–0.79 to 0.10)	0.12 (74)	17.78 (3.12)	–0.42 (–0.85 to 0.01)	0.06 (68)	18.53 (2.18)	–0.43 (–0.85 to –0.01)	0.04 (82)	0.07 (–0.54 to 0.69)	0.81 (142)	0.09 (–0.52 to 0.69)	0.78 (156)	0.01 (–0.59 to 0.61)	0.96 (150)
	Frenchay Activities Index (0 to 30 best)[77–79]	226	19.0 (7.12)	–1.34 (–2.35 to –0.33)	0.01 (73)	18.13 (8.39)	–0.67 (–1.78 to 0.45)	0.24 (68)	21.31 (6.83)	–1.95 (–3.02 to –0.88)	< 0.001 (82)	–0.67 (–2.16 to 0.82)	0.37 (141)	0.61 (–0.85 to 2.08)	0.41 (155)	1.29 (–0.25 to 2.82)	0.10 (150)
HRQoL (generic)	EQ-5D Thermometer (0 to 100 best)[80,81]	226	67.62 (18.49)	–3.49 (–7.54 to 0.56)	0.09 (74)	65.78 (18.31)	–3.16 (–8.30 to 1.98)	0.22 (68)	65.68 (20.62)	–2.26 (–7.12 to 2.59)	0.36 (81)	–0.33 (–6.77 to 6.10)	0.92 (142)	–1.23 (–7.51 to 5.04)	0.70 (152)	–0.90 (–7.93 to 6.14)	0.80 (149)
	EQ-5D Index (–0.57 to 1.0 best)[80,81]	227	0.61 (0.25)	–0.01 (–0.06 to 0.05)	0.84 (74)	0.53 (0.29)	0.07 (0.02 to 0.12)	0.01 (68)	0.58 (0.26)	0.00 (–0.06 to 0.05)	0.86 (82)	–0.08 (–0.15 to 0.00)	0.04 (142)	0.00 (–0.07 to 0.07)	0.98 (156)	0.08 (0.00 to 0.15)	0.04 (150)
	SF-36 PCS (0 to 100 best)[82]	225	34.06 (10.07)	–0.06 (–1.96 to 1.83)	0.95 (74)	33.81 (10.37)	–1.21 (–3.37 to 0.96)	0.27 (67)	35.23 (11.10)	–2.20 (–4.14 to –0.26)	0.03 (81)	1.14 (–1.69 to 3.98)	0.43 (141)	2.14 (–0.56 to 4.83)	0.12 (155)	0.99 (–1.88 to 3.87)	0.50 (148)
	SF-36 MCS (0 to 100 best)[82]	226	53.74 (9.48)	–2.90 (–4.74 to –1.06)	< 0.001 (74)	51.70 (9.78)	–0.01 (–2.08 to 2.06)	0.99 (68)	53.02 (10.03)	–2.62 (–4.42 to –0.83)	< 0.001 (81)	–2.88 (–5.62 to –0.15)	0.04 (142)	–0.27 (–2.83 to 2.28)	0.83 (155)	2.61 (–0.10 to 5.32)	0.06 (149)

			Group A: MDT			Group B: MDT + PCA			Group C: controls			Differences in changes weeks 24–0					
												A vs. B		A vs. C		B vs. C	
Category	Instrument	*n*	Baseline (week 0) mean (SD)	Change week 24–0 (95% CI)	*p*-value[a] (df)	Baseline (week 0) mean (SD)	Change week 24–0 (95% CI)	*p*-value[a] (df)	Baseline (week 0) mean (SD)	Change week 24–0 (95% CI)	*p*-value[a] (df)	Mean (95% CI)	*p*-value[a] (df)	Mean (95% CI)	*p*-value[a] (df)	Mean (95% CI)	*p*-value[a] (df)
Psycho-logical well-being (Yale Depression Screen below)	HADS – anxiety (0 to 21 worst)[83]	226	5.76 (3.82)	0.00 (–0.69 to 0.69)	1.00 (74)	5.87 (3.55)	–0.23 (–0.85 to 0.38)	0.45 (68)	6.10 (4.25)	0.51 (–0.09 to 1.11)	0.09 (81)	0.23 (–0.69 to 1.16)	0.62 (142)	–0.51 (–1.42 to 0.39)	0.26 (155)	–0.74 (–1.60 to 0.11)	0.09 (149)
	HADS – depression (0 to 21 worst)[83]	226	5.09 (3.43)	0.76 (0.16 to 1.36)	0.01 (74)	5.39 (3.20)	–0.20 (–0.79 to 0.38)	0.49 (68)	5.20 (2.94)	0.35 (–0.21 to 0.92)	0.22 (81)	0.96 (0.13 to 1.80)	0.02 (142)	0.41 (–0.41 to 1.23)	0.33 (155)	–0.56 (–1.37 to 0.26)	0.18 (149)
Self-efficacy	Self-Efficacy Scale (1 to 10 high)[86]	225	7.27 (1.87)	–0.61 (–0.99 to –0.22)	< 0.001 (74)	7.16 (1.76)	–0.37 (–0.84 to 0.10)	0.12 (68)	7.03 (2.13)	–0.31 (–0.69 to 0.07)	–0.11 (81)	–0.24 (–0.84 to 0.36)	0.44 (142)	–0.30 (–0.84 to 0.24)	0.28 (155)	–0.06 (–0.66 to 0.53)	0.84 (149)
Mobility (falls see below)	Timed Up and Go (seconds, low good)[87,88]	210	18.48 (11.68)	4.48 (0.28 to 8.68)	0.04 (71)	18.28 (13.29)	0.50 (–3.08 to 4.09)	0.78 (59)	16.08 (12.68)	1.07 (–0.92 to 3.06)	0.29 (77)	3.98 (–1.62 to 9.57)	0.16 (130)	3.41 (–1.21 to 8.03)	0.15 (101)	–0.57 (–4.40 to 3.27)	0.77 (136)
	UPDRS posture item (0 to 4 worst)[89]	212	0.94 (0.77)	0.06 (–0.12 to 0.23)	0.53 (71)	0.94 (0.87)	–0.35 (–0.51 to –0.19)	< 0.001 (61)	0.88 (0.72)	–0.03 (0.19 to 0.14)	0.75 (77)	0.41 (0.17 to 0.65)	< 0.001 (132)	0.08 (–0.16 to 0.32)	0.50 (148)	–0.33 (–0.56 to –0.10)	0.01 (138)
	UPDRS gait item (0 to 4 worst)[89]	212	1.14 (0.77)	–0.15 (–0.33 to 0.03)	0.09 (71)	1.19 (0.85)	–0.19 (–0.39 to 0.01)	0.06 (61)	1.00 (0.79)	–0.03 (–0.21 to 0.16)	0.78 (77)	0.04 (–0.22 to 0.31)	0.76 (132)	–0.13 (–0.38 to 0.13)	0.32 (148)	–0.17 (–0.44 to 0.10)	0.22 (138)
Pain 'on'	VAS (0 to 100 worst)[90–93]	164	26.00 (27.34)	7.19 (0.23 to 14.15)	0.04 (47)	27.32 (25.85)	2.70 (–6.20 to 11.60)	0.55 (54)	29.27 (25.10)	2.34 (–4.85 to 9.52)	0.52 (60)	4.49 (–6.91 to 15.89)	0.44 (101)	4.85 (–5.23 to 14.93)	0.34 (107)	0.36 (–10.85 to 11.58)	0.95 (114)
Speech	Speech Self Report Questionnaire (0 to 130 worst)	227	27.71 (22.96)	2.11 (–1.55 to 5.76)	0.25 (74)	27.09 (22.94)	–0.01 (–2.90 to 2.87)	0.99 (68)	22.84 (22.49)	6.77 (2.84 to 10.70)	< 0.00 (82)	2.12 (–2.55 to 6.79)	0.37 (142)	–4.66 (–10.02 to 0.69)	0.09 (156)	–6.79 (–11.62 to –1.95)	0.01 (143)
	UPDRS item (0 to 4 worst)[89]	226	0.80 (0.77)	–0.03 (–0.18 to 0.12)	0.73 (74)	0.78 (0.86)	–0.12 (–0.28 to 0.05)	0.17 (68)	0.59 (0.78)	0.07 (–0.10 to 0.24)	0.39 (81)	0.09 (–0.13 to 0.31)	0.43 (142)	–0.10 (–0.33 to 0.13)	0.38 (155)	–0.19 (–0.43 to 0.05)	0.12 (149)
	Emerson and Enderby – voice (0 to 4 worst)[94]	226	2.23 (0.80)	–0.36 (–0.52 to –0.20)	< 0.001 (74)	2.16 (0.90)	0.04 (–0.14 to 0.23)	0.64 (68)	1.94 (0.85)	–0.09 (–0.25 to 0.08)	0.30 (81)	–0.40 (–0.65 to –0.16)	< 0.001 (142)	–0.27 (–0.50 to –0.05)	0.02 (155)	0.13 (–0.12 to 0.37)	0.30 (149)
	Emerson and Enderby – articulation (0 to 4 worst)[94]	226	2.23 (0.80)	0.00 (0.16 to 0.16)	1.00 (74)	2.16 (0.90)	–0.14 (–0.31 to 0.02)	0.08 (68)	1.94 (0.85)	0.06 (–0.06 to 0.18)	0.30 (81)	0.14 (–0.08 to 0.37)	0.21 (142)	–0.06 (–0.26 to 0.14)	0.54 (155)	–0.21 (–0.40 to –0.01)	0.04 (128)

continued

TABLE 17 Primary and secondary clinical outcomes, within- and between-group differences at 24 weeks (end of PCA for group B): people with Parkinson's (*continued*)

			Group A: MDT			Group B: MDT + PCA			Group C: controls			Differences in changes weeks 24–0					
												A vs. B		A vs. C		B vs. C	
Category	Instrument	*n*	Baseline yes, *n* (%)	Change week 24–0	*p*-value[a]	Baseline yes, *n* (%)	Change week 24–0	*p*-value[a]	Baseline yes, *n* (%)	Change week 24–0	*p*-value[a]	Difference in changes	*p*-value[a]	Difference in changes	*p*-value[a]	Difference in changes	*p*-value[a]
Psychological well-being	Yale Depression Screen[a] (yes = 1; no = 0)[84,85]	225	13 (17.6)	Improve 6 (8.1)	0.76	19 (27.5)	Improve 9 (13)	0.17	28 (34.1)	Improve 16 (19.5)	0.007	Not applicable	0.38	Not applicable	0.055	Not applicable	0.31
				Same 63 (85.1)			Same 56 (81.2)			Same 62 (75.6)							
				Worse 5 (6.8)			Worse 4 (5.8)			Worse 4 (4.9)							
Mobility	Falls[a] (yes = 1; no = 0)	228	31 (41.3)	Improve 12 (16)	0.35	30 (42.9)	Improve 6 (8.7)	0.44	31 (37.3)	Improve 11 (13.4)	0.55	Not applicable	0.76	Not applicable	0.73	Not applicable	0.95
				Same 46 (61.3)			Same 54 (78.3)			Same 57 (69.5)							
				Worse 17 (22.7)			Worse 9 (13)			Worse 14 (17.1)							

df, degrees of freedom; HRQoL, health-related quality of life; PDQ-8, Parkinson's Disease Questionnaire-8 items.

a One-way ANOVA tests were used for comparisons between all three groups, and unpaired *t*-tests were used for comparisons between pairs of groups. Within-group changes between assessment points were also explored using paired *t*-tests. In each case, a two-sided test was used.

TABLE 18 Primary and secondary clinical outcomes, within- and between-group differences at 24 weeks (end of PCA for group B): live-in carers

			Group A: MDT			Group B: MDT + PCA			Group C: controls			Differences in changes weeks 24–0					
												A vs. B		A vs. C		B vs. C	
Category	Instrument	*n*	Baseline (week 0) mean (SD)	Change week 24–0 (95% CI)	*p*-value[a] (df)	Baseline (week 0) mean (SD)	Change week 24–0 (95% CI)	*p*-value[a] (df)	Baseline (week 0) mean (SD)	Change week 24–0 (95% CI)	*p*-value[a] (df)	Mean (95% CI)	*p*-value[a] (df)	Mean (95% CI)	*p*-value[a] (df)	Mean (95% CI)	*p*-value[a] (df)
Strain (primary outocme)	Modified Caregiver Strain Index (0 to 26 worst)[71]	125	6.58 (4.58)	–0.40 (–1.28 to 0.48)	0.37 (44)	8.11 (6.03)	–0.78 (–1.73 to 0.17)	0.10 (36)	7.44 (6.92)	0.30 (–0.97 to 1.58)	0.64 (42)	0.38 (–0.90 to 1.66)	0.55 (80)	–0.70 (–2.22 to 0.82)	0.36 (86)	–1.09 (–2.70 to 0.52)	0.18 (78)
General health	General Health Questionnaire-12 (0 to 36 worst)[95]	125	10.38 (3.87)	0.00 (–1.37 to 1.37)	1.00 (44)	11.38 (5.14)	–0.89 (–2.46 to 0.68)	0.26 (36)	10.53 (4.61)	0.98 (–1.16 to 3.11)	0.36 (42)	0.89 (–1.15 to 2.93)	0.39 (80)	–0.98 (–3.45 to 1.50)	0.43 (86)	–1.87 (–4.55 to 0.81)	0.17 (78)
Activities	Barthel ADL (0 to 20 independent)[76]	125	19.98 (0.15)	–0.09 (–0.28 to 0.10)	0.35 (44)	19.76 (0.76)	0.08 (–0.22 to 0.38)	0.58 (36)	19.84 (0.61)	0.09 (–0.15 to 0.33)	0.44 (42)	–0.17 (–0.51 to 0.17)	0.32 (80)	–0.18 (–0.48 to 0.12)	0.23 (86)	–0.01 (–0.38 to 0.36)	0.95 (78)
	Frenchay Activities Index (0 to 30 best)[77–79]	125	28.20 (2.30)	0.36 (–0.19 to 0.90)	0.19 (44)	27.11 (3.03)	–0.54 (–1.74 to 0.66)	0.37 (36)	27.63 (4.05)	–0.07 (–0.72 to 0.58)	0.83 (42)	0.90 (–0.41 to 2.20)	0.17 (50)	0.43 (–0.41 to 1.26)	0.31 (86)	–0.47 (–1.82 to 0.88)	0.49 (56)
HRQoL (generic)	EQ-5D Thermometer (0 to 100 best)[80,81]	125	80.57 (13.09)	–1.31 (–5.61 to 2.99)	0.54 (44)	80.22 (17.75)	–5.74 (–11.34 to –0.15)	0.04 (36)	78.26 (19.45)	–2.27 (–9.16 to 4.62)	0.51 (42)	4.43 (–2.40 to 11.26)	0.20 (80)	0.96 (–6.97 to 8.88)	0.81 (86)	–3.48 (–12.40 to 5.45)	0.44 (78)
	EQ-5D Index (–0.57 to 1.0 best)[80,81]	125	0.83 (0.20)	–0.01 (–0.07 to 0.04)	0.66 (44)	0.80 (0.21)	–0.02 (–0.09 to 0.05)	0.61 (36)	0.82 (0.23)	–0.02 (–0.08 to 0.04)	0.45 (42)	0.01 (–0.08 to 0.09)	0.90 (80)	0.01 (–0.07 to 0.09)	0.80 (86)	0.00 (–0.08 to 0.09)	0.92 (78)
	SF-36 PCS (0 to 100 best)[82]	125	44.59 (10.85)	1.16 (–1.16 to 3.48)	0.32 (44)	46.78 (9.48)	–3.49 (–5.93 to –1.05)	0.01 (36)	47.19 (8.92)	–1.77 (–3.88 to 0.34)	0.10 (42)	4.65 (1.31 to 7.98)	0.01 (80)	2.93 (–0.18 to 6.03)	0.06 (86)	–1.72 (–4.88 to 1.44)	0.28 (78)
	SF-36 MCS (0 to 100 best)[82]	125	53.69 (6.64)	–0.42 (–2.74 to 1.91)	0.72 (44)	50.29 (10.58)	0.92 (–1.54 to 3.38)	0.45 (36)	51.66 (9.79)	–2.59 (–5.16 to –0.02)	0.05 (42)	–1.33 (–4.68 to 2.01)	0.43 (80)	2.18 (–1.23 to 5.59)	0.21 (86)	3.51 (–0.02 to 7.05)	0.05 (78)
Psycho-logical well-being (Yale Depression Screen see below)	HADS – anxiety (0 to 21 worst)[83]	125	5.07 (3.28)	–0.16 (–0.83 to 0.52)	0.64 (44)	5.81 (4.21)	–0.11 (–0.89 to 0.67)	0.78 (36)	5.91 (3.95)	0.84 (–0.16 to 1.83)	0.10 (42)	–0.05 (–1.05 to 0.96)	0.93 (80)	–0.99 (–2.17 to 0.18)	0.10 (86)	–0.95 (–2.22 to 0.33)	0.14 (78)
	HADS – depression (0 to 21 worst)[83]	125	3.44 (2.52)	–0.29 (–0.92 to 0.34)	0.36 (44)	3.41 (2.90)	0.41 (–0.35 to 1.16)	0.28 (36)	3.65 (3.68)	0.86 (–0.04 to 1.76)	0.06 (42)	–0.69 (–1.66 to 0.27)	0.16 (80)	–1.15 (–2.23 to –0.07)	0.04 (86)	–0.46 (–1.64 to 0.73)	0.45 (78)

continued

TABLE 18 Primary and secondary clinical outcomes, within- and between-group differences at 24 weeks (end of PCA for group B): live-in carers (*continued*)

			Group A: MDT			Group B: MDT + PCA			Group C: controls			Differences in changes weeks 24–0					
												A vs. B		A vs. C		B vs. C	
Category	Instrument	*n*	Baseline yes, *n* (%)	Change week 24–0	*p*-value[a]	Baseline yes, *n* (%)	Change week 24–0	*p*-value[a]	Baseline yes, *n* (%)	Change week 24–0	*p*-value[a]	Difference in changes	*p*-value[a]	Difference in changes	*p*-value[a]	Difference in changes	*p*-value[a]
Psychological well-being	Yale Depression Screen[a] (yes = 1; no = 0)[84,85]	225	11 (24.4)	Improve 3 (6.7) Same 35 (77.8) Worse 7 (15.6)	0.21	11 (29.7)	Improve 4 (10.8) Same 27 (73) Worse 6 (16.2)	0.53	16 (37.2)	Improve 2 (4.7) Same 35 (81.4) Worse 6 (14)	0.16	Not applicable	0.77	Not applicable	0.98	Not applicable	0.74

df, degrees of freedom; HRQoL, health-related quality of life.

a One-way ANOVA tests were used for comparisons between all three groups, and unpaired *t*-tests were used for comparisons between pairs of groups. Within-group changes between assessment points were also explored using paired *t*-tests. In each case, a two-sided test was used.

TABLE 19 Primary and secondary clinical outcomes, within- and between-group differences from week 24 (end of PCA for group B) to week 36 (end of follow-up): people with Parkinson's

			Group A: MDT			Group B: MDT + PCA			Group C: controls			Difference in changes 36–24 weeks					
												A vs. B		A vs. C		B vs. C	
Category	Instrument	*n*	Week 24 mean (SD)	Change week 36–24 (95% CI)	*p*-value[a] (df)	Week 24 mean (SD)	Change week 36–24 (95% CI)	*p*-value[a] (df)	Week 24 mean (SD)	Change week 36–24 (95% CI)	*p*-value[a] (df)	Mean (95% CI)	*p*-value[a] (df)	Mean (95% CI)	*p*-value[a] (df)	Mean (95% CI)	*p*-value[a] (df)
Disability (primary outcome)	Self-Assessed Parkinson's Disability (25 to 125 worst)[69,70]	226	48.32 (19.83)	0.51 (–1.05 to 2.06)	0.52 (74)	50.43 (20.00)	2.46 (0.07 to 4.84)	0.04 (67)	47.96 (19.25)	–0.11 (–2.01 to 1.80)	0.91 (82)	–1.95 (–4.72 to 0.82)	0.17 (141)	0.62 (–1.86 to 3.09)	0.62 (156)	2.56 (–0.42 to 5.55)	0.09 (149)
Parkinson's specific	PDQ-8 (0 to 100 worst)[72,73]	227	24.08 (16.32)	1.50 (–0.58 to 3.58)	0.15 (74)	25.95 (17.03)	–0.14 (–2.27 to 2.00)	0.90 (68)	27.33 (19.77)	–0.68 (–3.15 to 1.79)	0.59 (82)	1.64 (–1.32 to 4.59)	0.28 (142)	2.18 (–1.06 to 5.42)	0.19 (156)	0.54 (–2.77 to 3.85)	0.75 (150)
	Non-Motor Symptoms Questionnaire (0 to 30 worst)[74,75]	227	10.08 (5.06)	0.32 (–0.30 to 0.94)	0.31 (74)	9.99 (5.09)	0.48 (–0.26 to 1.21)	0.20 (68)	10.47 (5.69)	–0.01 (–0.69 to 0.67)	0.97 (82)	–0.16 (–1.11 to 0.79)	0.74 (142)	0.33 (–0.59 to 1.25)	0.48 (156)	0.49 (–0.50 to 1.48)	0.33 (150)
Activities	Barthel ADL (0 to 20 independent)[76]	226	18.13 (2.59)	–0.24 (–0.65 to 0.17)	0.25 (74)	17.36 (3.52)	–0.38 (–0.83 to 0.07)	0.10 (68)	18.10 (3.03)	–0.07 (–0.44 to 0.30)	0.70 (82)	0.14 (–0.47 to 0.74)	0.65 (142)	–0.17 (–0.72 to 0.38)	0.55 (156)	–0.30 (–0.88 to 0.27)	0.30 (150)
	Frenchay Activities Index (0 to 30 best)[77–79]	226	17.68 (7.66)	–0.22 (–1.50 to 1.07)	0.74 (73)	17.46 (8.88)	–1.07 (–2.24 to 0.10)	0.07 (68)	19.36 (7.40)	–0.46 (–1.32 to 0.40)	0.29 (82)	0.86 (–0.88 to 2.59)	0.33 (141)	0.24 (–1.27 to 1.75)	0.75 (155)	–0.61 (–2.03 to 0.80)	0.39 (150)
HRQoL (generic)	EQ-5D Thermometer (0 to 100 best)[80,81]	226	64.13 (18.94)	2.26 (–1.27 to 5.79)	0.21 (74)	62.62 (21.50)	2.44 (–1.36 to 6.25)	0.20 (68)	63.41 (20.18)	2.00 (–1.78 to 5.78)	0.30 (81)	–0.18 (–5.32 to 4.96)	0.94 (142)	0.26 (–4.90 to 5.42)	0.92 (155)	0.44 (–4.92 to 5.80)	0.87 (149)
	EQ-5D Index (–0.57 to 1.0 best)[80,81]	227	0.61 (0.27)	–0.01 (–0.06 to 0.04)	0.61 (74)	0.60 (0.27)	–0.04 (–0.10 to 0.02)	0.15 (68)	0.57 (0.28)	0.02 (–0.03 to 0.06)	0.49 (82)	0.03 (–0.05 to 0.11)	0.43 (142)	–0.03 (–0.10 to 0.04)	0.40 (156)	–0.06 (–0.13 to 0.01)	0.11 (150)
	SF-36 PCS (0 to 100 best)[82]	225	33.99 (10.62)	–1.14 (–2.66 to 0.37)	0.14 (74)	32.61 (9.89)	–1.10 (–2.85 to 0.65)	0.21 (67)	33.03 (10.41)	1.12 (–0.44 to 2.67)	0.16 (81)	–0.04 (–2.33 to 2.24)	0.97 (141)	–2.26 (–4.43 to –0.10)	0.04 (155)	–2.22 (–4.54 to 0.09)	0.06 (148)
	SF-36 MCS (0 to 100 best)[82]	226	50.84 (10.08)	–0.41 (–2.06 to 1.25)	0.62 (74)	51.69 (9.73)	–0.29 (–2.50 to 1.91)	0.79 (68)	50.40 (11.11)	–0.41 (–2.43 to 1.62)	0.69 (81)	–0.12 (–2.82 to 2.59)	0.93 (142)	0.00 (–2.62 to 2.62)	1.00 (155)	0.12 (–2.85 to 3.09)	0.94 (149)

continued

TABLE 19 Primary and secondary clinical outcomes, within- and between-group differences from week 24 (end of PCA for group B) to week 36 (end of follow-up): people with Parkinson's (*continued*)

			Group A: MDT			Group B: MDT + PCA			Group C: controls			Difference in changes 36–24 weeks					
												A vs. B		A vs. C		B vs. C	
Category	Instrument	*n*	Week 24 mean (SD)	Change week 36–24 (95% CI)	*p*-value[a] (df)	Week 24 mean (SD)	Change week 36–24 (95% CI)	*p*-value[a] (df)	Week 24 mean (SD)	Change week 36–24 (95% CI)	*p*-value[a] (df)	Mean (95% CI)	*p*-value[a] (df)	Mean (95% CI)	*p*-value[a] (df)	Mean (95% CI)	*p*-value[a] (df)
Psychological well-being (Yale Depression Screen below)	HADS – anxiety (0 to 21 worst)[83]	226	5.76 (4.03)	–0.31 (–0.85 to 0.24)	0.27 (74)	5.64 (3.80)	0.20 (–0.31 to 0.72)	0.43 (68)	6.61 (4.18)	–0.17 (–0.71 to 0.37)	0.53 (81)	–0.51 (–1.26 to 0.24)	0.18 (142)	–0.14 (–0.90 to 0.62)	0.72 (155)	0.37 (–0.37 to 1.12)	0.32 (149)
	HADS – depression (0 to 21 worst)[83]	226	5.85 (3.71)	–0.31 (–0.79 to 0.18)	0.21 (74)	5.19 (3.17)	0.23 (–0.23 to 0.69)	0.32 (68)	5.55 (3.70)	–0.10 (–0.66 to 0.47)	0.73 (81)	–0.54 (–1.21 to 0.13)	0.11 (142)	–0.21 (–0.96 to 0.54)	0.58 (155)	0.33 (–0.40 to 1.06)	0.37 (147)
Self-efficacy	Self-Efficacy Scale (1 to 10 high)[86]	226	6.66 (2.14)	0.01 (–0.38 to 0.39)	0.97 (74)	6.79 (2.09)	–0.03 (–0.40 to 0.34)	0.87 (68)	6.72 (2.25)	–0.16 (–0.55 to 0.23)	0.43 (81)	0.04 (–0.49 to 0.57)	0.89 (142)	0.16 (–0.38 to 0.71)	0.55 (155)	0.13 (–0.42 to 0.67)	0.65 (149)
Mobility (falls see below)	Timed Up and Go (seconds, low good)[87,88]	210	22.96 (21.82)	–5.93 (–10.09 to –1.76)	0.01 (71)	18.78 (18.41)	–0.85 (–6.45 to 4.75)	0.76 (59)	17.15 (15.64)	0.17 (–1.98 to 2.32)	0.88 (77)	–5.08 (–11.86 to 1.71)	0.14 (130)	–6.10 (–10.76 to –1.43)	0.01 (106)	–1.02 –6.45 to 4.41)	0.71 (136)
	UPDRS posture item (0 to 4 worst)[89]	212	1.00 (0.84)	–0.32 (–0.49 to –0.15)	< 0.001 (71)	0.58 (0.64)	0.10 (–0.02 to 0.22)	0.11 (61)	0.86 (0.72)	–0.23 (–0.37 to –0.09)	< 0.001 (77)	–0.42 (–0.62 to –0.21)	< 0.001 (124)	–0.09 (–0.30 to 0.13)	0.42 (148)	0.33 (0.15 to 0.51)	< 0.001 (137)
	UPDRS gait item (0 to 4 worst)[89]	212	0.99 (0.90)	0.10 (–0.08 to 0.27)	0.28 (71)	1.00 (0.75)	–0.10 (–0.25 to 0.06)	0.22 (61)	0.97 (0.79)	–0.18 (–0.31 to –0.04)	0.01 (77)	0.19 (–0.04 to 0.43)	0.11 (132)	0.28 (0.06 to 0.50)	0.01 (148)	0.08 (–0.12 to 0.29)	0.42 (138)
Pain 'on'	VAS (0 to 100 worst)[90–93]	164	48.32 (19.83)	1.74 (–3.86 to 7.34)	0.54 (47)	50.43 (20.00)	–1.35 (–7.70 to 5.01)	0.67 (54)	47.96 (19.25)	2.95 (–4.51 to 10.42)	0.43 (60)	3.09 (–5.40 to 11.57)	0.47 (101)	–1.21 (–10.89 to 8.46)	0.80 (107)	–4.30 (–14.10 to 5.51)	0.39 (114)

			Group A: MDT			Group B: MDT + PCA			Group C: controls			Difference in changes 36–24 weeks: A vs. B		A vs. C		B vs. C	
Category	Instrument	*n*	Week 24 mean (SD)	Change week 36–24 (95% CI)	*p*-value[a] (df)	Week 24 mean (SD)	Change week 36–24 (95% CI)	*p*-value[a] (df)	Week 24 mean (SD)	Change week 36–24 (95% CI)	*p*-value[a] (df)	Mean (95% CI)	*p*-value[a] (df)	Mean (95% CI)	*p*-value[a] (df)	Mean (95% CI)	*p*-value[a] (df)
Speech	Speech Self Report Questionnaire (0 to 130 worst)	227	24.08 (16.32)	5.17 (0.53 to 9.81)	0.03 (74)	25.95 (17.03)	0.77 (–2.11 to 3.64)	0.60 (68)	27.33 (19.77)	–0.87 (–4.05 to 2.31)	0.59 (82)	4.41 (–1.02 to 9.83)	0.11 (122)	6.04 (0.45 to 11.63)	0.03 (133)	1.64 (–2.69 to 5.96)	0.46 (150)
	UPDRS item (0 to 4 worst)[89]	226	10.08 (5.06)	–0.03 (–0.16 to 0.11)	0.70 (74)	9.99 (5.09)	0.10 (–0.03 to 0.23)	0.13 (68)	10.47 (5.69)	–0.07 (–0.21 to 0.06)	0.29 (81)	–0.13 (–0.32 to 0.06)	0.18 (142)	0.05 (–0.15 to 0.24)	0.63 (155)	0.17 (–0.02 to 0.37)	0.07 (149)
	Emerson and Enderby – voice (0 to 4 worst)[94]	226	18.13 (2.59)	0.47 (0.30 to 0.63)	< 0.001 (74)	17.36 (3.52)	0.10 (–0.03 to 0.23)	0.13 (68)	18.10 (3.03)	0.20 (0.04 to 0.35)	0.02 (81)	0.37 (0.16 to 0.57)	< 0.001 (138)	0.27 (0.05 to 0.50)	0.02 (155)	–0.09 (–0.30 to 0.11)	0.37 (147)
	Emerson and Enderby – Articulation (0 to 4 worst)[94]	226	17.68 (7.66)	–0.29 (–0.42 to –0.16)	< 0.001 (74)	17.46 (8.88)	–0.06 (–0.17 to 0.05)	0.29 (68)	19.36 (7.40)	–0.28 (–0.40 to –0.16)	0.00 (81)	–0.24 (–0.40 to –0.07)	0.01 (139)	–0.01 (–0.19 to 0.16)	0.89 (155)	0.22 (0.06 to 0.38)	0.01 (148)

			Group A: MDT			Group B: MDT + PCA			Group C: controls			Difference in changes 36–24 weeks: A vs. B		A vs. C		B vs. C	
Category	Instrument	*n*	Week 24 yes, *n* (%)	Change week 36–24	*p*-value[a]	Week 24 yes, *n* (%)	Change week 36–24	*p*-value[a]	Week 24 yes, *n* (%)	Change week 36–24	*p*-value[a]	Difference in changes	*p*-value[a]	Difference in changes	*p*-value[a]	Difference in changes	*p*-value[a]
Psychological well-being	Yale Depression Screen[a] (yes = 1; no = 0)[84,85]	225	12 (16.2)	Improve 5 (6.8) Same 60 (81.1) Worse 9 (12.2)	0.29	14 (20.3)	Improve 4 (5.8) Same 60 (87) Worse 5 (7.2)	0.74	16 (19.5)	Improve 6 (7.3) Same 65 (79.3) Worse 11 (13.4)	0.23	Not applicable	0.55	Not applicable	0.92	Not applicable	0.48
Mobility	Falls[a] (yes = 1; no = 0)	228	36 (48.0)	Improve 16 (21.3) Same 54 (72.0) Worse 5 (6.7)	0.02	32 (46.4)	Improve 8 (11.6) Same 55 (79.7) Worse 6 (8.7)	0.59	33 (40.2)	Improve 18 (22.0) Same 56 (68.3) Worse 8 (9.8)	0.05	Not applicable	0.14	Not applicable	0.80	Not applicable	0.24

df, degrees of freedom; HRQoL, health-related quality of life; PDQ-8, Parkinson's Disease Questionnaire-8 items.

a One-way ANOVA tests were used for comparisons between all three groups, and unpaired *t*-tests were used for comparisons between pairs of groups. Within-group changes between assessment points were also explored using paired *t*-tests. In each case, a two-sided test was used.

TABLE 20 Primary and secondary clinical outcomes, within- and between-group differences from week 24 (end of PCA for group B) to week 36 (end of follow-up): live-in carers

			Group A: MDT			Group B: MDT + PCA			Group C: controls			Differences in changes weeks 36–24					
												A vs. B		A vs. C		B vs. C	
Category	Instrument	*n*	Week 24 mean (SD)	Change week 36–24 (95% CI)	*p*-value[a] (df)	Week 24 mean (SD)	Change week 36–24 (95% CI)	*p*-value[a] (df)	Week 24 mean (SD)	Change week 36–24 (95%CI)	*p*-value[a] (df)	Mean (95% CI)	*p*-value[a] (df)	Mean (95% CI)	*p*-value[a] (df)	Mean (95% CI)	*p*-value[a] (df)
Strain (primary outcome)	Modified Caregiver Strain Index (0 to 26 worst)[71]	125	6.18 (4.38)	0.82 (0.09 to 1.56)	0.03 (44)	7.32 (6.57)	0.57 (–0.83 to 1.97)	0.42 (36)	7.74 (7.53)	0.33 (–0.88 to 1.53)	0.59 (42)	0.25 (–1.22 to 1.73)	0.73 (80)	0.50 (–0.88 to 1.87)	0.47 (86)	0.24 (–1.56 to 2.05)	0.79 (78)
General health	General Health Questionnaire-12 (0 to 36 worst)[95]	125	10.38 (4.29)	1.33 (0.00 to 2.66)	0.05 (44)	10.49 (5.67)	0.95 (–0.76 to 2.65)	0.27 (36)	11.51 (7.44)	–0.44 (–2.53 to 1.64)	0.67 (42)	0.39 (–1.71 to 2.49)	0.71 (80)	1.78 (–0.67 to 4.22)	0.15 (71)	1.39 (–1.32 to 4.10)	0.31 (78)
Activities	Barthel ADL (0 to 20 independent)[76]	125	19.89 (0.61)	0.09 (–0.10 to 0.28)	0.35 (44)	19.84 (0.44)	0.03 (–0.07 to 0.12)	0.57 (36)	19.93 (0.46)	–0.14 (–0.35 to 0.07)	0.18 (42)	0.06 (–0.16 to 0.29)	0.58 (80)	0.23 (–0.05 to 0.51)	0.11 (86)	0.17 (–0.07 to 0.40)	0.17 (78)
	Frenchay Activities Index (0 to 30 best)[77–79]	125	28.56 (2.12)	–0.36 (–1.19 to 0.48)	0.40 (44)	26.57 (3.75)	0.35 (–0.31 to 1.01)	0.29 (36)	27.56 (3.35)	0.47 (–0.20 to 1.13)	0.17 (42)	–0.71 (–1.79 to 0.38)	0.20 (80)	–0.82 (–1.88 to 0.24)	0.13 (86)	–0.11 (–1.05 to 0.82)	0.81 (78)
HRQoL (generic)	EQ-5D Thermometer (0 to 100 best)[80,81]	125	79.26 (15.46)	–2.17 (–5.06 to 0.72)	0.14 (44)	74.47 (23.33)	2.47 (–1.68 to 6.62)	0.23 (36)	75.99 (17.38)	2.72 (–1.39 to 6.83)	0.19 (42)	–4.64 (–9.49 to 0.21)	0.06 (80)	–4.89 (–9.80 to 0.03)	0.05 (86)	–0.25 (–6.03 to 5.53)	0.93 (78)
	EQ-5D Index (–0.57 to 1.0 best)[80,81]	125	0.82 (0.22)	–0.01 (–0.05 to 0.04)	0.71 (44)	0.79 (0.29)	0.02 (–0.04 to 0.07)	0.48 (36)	0.80 (0.21)	0.02 (–0.03 to 0.07)	0.45 (42)	–0.03 –0.10 to 0.04)	0.43 (80)	–0.03 (–0.09 to 0.04)	0.42 (86)	0.00 (–0.07 to 0.07)	0.98 (78)
	SF-36 PCS (0 to 100 best)[82]	125	45.75 (11.17)	0.39 (–1.28 to 2.06)	0.64 (44)	43.29 (11.02)	1.98 (0.04 to 3.92)	0.05 (36)	45.42 (9.79)	–0.21 (–2.78 to 2.36)	0.87 (42)	–1.59 (–4.09 to 0.92)	0.21 (80)	0.60 (–2.42 to 3.63)	0.69 (72)	2.19 (–1.06 to 5.44)	0.18 (78)
	SF-36 MCS (0 to 100 best)[82]	125	53.27 (7.55)	–2.76 (–4.99 to –0.54)	0.02 (44)	51.21 (8.67)	–0.36 (–3.13 to 2.41)	0.79 (36)	49.07 (11.91)	0.93 (–2.02 to 3.88)	0.53 (42)	–2.40 (–5.86 to 1.05)	0.17 (80)	–3.69 (–7.31 to –0.07)	0.05 (86)	–1.29 (–5.31 to 2.73)	0.53 (78)
Psychological well-being (Yale Depression Screen below)	HADS – anxiety (0 to 21 worst)[83]	125	4.91 (3.42)	0.27 (–0.40 to 0.94)	0.43 (44)	5.70 (4.31)	–0.05 (–0.99 to 0.88)	0.91 (36)	6.74 (4.17)	–0.33 (–1.11 to 0.46)	0.41 (42)	0.32 (–0.78 to 1.43)	0.57 (80)	0.59 (–0.42 to 1.61)	0.25 (86)	0.27 (–0.92 to 1.46)	0.65 (78)
	HADS – depression (0 to 21 worst)[83]	125	3.16 (2.82)	0.73 (0.14 to 1.33)	0.02 (44)	3.81 (3.61)	–0.16 (–0.71 to 0.39)	0.55 (36)	4.51 (3.22)	–0.40 (–1.03 to 0.24)	0.21 (42)	0.90 (0.09 to 1.70)	0.03 (80)	1.13 (0.28 to 1.98)	0.01 (86)	0.23 (–0.60 to 1.07)	0.58 (78)

			Group A: MDT			Group B: MDT + PCA			Group C: controls			Differences in changes weeks 36–24					
												A vs. B		A vs. C		B vs. C	
Category	Instrument	*n*	Week 24 yes, *n* (%)	Change week 36–24	*p*-value[a]	Week 24 yes, *n* (%)	Change week 36–24	*p*-value[a]	Week 24 yes, *n* (%)	Change week 36–24	*p*-value[a]	Difference in changes	*p*-value[a]	Difference in changes	*p*-value[a]	Difference in changes	*p*-value[a]
Psychological well-being	Yale Depression Screen (yes = 1; no = 0)[84,85]	125	15 (33.3)	Improve 4 (8.9) Same 38 (84.4) Worse 3 (6.7)	0.71	13 (35.1)	Improve 4 (10.8) Same 33 (89.2) Worse 0 (0.0)	0.05	20 (46.5)	Improve 4 (9.3) Same 36 (83.7) Worse 3 (7.0)	0.71	Not applicable	0.30	Not applicable	0.99	Not applicable	0.32

df, degrees of freedom; HRQoL, health-related quality of life.

a One-way ANOVA tests were used for comparisons between all three groups, and unpaired *t*-tests were used for comparisons between pairs of groups. Within-group changes between assessment points were also explored using paired *t*-tests. In each case, a two-sided test was used.

Significant differences were found in the change scores of people with Parkinson's in groups B and C with respect to UPDRS posture[89] ($p < 0.001$) and the Emerson and Enderby articulation measure[94] ($p = 0.01$) (C significantly improved in both measures). Marginal differences in change scores in favour of group C were recorded for UPDRS speech[89] ($p = 0.07$) and SF-36 PCS[82] ($p = 0.06$) (arising from non-significant improvements in C and deteriorations in B), and, in the primary outcome, Parkinson's self-reported disability[69,70] ($p = 0.09$) (due to a significant worsening in B). There were no differences between the change scores of live-in carers in groups B and C during this follow-up period.

Long-term effect (baseline to week 36): groups A versus B; A versus C; B versus C

Over the entire study period, there were relatively few differences between groups in outcome trends. Comparing group A (had MDT) with B (MDT + PCA), significant differences in change scores were observed for people with Parkinson's on SF-36 MCS[82] ($p = 0.02$) and Speech Self Report ($p = 0.02$) (group A worsened significantly on both measures), and marginally on UPDRS gait ($p = 0.09$) (group B improved significantly) (*Table 21*). Live-in carers in group A also worsened significantly on SF-36 MCS[82] ($p = 0.04$), compared with group B. There was a difference in change scores between groups A and B for live-in carers on SF-36 PCS ($p = 0.06$) (due to improvements in A and deteriorations in B, both changes non-significant) (*Table 22*).

Comparing group A (had MDT) with control group C, there was one marginally significant difference in change scores for people with Parkinson's between groups A and C, in the Timed Up and Go test[87,88] ($p = 0.06$), reflecting a marginal improvement over the study period in group A. For live-in carers, there was a significant difference in change scores on SF-36 PCS[82] ($p = 0.05$) due to improvements in group A and deteriorations in group C, both non-significant.

Comparing group B (had MDT + PCA) with control group C, there were significant differences in change scores for people with Parkinson's on SF-36 MCS[82] ($p = 0.05$) and Speech Self Report ($p = 0.03$) (due to significant worsening in group C on both measures). There were no significant differences in change scores of live-in carers in groups B and C on any measure over the study period.

Multidiscplinary team process outcomes

Data from the CRF showed that, over the course of the 6-week intervention, the MDT made a total of 23 referrals to other professionals (12 to participants in group A, 11 to group B). The PNSs made 40 medication changes and a further 11 recommendations for changes in timing of dose or means of administration (total changes: 30 to group A and 21 to group B). The OT made multiple recommendations for new aids and equipment (*Table 26*).

Acceptability of the programme to participants

Quantitative analysis of feedback questionnaires

At the 6-week assessment, just after the end of the MDT intervention, over 80% of people with Parkinson's responding to the acceptability questionnaire (which was sent only to groups A and B in cohorts 4–10) stated that they found the treatment programme very or extremely helpful, and over 90% stated that they had learnt a lot of new things about Parkinson's disease (*Table 27a*). Almost all of the respondents stated that they would recommend the MDT treatment programme to others. Three-quarters said that they would like the programme repeated, mostly on an annual basis. Feedback from group B at 24 weeks about the PCA intervention was positive, with 84% of people with Parkinson's reporting that they found it very or extremely helpful, and that it more than met their expectations [mean score of 75% on a VAS with range of 0 (greatly fell short of expectations) to 100 (greatly exceeded expectations), and with 50th percentile representing 'met my expectations'] (*Table 27b*). The responses of carers were similar to those of the people

TABLE 21 Primary and secondary clinical outcomes, within- and between-group differences at 36 weeks (end of follow-up): people with Parkinson's

			Group A: MDT			Group B: MDT + PCA			Group C: controls			Differences in changes weeks 36–0					
												A vs. B		A vs. C		B vs. C	
Category	Instrument	*n*	Baseline (week 0) mean (SD)	Change week 36–0 (95% CI)	*p*-value[a] (df)	Baseline (week 0) mean (SD)	Change week 36–0 (95% CI)	*p*-value[a] (df)	Baseline (week 0) mean (SD)	Change week 36–0 (95%CI)	*p*-value[a] (df)	Mean (95% CI)	*p*-value[a] (df)	Mean (95% CI)	*p*-value[a] (df)	Mean (95% CI)	*p*-value[a] (df)
Disability (primary outcome)	Self-Assessed Parkinson's Disability (25 to 125 worst)[69,70]	226	48.51 (17.15)	0.32 (–1.69 to 2.33)	0.75 (74)	50.66 (18.17)	2.22 (–1.12 to 5.56)	0.19 (67)	46.95 (16.30)	0.90 (–1.50 to 3.30)	0.46 (82)	–1.90 (–5.77 to 1.97)	0.33 (111)	–0.58 (–3.69 to 2.52)	0.71 (153)	1.32 (–2.67 to 5.31)	0.52 (149)
Parkinson's specific	PDQ-8 (0 to 100 worst)[72,73]	227	23.04 (17.16)	2.54 (–0.44 to 5.53)	0.09 (74)	24.50 (17.46)	1.31 (–1.89 to 4.52)	0.42 (68)	23.64 (18.30)	3.01 (0.35 to 5.68)	0.03 (82)	1.23 (–3.11 to 5.56)	0.58 (142)	–0.47 (–4.43 to 3.49)	0.81 (156)	–1.70 (–5.80 to 2.40)	0.41 (150)
	Non-Motor Symptoms Questionnaire (0 to 30 worst)[74,75]	227	10.25 (5.03)	0.15 (–0.63 to 0.93)	0.71 (74)	10.62 (5.19)	–0.16 (–0.99 to 0.67)	0.70 (68)	10.01 (5.32)	0.45 (–0.31 to 1.20)	0.25 (82)	0.31 (–0.82 to 1.44)	0.59 (142)	–0.30 (–1.38 to 0.78)	0.59 (156)	–0.61 (–1.72 to 0.51)	0.29 (150)
Activities	Barthel ADL (0 to 20 independent)[76]	226	18.48 (2.09)	–0.59 (–1.08 to –0.10)	0.02 (74)	17.78 (3.12)	–0.80 (–1.38 to –0.22)	0.01 (68)	18.53 (2.18)	–0.51 (–0.89 to –0.12)	0.01 (82)	0.21 (–0.54 to 0.96)	0.58 (142)	–0.08 (–0.69 to 0.53)	0.80 (156)	–0.29 (–0.96 to 0.38)	0.39 (150)
	Frenchay Activities Index (0 to 30 best)[77–79]	226	19.01 (7.12)	–1.55 (–2.94 to –0.17)	0.03 (73)	18.13 (8.39)	–1.74 (–2.83 to –0.65)	< 0.001 (68)	21.31 (6.83)	–2.41 (–3.46 to –1.36)	< 0.001 (82)	0.19 (–1.58 to 1.95)	0.84 (141)	0.86 (–0.85 to 2.56)	0.32 (155)	0.67 (–0.84 to 2.18)	0.38 (150)
HRQoL (generic)	EQ-5D Thermometer (0 to 100 best)[80,81]	226	67.62 (18.49)	–1.23 (–5.07 to 2.61)	0.52 (74)	65.78 (18.31)	–0.72 (–6.07 to 4.64)	0.79 (68)	65.68 (20.62)	–0.26 (–4.70 to 4.18)	0.91 (81)	–0.52 (–6.97 to 5.94)	0.87 (142)	–0.97 (–6.84 to 4.90)	0.74 (155)	–0.46 (–7.29 to 6.38)	0.90 (149)
	EQ-5D Index (–0.57 to 1.0 best)[80,81]	227	0.61 (0.25)	–0.02 (–0.06 to 0.02)	0.38 (74)	0.53 (0.29)	0.03 (–0.04 to 0.09)	0.39 (68)	0.58 (0.26)	0.01 (–0.04 to 0.06)	0.67 (82)	–0.05 (–0.12 to 0.03)	0.23 (118)	–0.03 (–0.10 to 0.04)	0.38 (156)	0.02 (–0.06 to 0.10)	0.69 (150)
	SF-36 PCS (0 to 100 best)[82]	225	34.06 (10.07)	–1.21 (–3.19 to 0.77)	0.23 (74)	33.81 (10.37)	–2.31 (–4.23 to –0.39)	0.02 (67)	35.23 (11.10)	–1.08 (–3.18 to 1.02)	0.31 (81)	1.10 (–1.64 to 3.85)	0.43 (141)	–0.13 (–3.00 to 2.75)	0.93 (155)	–1.23 (–4.10 to 1.64)	0.40 (148)
	SF-36 MCS (0 to 100 best)[82]	226	53.74 (9.48)	–3.30 (–5.50 to –1.11)	< 0.001 (74)	51.70 (9.78)	–0.30 (–2.29 to 1.69)	0.76 (68)	53.02 (10.03)	–3.03 (–4.96 to –1.10)	< 0.001 (81)	–3.00 (–5.96 to –0.05)	0.05 (142)	–0.27 (–3.16 to 2.62)	0.85 (155)	2.73 (–0.03 to 5.49)	0.05 (149)

continued

TABLE 21 Primary and secondary clinical outcomes, within- and between-group differences at 36 weeks (end of follow-up): people with Parkinson's (*continued*)

			Group A: MDT			Group B: MDT + PCA			Group C: controls			Differences in changes weeks 36–0					
												A vs. B		A vs. C		B vs. C	
Category	Instrument	*n*	Baseline (week 0) mean (SD)	Change week 36–0 (95% CI)	*p*-value[a] (df)	Baseline (week 0) mean (SD)	Change week 36–0 (95% CI)	*p*-value[a] (df)	Baseline (week 0) mean (SD)	Change week 36–0 (95%CI)	*p*-value[a] (df)	Mean (95% CI)	*p*-value[a] (df)	Mean (95% CI)	*p*-value[a] (df)	Mean (95% CI)	*p*-value[a] (df)
Psychological well-being (Yale Depression Screen below)	HADS – anxiety (0 to 21 worst)[83]	226	5.76 (3.82)	–0.31 (–0.95 to 0.34)	0.35 (74)	5.87 (3.55)	–0.03 (–0.59 to 0.53)	0.92 (68)	6.10 (4.25)	0.34 (–0.30 to 0.98)	0.29 (81)	–0.28 (–1.13 to 0.58)	0.52 (142)	–0.65 (–1.55 to 0.26)	0.16 (155)	–0.37 (–1.23 to 0.49)	0.40 (149)
	HADS – depression (0 to 21 worst)[83]	226	5.09 (3.43)	0.45 (–0.12 to 1.03)	0.12 (74)	5.39 (3.20)	0.03 (–0.59 to 0.65)	0.93 (68)	5.20 (2.94)	0.26 (–0.23 to 0.74)	0.30 (81)	0.42 (–0.41 to 1.26)	0.32 (142)	0.20 (–0.54 to 0.94)	0.60 (155)	–0.23 (–1.00 to 0.54)	0.56 (149)
Self-efficacy	Self-Efficacy Scale (1 to 10 high)[86]	226	7.27 (1.87)	–0.60 (–0.93 to –0.27)	< 0.001 (74)	7.16 (1.76)	–0.40 (–0.88 to 0.08)	0.10 (68)	7.03 (2.13)	–0.47 (–0.85 to –0.08)	0.02 (81)	–0.20 (–0.77 to 0.38)	0.50 (142)	–0.13 (–0.64 to 0.37)	0.60 (155)	0.06 (–0.54 to 0.67)	0.83 (149)
Mobility	Timed Up and Go (seconds, low good)[87,88]	210	18.48 (11.68)	–1.45 (–3.12 to 0.22)	0.09 (71)	18.28 (13.29)	–0.35 (–4.47 to 3.78)	0.87 (59)	16.08 (12.68)	1.24 (–1.04 to 3.51)	0.28 (77)	–1.10 (–5.24 to 3.04)	0.60 (130)	–2.69 (–5.52 to 0.15)	0.06 (148)	–1.58 (–5.99 to 2.82)	0.48 (136)
	UPDRS posture item (0 to 4 worst)[89]	212	0.94 (0.77)	–0.26 (–0.44 to –0.09)	< 0.001 (71)	0.94 (0.87)	–0.26 (–0.42 to –0.10)	< 0.001 (61)	0.88 (0.72)	–0.26 (–0.43 to –0.08)	< 0.001 (77)	–0.01 (–0.24 to 0.23)	0.96 (132)	–0.01 (–0.25 to 0.24)	0.95 (148)	0.00 (–0.24 to 0.24)	0.99 (138)
	UPDRS gait item (0 to 4 worst)[89]	212	1.14 (0.77)	–0.06 (–0.26 to 0.15)	0.58 (71)	1.19 (0.85)	–0.29 (–0.47 to –0.11)	< 0.001 (61)	1.00 (0.79)	–0.21 (–0.38 to –0.03)	0.03 (77)	0.23 (–0.04 to 0.51)	0.09 (132)	0.15 (–0.12 to 0.42)	0.27 (148)	–0.09 (–0.34 to 0.17)	0.51 (138)
Pain 'on'	VAS (0 to 100 worst)[90–93]	164	26.00 (27.34)	8.93 (1.25 to 16.60)	0.02 (47)	27.32 (25.85)	1.35 (–7.62 to 10.33)	0.76 (54)	29.27 (25.10)	5.29 (–1.29 to 11.87)	0.11 (60)	7.57 (–4.27 to 19.42)	0.21 (101)	3.64 (–6.31 to 13.59)	0.47 (107)	–3.93 (–14.79 to 6.93)	0.47 (114)
Speech	Speech Self Report Questionnaire (0 to 130 worst)	227	27.71 (22.96)	7.28 (2.76 to 11.80)	< 0.001 (74)	27.09 (22.94)	0.75 (–2.75 to 4.26)	0.67 (68)	22.84 (22.49)	5.90 (2.66 to 9.15)	< 0.001 (82)	6.53 (0.85 to 12.20)	0.02 (136)	1.38 (–4.07 to 6.82)	0.62 (156)	–5.15 (–9.90 to –0.40)	0.03 (150)
	UPDRS item (0 to 4 worst)[89]	226	0.80 (0.77)	–0.05 (–0.20 to 0.09)	0.47 (74)	0.78 (0.86)	–0.01 (–0.19 to 0.16)	0.87 (68)	0.59 (0.78)	0.00 (–0.16 to 0.16)	1.00 (81)	–0.04 (–0.26 to 0.19)	0.73 (142)	–0.05 (–0.27 to 0.16)	0.62 (155)	–0.01 (–0.25 to 0.22)	0.90 (149)

			Group A: MDT			Group B: MDT + PCA			Group C: controls			Differences in changes weeks 36–0					
												A vs. B		A vs. C		B vs. C	
Category	Instrument	*n*	Baseline (week 0) mean (SD)	Change week 36–0 (95% CI)	*p*-value[a] (df)	Baseline (week 0) mean (SD)	Change week 36–0 (95% CI)	*p*-value[a] (df)	Baseline (week 0) mean (SD)	Change week 36–0 (95%CI)	*p*-value[a] (df)	Mean (95% CI)	*p*-value[a] (df)	Mean (95% CI)	*p*-value[a] (df)	Mean (95% CI)	*p*-value[a] (df)
	Abridged Emerson and Enderby Screening Assessment Rating Scale – voice (0 to 4 worst)[94]	226	2.23 (0.80)	0.11 (–0.05 to 0.26)	0.17 (74)	2.16 (0.90)	0.14 (–0.01 to 0.30)	0.07 (68)	1.94 (0.85)	0.11 (–0.04 to 0.26)	0.16 (81)	–0.04 (–0.26 to 0.18)	0.73 (142)	0.00 (–0.22 to 0.21)	0.98 (155)	0.04 (–0.18 to 0.25)	0.75 (149)
	Abridged Emerson and Enderby Screening Assessment Rating Scale – articulation (0 to 4 worst)[94]	226	1.75 (0.79)	–0.29 (–0.45 to –0.13)	< 0.001 (74)	1.65 (0.80)	–0.20 (–0.34 to –0.06)	0.01 (68)	1.46 (0.63)	–0.22 (–0.33 to –0.10)	< 0.001 (81)	–0.09 (–0.30 to 0.12)	0.40 (142)	–0.07 (–0.27 to 0.12)	0.46 (137)	0.02 (–0.16 to 0.19)	0.85 (149)

			Group A: MDT			Group B: MDT + PCA			Group C: controls			Differences in changes weeks 36–0					
												A vs. B		A vs. C		B vs. C	
Category	Instrument	*n*	Baseline yes, *n* (%)	Change week 36–0	*p*-value[a]	Baseline yes, *n* (%)	Change week 36–0	*p*-value[a]	Baseline yes, *n* (%)	Change week 36–0	*p*-value[a]	Difference in changes	*p*-value[a]	Difference in changes	*p*-value[a]	Difference in changes	*p*-value[a]
Psychological well-being	Yale Depression Screen[a] (yes = 1; no = 0)[84,85]	225	13 (17.6)	Improve 6 (8.1) Same 59 (79.7) Worse 9 (12.2)	0.44	19 (27.5)	Improve 11 (15.9) Same 51 (73.9) Worse 7 (10.1)	0.35	28 (34.1)	Improve 14 (17.1) Same 61 (74.4) Worse 7 (8.5)	0.13	Not applicable	0.22	Not applicable	0.10	Not applicable	0.74
Mobility	Falls[a] (yes = 1; no = 0)	228	31 (41.3)	Improve 16 (21.3) Same 49 (65.3) Worse 10 (13.3)	0.24	30 (42.9)	Improve 7 (10.0) Same 55 (78.6) Worse 8 (11.4)	0.80	31 (37.3)	Improve 16 (19.3) Same 59 (71.1) Worse 8 (9.6)	0.10	Not applicable	0.27	Not applicable	0.88	Not applicable	0.17

df, degrees of freedom; HRQoL, health-related quality of life; PDQ-8, Parkinson's Disease Questionnaire-8 items.

a One-way ANOVA tests were used for comparisons between all three groups, and unpaired *t*-tests were used for comparisons between pairs of groups. Within-group changes between assessment points were also explored using paired *t*-tests. In each case, a two-sided test was used.

TABLE 22 Primary and secondary clinical outcomes, within- and between-group differences at 36 weeks (end of follow-up): live-in carers

			Group A: MDT			Group B: MDT + PCA			Group C: controls			Differences in changes weeks 36–0					
												A vs. B		A vs. C		B vs. C	
Category	Instrument	*n*	Baseline (week 0) mean (SD)	Change week 36–0 (95% CI)	*p*-value[a] (df)	Baseline (week 0) mean (SD)	Change week 36–0 (95% CI)	*p*-value[a] (df)	Baseline (week 0) mean (SD)	Change week 36–0 (95%CI)	*p*-value[a] (df)	Mean (95% CI)	*p*-value[a] (df)	Mean (95% CI)	*p*-value[a] (df)	Mean (95% CI)	*p*-value[a] (df)
Strain (primary outcome)	Modified Caregiver Strain Index (0 to 26 worst)[71]	125	6.58 (4.58)	0.42 (–0.44 to 1.28)	0.33 (44)	8.11 (6.03)	–0.22 (–1.52 to 1.09)	0.74 (36)	7.44 (6.92)	0.63 (–0.60 to 1.86)	0.31 (42)	0.64 (–0.85 to 2.13)	0.40 (80)	–0.21 (–1.67 to 1.26)	0.78 (86)	–0.84 (–2.61 to 0.92)	0.34 (78)
General health	General Health Questionnaire-12 (0 to 36 worst)[95]	125	10.38 (3.87)	1.33 (–0.05 to 2.72)	0.06 (44)	11.38 (5.14)	0.05 (–1.53 to 1.64)	0.95 (36)	10.53 (4.61)	0.53 (–1.33 to 2.40)	0.57 (42)	1.28 (–0.78 to 3.34)	0.22 (80)	0.80 (–1.48 to 3.07)	0.49 (86)	–0.48 (–2.93 to 1.97)	0.70 (78)
Activities	Barthel ADL (0 to 20 independent)[76]	125	19.98 (0.15)	0.00 (0 to 0)	1.00 (44)	19.76 (0.76)	0.11 (–0.17 to 0.39)	0.44 (36)	19.84 (0.61)	–0.05 (–0.22 to 0.13)	0.60 (42)	–0.11 (–0.39 to 0.17)	0.44 (36)	0.05 (–0.13 to 0.22)	0.60 (42)	0.15 (–0.16 to 0.47)	0.34 (78)
	Frenchay Activities Index (0 to 30 best)[77–79]	125	28.20 (2.30)	0.00 (–0.68 to 0.68)	1.00 (44)	27.11 (3.03)	–0.19 (–1.31 to 0.93)	0.73 (36)	27.63 (4.05)	0.40 (–0.47 to 1.26)	0.36 (42)	0.19 (–1.06 to 1.43)	0.76 (80)	–0.40 (–1.48 to 0.68)	0.47 (86)	–0.58 (–1.96 to 0.79)	0.40 (78)
HRQoL (generic)	EQ-5D Thermometer (0 to 100 best)[80,81]	125	80.57 (13.09)	–3.48 (–7.23 to 0.27)	0.07 (44)	80.22 (17.75)	–3.27 (–7.13 to 0.59)	0.09 (36)	78.26 (19.45)	0.45 (–5.11 to 6.02)	0.87 (42)	–0.21 (–5.54 to 5.13)	0.94 (80)	–3.93 (–10.49 to 2.63)	0.24 (86)	–3.72 (–10.61 to 3.16)	0.28 (78)
	EQ-5D Index (–0.57 to 1.0 best)[80,81]	125	0.83 (0.20)	–0.02 (–0.05 to 0.01)	0.18 (44)	0.80 (0.21)	0.00 (–0.05 to 0.05)	0.94 (36)	0.82 (0.23)	0.00 (–0.05 to 0.05)	0.90 (42)	–0.02 (–0.08 to 0.03)	0.43 (80)	–0.02 (–0.07 to 0.04)	0.55 (86)	0.01 (–0.07 to 0.08)	0.89 (78)
	SF-36 PCS (0 to 100 best)[82]	125	44.59 (10.85)	1.55 (–0.35 to 3.45)	0.11 (44)	46.78 (9.48)	–1.51 (–4.26 to 1.23)	0.27 (36)	47.19 (8.92)	–1.98 (–4.46 to 0.50)	0.11 (42)	3.06 (–0.14 to 6.26)	0.06 (80)	3.53 (0.47 to 6.59)	0.02 (86)	0.47 (–3.16 to 4.10)	0.80 (78)
	SF-36 MCS (0 to 100 best)[82]	125	53.69 (6.64)	–3.18 (–5.17 to –1.18)	< 0.001 (44)	50.29 (10.58)	0.56 (–2.60 to 3.72)	0.72 (36)	51.66 (9.79)	–1.66 (–4.51 to 1.18)	0.24 (42)	–3.74 (–7.29 to –0.19)	0.04 (80)	–1.51 (–4.91 to 1.88)	0.38 (86)	2.22 (–1.95 to 6.39)	0.29 (78)

			Group A: MDT			Group B: MDT + PCA			Group C: controls			Differences in changes weeks 36–0					
												A vs. B		A vs. C		B vs. C	
Category	Instrument	*n*	Baseline (week 0) mean (SD)	Change week 36–0 (95% CI)	*p*-value[a] (df)	Baseline (week 0) mean (SD)	Change week 36–0 (95% CI)	*p*-value[a] (df)	Baseline (week 0) mean (SD)	Change week 36–0 (95%CI)	*p*-value[a] (df)	Mean (95% CI)	*p*-value[a] (df)	Mean (95% CI)	*p*-value[a] (df)	Mean (95% CI)	*p*-value[a] (df)
Psychological well-being (Yale Depression Screen below	HADS – anxiety (0 to 21 worst)[83]	125	5.07 (3.28)	0.11 (–0.72 to 0.94)	0.79 (44)	5.81 (4.21)	–0.16 (–1.13 to 0.81)	0.74 (36)	5.91 (3.95)	0.51 (–0.42 to 1.44)	0.27 (42)	0.27 (–0.98 to 1.52)	0.66 (80)	–0.40 (–1.63 to 0.83)	0.52 (86)	–0.67 (–2.00 to 0.65)	0.32 (78)
	HADS – depression (0 to 21 worst)[83]	125	3.44 (2.52)	0.44 (–0.12 to 1.01)	0.12 (44)	3.41 (2.90)	0.24 (–0.60 to 1.08)	0.56 (36)	3.65 (3.68)	0.47 (–0.42 to 1.35)	0.29 (42)	0.20 (–0.77 to 1.17)	0.68 (80)	–0.02 (–1.04 to 1.00)	0.97 (86)	–0.22 (–1.43 to 0.99)	0.72 (78)

			Group A: MDT			Group B: MDT + PCA			Group C: controls			Differences in changes weeks 36–0					
												A vs. B		A vs. C		B vs. C	
Category	Instrument	*n*	Baseline yes, *n* (%)	Change week 36–0	*p*-value[a]	Baseline yes, *n* (%)	Change week 36–0	*p*-value[a]	Baseline yes, *n* (%)	Change week 36–0	*p*-value[a]	Difference in changes	*p*-value[a]	Difference in changes	*p*-value[a]	Difference in changes	*p*-value[a]
Psychological well-being	Yale Depression Screen[a] (yes = 1; no = 0)[84,85]	125	15 (33.3)	Improve 4 (8.9) Same 34 (75.6) Worse 7 (15.6)	0.37	13 (35.1)	Improve 5 (13.5) Same 29 (78.4) Worse 3 (8.1)	0.48	20 (46.5)	Improve 3 (7.0) Same 34 (79.1) Worse 16 (14.0)	0.32	Not applicable	0.26	Not applicable	0.99	Not applicable	0.32

df, degrees of freedom; HRQoL, health-related quality of life.

a One-way ANOVA tests were used for comparisons between all three groups, and unpaired *t*-tests were used for comparisons between pairs of groups. Within-group changes between assessment points were also explored using paired *t*-tests. In each case, a two-sided test was used.

TABLE 23 Summary of outcomes by assessment[a]

		People with Parkinson's: outcomes where change scores between groups differ		Live-in carers: outcomes where change scores between groups differ	
Time period	**Group comparisons**	**$p < 0.05$**	**$0.05 \leq p < 0.10$**	**$p < 0.05$**	**$0.05 \leq p < 0.10$**
Baseline to week 6: effect of MDT	A + B (receive MDT) vs. C (control)	A + B improve significantly: • Anxiety (HADS) C worsens significantly: • Depression (HADS) • SF-36 MCS	A + B improve significantly: • Parkinson's disability (primary outcome) • Parkinson's Non-Motor Symptoms • EQ-5D Index C worsens significantly: • Speech Self Report	A + B improve significantly: • SF-36 MCS	None
Week 6 (end of MDT) to week 24 (end of PCA): effect of PCA	A (no PCA support) vs. B (PCA support)	A worsens significantly: • Parkinson's Non-Motor Symptoms • Posture A improves significantly: • Voice (Emerson and Enderby)	A worsens significantly: • EQ-5D Index • Self-efficacy	None	A worsens, B improves (both non-significant): • Carer strain (primary outcome)
Baseline to week 24	A vs. B	B improves significantly: • EQ-5D Index • Posture (UPDRS) A worsens significantly: • SF-36 MCS • Depression (HADS) A improves significantly: • Voice (Emerson and Enderby)	None	B worsens significantly: • SF-36 PCS	None
	A vs. C	A improves significantly: • Voice (Emerson and Enderby)	C worsens significantly: • Speech Self Report	C worsens significantly: • Depression (HADS)	A improves, C worsens (both non-significant): • SF-36 PCS
	B vs. C	B improves, C worsens (both non-significant): • Parkinson's Non-Motor Symptoms	C worsens significantly: • SF-36 MCS • Anxiety (HADS) marginal	C worsens significantly: • SF-36 MCS	None

Time period	Group comparisons	People with Parkinson's: outcomes where change scores between groups differ		Live-in carers: outcomes where change scores between groups differ	
		$p < 0.05$	$0.05 \leq p < 0.10$	$p < 0.05$	$0.05 \leq p < 0.10$
		B improves significantly: • EQ-5D Index • Posture (UPDRS) • Articulation (Emerson and Enderby) marginal C worsens significantly: • Speech Self Report			
Week 24 to week 36 (final end point): follow-up when there is no intervention for any group	A vs. B	A improves significantly: • Posture (UPDRS) • Articulation (Emerson and Enderby) A worsens significantly: • Voice (Emerson and Enderby)	None	A worsens significantly: • Depression (HADS)	A worsens, B improves (both non-significant): • EQ-5D Thermometer
	A vs. C	A worsens, C improves (both non-significant): • SF-36 PCS A improves significantly: • Timed Up and Go (mobility) A worsens significantly: • Speech Self Report A and C worsen significantly, A greatest: • Voice (Emerson and Enderby) C improves significantly: • Gait (UPDRS)	None	A worsens significantly: • Depression (HADS) • EQ-5D Thermometer • SF-36 MCS	None

continued

TABLE 23 Summary of outcomes by assessment[a] (*continued*)

		People with Parkinson's: outcomes where change scores between groups differ		Live-in carers: outcomes where change scores between groups differ	
Time period	**Group comparisons**	**$p < 0.05$**	**$0.05 \leq p < 0.10$**	**$p < 0.05$**	**$0.05 \leq p < 0.10$**
	B vs. C	C improves significantly: • Posture (UPDRS) • Articulation (Emerson and Enderby)	B worsens, C improves (both non-significant): • Speech (UPDRS) • SF-36 PCS B worsens significantly: • Parkinson's disability (primary outcome)	None	None
Baseline to week 36 (final end point): long-term effects	A vs. B	A worsens significantly: • SF-36 MCS • Speech Self Report	B improves significantly: • Gait (UPDRS)	A worsens significantly: • SF-36 MCS	A improves, B worsens (both non-significant): • SF-36 PCS
	A vs. C	None	A improves significantly: • Timed Up and Go (mobility)	A improves, C worsens (both non-significant): • SF-36 PCS	None
	B vs. C	C worsens significantly: • SF-36 MCS • Speech Self Report	None	None	None

a Outcomes where significant ($p < 0.05$) and marginally significant ($p < 0.10$) differences in change scores between groups are shown. Text in the cells provides information on the within-group changes that account for the observed differences in the between-group change scores.

TABLE 24 Summary of outcomes for people with Parkinson's: effect of the MDT; effect of ongoing PCA support; long-term effect (6 months)

Category	Instrument	Score	*n*	Baseline (week 0) mean scores	Short-term effect of MDT, 0–6 weeks	Medium-term effect of PCA, 6–24 weeks: A vs. B	Longer-term (6-month), 0–36 weeks: 6-month effect of interventions
Disability (primary outcome)	Self-Assessment Parkinson's Disability scale[69,70]	25 to 125 (most disabled)	226	Difference between groups not significant	A + B vs. C $p = 0.09$ A + B improve ($p < 0.005$); C no significant change	Group change scores not significantly different	Group change scores not significantly different
Parkinson's specific	PDQ-8[72,73]	0 to 100 (worst)	227	Difference between groups not significant	Group change scores not significantly different	Group change scores not significantly different	Group change scores not significantly different
	Non-Motor Symptoms Questionnaire[74,75]	0 to 30 (worst)	227	Difference between groups not significant	A + B vs. C, $p = 0.06$; A + B improve ($p < 0.005$); C no significant change	A vs. B, $p = 0.05$; A worsens ($p = 0.005$); B no significant change	Group change scores not significantly different
Activities	Barthel ADL[76]	0 to 20 (independent)	227	Difference between groups not significant	Group change scores not significantly different	Group change scores not significantly different	Group change scores not significantly different
	Frenchay Activities Index[77–79]	0 to 30 (best)	226	Groups differ ($p = 0.012$)	Group change scores not significantly different	Group change scores not significantly different	Group change scores not significantly different
			226				

continued

TABLE 24 Summary of outcomes for people with Parkinson's: effect of the MDT; effect of ongoing PCA support; long-term effect (6 months) (*continued*)

Category	Instrument	Score	*n*	Baseline (week 0) mean scores	Short-term effect of MDT, 0–6 weeks	Medium-term effect of PCA, 6–24 weeks: A vs. B	Longer-term (6-month), 0–36 weeks: 6-month effect of interventions
HRQoL (generic)	EQ-5D Thermometer[80,81]	0 to 100 (best)		Difference between groups not significant	Group change scores not significantly different	Group change scores not significantly different	Group change scores not significantly different
	EQ-5D Index[80,81]	–0.57 to 1.0 (best)	227	Difference between groups not significant	A + B vs. C, $p = 0.07$; A + B improve ($p < 0.005$); C no significant change	A vs. B, $p = 0.07$; A worsens ($p = 0.02$); B no significant change	Group change scores not different
	SF-36 PCS[82]	0 to 100 (best)	225	Difference between groups not significant	Group change scores not significantly different	Group change scores not significantly different	Group change scores not significantly different
	SF-36 MCS[82]	0 to 100 (best)	226	Difference between groups not significant	A + B vs. C, $p = 0.04$; A + B no significant change; C worsens ($p = 0.01$)	Group change scores not significantly different	A vs. B, $p = 0.05$; B vs. C, $p = 0.05$; A and C worsen (both $p < 0.005$); B no significant change
Psychological well-being	HADS – anxiety[83]	0 to 21 (worst)	226	Difference between groups not significant	A + B vs. C, $p = 0.02$; A + B improve ($p = 0.01$); C no significant change	Group change scores not significantly different	Group change scores not significantly different
	HADS – depression[83]	0 to 21 (worst)	226	Difference between groups not significant	A + B vs. C, $p = 0.05$; A + B no significant change; C worsens ($p = 0.02$)	Group change scores not significantly different	Group change scores not significantly different

Category	Instrument	Score	*n*	Baseline (week 0) mean scores	Short-term effect of MDT, 0–6 weeks	Medium-term effect of PCA, 6–24 weeks: A vs. B	Longer-term (6-month), 0–36 weeks: 6-month effect of interventions
	Yale Depression Screen[84,85]	Yes = 1, no = 0	225	Groups differ ($p = 0.009$)	Group change scores not significantly different	Group change scores not significantly different	Group change scores not significantly different
Self-efficacy	Self-Efficacy Scale[86]	1 to 10 (best)	226	Difference between groups not significant	Group change scores not significantly different	A vs. B, $p = 0.09$; A worsens ($p = 0.005$); B no significant change	Group change scores not significantly different
Mobility	Timed Up and Go[87,88]	Seconds (low good)	210	Difference between groups not significant	Group change scores not significantly different	Group change scores not significantly different	A vs. C, $p = 0.06$; A improves ($p = 0.09$); C no significant change
	Falls (self-report)	Yes = 1, no = 0	228	Difference between groups not significant	Group change scores not significantly different	Group change scores not significantly different	Group change scores not significantly different
	UPDRS – posture	0 to 4 (worst)[89]	212	Difference between groups not significant	Group change scores not significantly different	A vs. B, $p > 0.001$; A worsens ($p = 0.005$); B no significant change	Group change scores not significantly different
	UPDRS – gait	0 to 4 (worst)[89]	212	Difference between groups not significant	Group change scores not significantly different	Group change scores not significantly different	A vs. B, $p = 0.09$; A no significant change; B improves ($p < 0.005$)
Pain	VAS, in 'on' states[90–93]	0 to 100 (worst)	164	Difference between groups not significant	Group change scores not significantly different	Group change scores not significantly different	Group change scores not significantly different

continued

TABLE 24 Summary of outcomes for people with Parkinson's: effect of the MDT; effect of ongoing PCA support; long-term effect (6 months) (*continued*)

Category	Instrument	Score	*n*	Baseline (week 0) mean scores	Short-term effect of MDT, 0–6 weeks	Medium-term effect of PCA, 6–24 weeks: A vs. B	Longer-term (6-month), 0–36 weeks: 6-month effect of interventions
	VAS, in 'off' states[90–93]	0 to 100 (worst)	143	Difference between groups not significant	Group change scores not significantly different	Group change scores not significantly different	Group change scores not significantly different
Speech	Speech Self Report Questionnaire	0 to 130 (worst)	227	Difference between groups not significant	A + B vs. C, $p = 0.07$; A + B no significant change; C worsens ($p = 0.02$)	Group change scores not significantly different	A vs. B, $p = 0.02$; B vs. C, $p = 0.03$; A and C worsen (both $p < 0.005$); B no significant change
	UPDRS – speech	0 to 4 (worst)[89]	226	Difference between groups not significant	Group change scores not significantly different	Group change scores not significantly different	Group change scores not significantly different
	Abridged Emerson and Enderby Screening Assessment Rating Scale – voice[94]	1 to 4 (worst)	226	Difference between groups not significant	Group change scores not significantly different	A vs. B, $p < 0.005$; A improves ($p < 0.005$); B no significant change	Group change scores not significantly different
	Abridged Emerson and Enderby Screening Assessment Rating Scale – articulation[94]	1 to 4 (worst)	226	Difference between groups not significant	Group change scores not significantly different	Group change scores not significantly different	Group change scores not significantly different

HRQoL, health-related quality of life; PDQ-8, Parkinson's Disease Questionnaire-8 items.
Significant treatment effects ($p < 0.05$), and trends ($p < 0.10$) are shaded light green; contrary effects are shaded dark green.
Changes between baseline and week 24 and between weeks 24 and 36 are not shown in the table.
Statistical tests: within-group comparisons are paired *t*-tests; comparisons between all three groups are one-way ANOVAs; comparisons between pairs of groups are unpaired *t*-tests.
Light blue shading indicates when randomisation occurred.
Medium blue shading indicates when 6-week MDT rehabilitation (Groups A and B) occurred.
Dark blue shading indicates when 18-week PCA support (Group B only) occurred.

TABLE 25 Summary of outcomes for live-in carers: effect of the MDT; effect of ongoing PCA support; long-term effect (6 months)

Category	Instrument	Score	*n*	Baseline (week 0) mean scores	Short-term effect of MDT, 0–6 weeks: A + B vs. C	Medium-term effect of PCA, 6–24 weeks: A vs. B	Longer-term (6-month), 0–36 weeks: 6-month effect of interventions
Strain (primary outcome)	Modified Caregiver Strain Index[71]	0 to 26 (worst)	125	Difference between groups not significant	Group change scores not significantly different	A vs. B, $p = 0.06$; B improves (NS); A worsens (NS)	Group change scores not significantly different
General health	General Health Questionnaire-12[95]	0 to 36 (worst)	125	Difference between groups not significant	Group change scores not significantly different	Group change scores not significantly different	Group change scores not significantly different
Activities	Barthel ADL[76]	0 to 20 (independent)	125	Difference between groups not significant	Group change scores not significantly different	Group change scores not significantly different	Group change scores not significantly different
	Frenchay Activities Index[77–79]	0 to 30 (best)	125	Difference between groups not significant	Group change scores not significantly different	Group change scores not significantly different	Group change scores not significantly different
HRQoL (generic)	EQ-5D Thermometer[80,81]	0 to 100 (best)	125	Difference between groups not significant	Group change scores not significantly different	Group change scores not significantly different	Group change scores not significantly different
	EQ-5D Index[80,81]	–0.57 to 1.0 (best)	125	Difference between groups not significant	Group change scores not significantly different	Group change scores not significantly different	Group change scores not significantly different

continued

TABLE 25 Summary of outcomes for live-in carers: effect of the MDT; effect of ongoing PCA support; long-term effect (6 months) *(continued)*

Category	Instrument	Score	*n*	Baseline (week 0) mean scores	Short-term effect of MDT, 0–6 weeks: A + B vs. C	Medium-term effect of PCA, 6–24 weeks: A vs. B	Longer-term (6-month), 0–36 weeks: 6-month effect of interventions
HRQoL (generic)	SF-36 PCS[82]	0 to 100 (best)	125	Difference between groups not significant	Group change scores not significantly different	Group change scores not significantly different	A vs. B, $p = 0.06$; A vs. C, $p = 0.02$ A improves (NS); B and C worsen (NS)
	SF-36 MCS[82]	0 to 100 (best)	125	Difference between groups not significant	A + B vs. C, $p = 0.02$; A + B improve ($p = 0.05$); C no significant change	Group change scores not significantly different	A vs. B, $p = 0.04$; A worsens ($p < 0.005$); B no significant change
Psychological well-being	HADS – anxiety[83]	0 to 21 (worst)	125	Difference between groups not significant	Group change scores not significantly different	Group change scores not significantly different	Group change scores not significantly different
	HADS – depression[83]	0 to 21 (worst)	125	Difference between groups not significant	Group change scores not significantly different	Group change scores not significantly different	Group change scores not significantly different
	Yale Depression Screen[84,85]	Yes = 1, no = 0	125	Difference between groups not significant	Group change scores not significantly different	Group change scores not significantly different	Group change scores not significantly different

HRQoL, health-related quality of life; NS, non-significant.
Significant treatment effects ($p < 0.05$), and trends ($p < 0.10$) are shaded light green; contrary effects are shaded dark green.
Changes between baseline and week 24 and between weeks 24 and 36 are not shown in the table.
Statistical tests: within-group comparisons are paired *t*-tests; comparisons between all three groups are one-way ANOVAs; comparisons between pairs of groups are unpaired *t*-tests.
Light blue shading indicates when randomisation occurred.
Medium blue shading indicates when 6-week MDT rehabilitation (groups A and B) occurred.
Dark blue shading indicates when 18-week PCA support (group B only) occurred.

TABLE 26 Multidisciplinary team process outcomes

Process outcome	Group A, *n*		Group B, *n*	
Referrals to:				
Neurologist	2		1	
Geriatrician	0		0	
GP	0		2	
Community PNS	4		6	
Community PT	0		0	
Community OT	1		0	
Community SLT	3		0	
Counselling	1		1	
Community mental health services	0		0	
Parkinson's UK support worker	1		1	
PNS medication changes				
Change of medication	23		17	
Timing change	5		3	
Alter means of administration	2		1	
	Recommendations		Recommendations	
	Number	Paticipants, *n*	Number	Paticipants, *n*
OT recommendations for new aids and equipment for:				
Dressing	31	26	27	22
Eating/drinking	37	26	43	28
Bath	21	19	30	24
Bed mobility	38	31	51	39
Toilet	34	31	33	32
Walking	7	7	10	9
Stairs	14	13	7	7
Chair/sitting	8	7	5	5
Car	42	33	40	31
Handwriting	25	24	18	18
Garden	2	2	1	1
Shopping	30	24	14	11
Medications	2	2	2	2
Household	51	39	46	34
Hobbies	7	4	3	3
Number of new aids and adaptations reported by participants at 24-week (36-week) assessments[a]				
	26 (13)		23 (12)	

a Control group reported 19 (17).

TABLE 27a Quantitative analysis of the feedback on the acceptability of the MDT interventions by people with Parkinson's and live-in carers: responses at the 6-week assessment, *n* (%)

Group	Person with Parkinson's (group A, *N* = 88; group B, *N* = 88)						Live-in carer (group A, *N* = 52; group B, *N* = 50)					
	How helpful did you find the treatment programme overall?						How helpful did you find the treatment programme overall, for the person you care for?					
	Not at all helpful	A little helpful	Moderately helpful	Very helpful	Extremely helpful	Total	Not at all helpful	A little helpful	Moderately helpful	Very helpful	Extremely helpful	Total
A	0 (0.0)	2 (3.9)	7 (13.7)	35 (68.6)	7 (13.7)	51 (100)	0 (0.0)	0 (0.0)	5 (17.9)	16 (57.1)	7 (25.0)	28 (100)
B	0 (0.0)	4 (7.4)	8 (14.8)	23 (42.6)	19 (35.2)	54 (100)	0 (0.0)	0 (0.0)	4 (13.8)	12 (41.4)	13 (44.8)	29 (100)
Total	0 (0.0)	6 (5.7)	15 (14.3)	58 (55.2)	26 (24.8)	105 (100)	0 (0.0)	0 (0.0)	9 (15.8)	28 (49.1)	20 (35.1)	57 (100)
	I learnt new things about Parkinson's and my condition						I learnt new things about Parkinson's					
	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Total	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Total
A	0 (0.0)	1 (2.0)	2 (4.0)	34 (68.0)	13 (26.0)	50 (100)	0 (0.0)	0 (0.0)	3 (10.7)	18 (64.3)	7 (25.0)	28 (100)
B	0 (0.0)	2 (3.6)	3 (5.5)	37 (67.3)	13 (23.6)	55 (100)	1 (3.4)	1 (3.4)	1 (3.4)	21 (72.4)	5 (17.2)	29 (100)
Total	0 (0.0)	3 (2.9)	5 (4.8)	71 (67.6)	26 (24.8)	105 (100)	1 (1.8)	1 (1.8)	4 (7.0)	39 (68.4)	12 (21.1)	57 (100)

Group	Person with Parkinson's (group A, $N = 88$; group B, $N = 88$)				Live-in carer (group A, $N = 52$; group B, $N = 50$)			
	Would you recommend the 6-week multidisciplinary rehabilitation treatment to others?				Would you recommend the 6-week multidisciplinary rehabilitation treatment to others?			
	No	Don't know	Yes	Total	No	Don't know	Yes	Total
A	2 (4.0)	2 (4.0)	46 (92.0)	50 (100)	0 (0.0)	3 (10.7)	25 (89.3)	28 (100)
B	2 (3.7)	1 (1.90)	51 (94.4)	54 (100)	2 (6.9)	0 (0.0)	27 (93.1)	29 (100)
Total	4 (3.8)	3 (2.9)	97 (93.3)	104 (100)	2 (3.5)	3 (5.3)	52 (91.2)	57 (100)
	Would you like the 6-week multidisciplinary rehabilitation treatment repeated?				Would you like the 6-week multidisciplinary rehabilitation treatment repeated?			
	No	Don't know	Yes	Total	No	Don't know	Yes	Total
A	13 (26.0)	2 (4.0)	35 (70.0)	13 (100)	2 (7.1)	0 (0.0)	26 (92.9)	28 (100)
B	6 (11.3)	4 (7.5)	43 (81.1)	53 (100)	2 (6.9)	2 (6.9)	25 (86.2)	29 (100)
Total	19 (18.4)	6 (5.8)	78 (75.7)	103 (100)	4 (7.0)	2 (3.5)	51 (89.5)	57 (100)
	If you would like the 6-week multidisciplinary rehabilitation treatment repeated, how often would you like this?				If you would like the 6-week multidisciplinary rehabilitation treatment repeated, how often would you like this?			
	Not applicable	Once a year	Twice a year	Three times a year	Total	Not applicable	Once a year	Twice a year	Three times a year	Total
A	0 (0.0)	25 (65.8)	10 (26.3)	3 (7.9)	38 (100)	0 (0.0)	17 (65.4)	6 (23.1)	3 (11.5)	26 (100)
B	0 (0.0)	25 (54.3)	15 (32.6)	6 (13.0)	46 (100)	0 (0.0)	19 (70.4)	6 (22.2)	2 (7.4)	27 (100)
Total	0 (0.0)	50 (59.5)	25 (29.8)	9 (10.7)	84 (100)	0 (0.0)	36 (67.9)	12 (22.6)	5 (9.4)	53 (100)

TABLE 27b Quantitative analysis of the feedback on the acceptability of the MDT interventions by people with Parkinson's and live-in carers: responses at the 24-week assessment, *n* (%)

Group	Person with Parkinson's (group A, *N* = 88; group B, *N* = 88)						Live-in carer (group A, *N* = 52; group B, *N* = 50)					
	When the 6-week multidisciplinary treatment ended, did you continue to benefit from the treatment?						When the 6-week multidisciplinary treatment ended, did you and the person you care for continue to benefit from the treatment?					
	Not at all	Yes, a little	Yes, somewhat	Yes, a lot	Yes, to a great extent	Total	Not all all	Yes, a little	Yes, somewhat	Yes, a lot	Yes, to a great extent	Total
A	3 (4.2)	19 (26.4)	29 (40.3)	20 (27.8)	1 (1.4)	72 (100)	0 (0.01)	13 (30.2)	17 (39.5)	8 (18.6)	5 (11.6)	43 (100)
B	0 (0.0)	15 (20.8)	27 (37.5)	25 (34.7)	5 (6.9)	72 (100)	0 (0.0)	11 (29.7)	8 (21.6)	16 (43.2)	2 (5.4)	37 (100)
Total	3 (2.1)	34 (23.6)	56 (38.9)	45 (31.3)	6 (4.2)	144 (100)	0 (0.0)	24 (30.0)	25 (31.3)	24 (30.0)	7 (8.8)	80 (100)
	How helpful did you find the care assistant input?						How helpful did you find the care assistant input?					
	Not at all helpful	A little helpful	Moderately helpful	Very helpful	Extremely helpful	Total	Not at all helpful	A little helpful	Moderately helpful	Very helpful	Extremely helpful	Total
B	0 (0.0)	1 (1.4)	10 (14.5)	28 (40.6)	30 (43.5)	69 (100)	0 (0.0)	0 (0.0)	4 (11.8)	19 (55.9)	11 (32.4)	34 (100)
	Extent to which (if at all) your expectations of the care assistant input have been met (scale: 0–100 mm): greatly fell short – 0 mm; just met – 50 mm; greatly exceeded – 100 mm						Extent to which (if at all) your expectations of the care assistant input have been met (scale: 0–100 mm): greatly fell short – 0 mm; just met – 50 mm; greatly exceeded – 100 mm					
	n	Mean	SD	Range			*n*	Mean	SD	Range		
B	70	75.76	20.39	10–100			35	80.03	14.44	50–100		

with Parkinson's, except that a higher proportion (90%) stated that they would like the programme repeated and they rated the PCA input slightly higher.

There were many missing responses to the question on value for money for the rehabilitation programme (asked at 6 weeks, immediately after the end of the treatment programme). People with Parkinson's and carers were asked if they thought that the MDT programme would be good value for money for the NHS at each of four costs: £235, £435, £635 and £835. These costs were set to provide a range of values either side of the estimated cost of the intervention of £635. As a group, the live-in carers thought it was better value for money than did the patients (*Table 28*).

Qualitative analysis of open-text questions

The main themes emerging from the analysis of the written feedback at the 6-week assessment point from the people with Parkinson's and their carers who had received the MDT intervention were that they valued the individual attention, the opportunity to discuss their problems with knowledgeable professionals, tailored advice and home visits (*Tables 29* and *30*). They also commented that they had learnt a lot about Parkinson's disease, and how to manage it. These views were echoed by live-in carer respondents. Suggestions for improvement included more carer involvement, more local health service involvement, and greater spreading out of the visits. Some also noted the lack of contact with other people with Parkinson's (a feature of home-based treatment), and that it would have been useful to have had the intervention sooner after diagnosis. The full text of all responses from people with Parkinson's and live-in carers is given in *Appendix 24*.

Many of the responses to the question at 24 weeks on continuing benefit from the MDT mentioned continuing to follow the advice of health professionals and especially doing the exercises that were suggested (*Table 31*). Some of the people with Parkinson's in group B referred to the PCA input that they had received. They regarded the PCA as a supporter and motivator. However, none of the carers specifically mentioned the PCA input. This may be a reflection of the wording of the question, which asked about the benefit from the MDT (not the PCA). The full text of all responses from people with Parkinson's and live-in carers is given in *Appendix 25*.

TABLE 28 Value for money of the MDT

Providing the 6-week multidisciplinary rehabilitation to people with Parkinson's is an expense to the NHS. What is the upper sum you think that would be good value? [*n* (%)]					
Respondents	**£235**	**£435**	**£635**	**£835**	**Total**
People with Parkinson's	3 (6.8)	12 (27.3)	14 (31.8)	15 (34.1)	44 (100)
Live-in carers	1 (3.7)	3 (11.1)	10 (37.0)	13 (48.1)	27 (100)

Participants in groups A and B only, cohorts 4–10, responding at assessment 2 – immediately post treatment.

TABLE 29 Qualitative analysis of the feedback on the MDT interventions by people with Parkinson's, groups A and B only, cohorts 4–10, at assessment 2 (6 weeks)

Question	Number of responses to question	Number of comments used per question	Themes emerging from data
Question 1: how helpful did you find the treatment programme overall? Please explain	81	75	Increased knowledge and insight into Parkinson's including helpful hints and practical advice
			Understanding of how to manage their own condition, boost in confidence and morale
			Individual health-care professional contact and tailored input
			Having time to talk to well-informed health-care professional who understood them
Question 5: please explain, in your view, what were the most successful aspects of the programme?	87	84	Individual health-care professionals, personal attention – 'felt I mattered'
			Learning new things/confirming old knowledge, being able to talk
			Visits in the home
			Co-ordinated multidisciplinary input
Question 6: please explain, in your view, what were the least successful aspects of the programme?	82	73	Individual health-care professionals; some felt that speech therapy was not needed
			Length of programme (too short) – would like follow-ups
			A lot of useful information in a short period of time – too much to take in
			Difficult to maintain self-motivation post intervention
			33 responses: nothing to improve on/all successful
Question 7: can you think of ways in which the programme can be improved?	85	70	More visits from individual health-care professionals/follow-up post input
			Spread out the visits
			Have meeting with other PD sufferers
			Make it more individualised
			Have more carer involvement
			37 responses: no way to improve
Question 14: do you have any other comments about the treatment or study overall?	76	64	Positive experience, glad to have taken part
			Team were professional/approachable/knowledgeable
			Would like it to continue/be available to others
Other comments across questions	–	–	Needed just after diagnosis
			At early stage no problems so unnecessary, but found tips for the future useful

Selected quotes:

I have not been able to talk to people about PD beforehand

I now understand a great deal more about Parkinson's

Although I had a lot of knowledge about Parkinson's I found that the treatment filled many gaps that I did not appreciate existed

Helped with motivation but this faded as the visits decreased

All of it was useful and relevant

Very good, would recommend to other Parkinson people

PD, Parkinson's disease.
Total number of questionnaires sent: 127; total number received: 106.

TABLE 30 Qualitative analysis of the feedback on the MDT interventions by live-in carers, groups A and B only, cohorts 4–10, at assessment 2 (6 weeks)

Question	Number of responses to question	Number of comments used per question	Themes emerging from data
Question 1: how helpful did you find the treatment programme overall, for the person that you care for? Please explain	52	49	Learnt new things and gained a better understanding of Parkinson's disease
			Learnt how to manage specific symptoms
			Gave motivation and encouragement
Question 5: please explain, in your view, what were the most successful aspects of the programme?	55	52	Individual health-care professions
			One-to-one home visits
			Reassurance and encouragement from health-care professionals
Question 6: please explain, in your view, what were the least successful aspects of the programme?	51	41	Individual health-care professions
			Not covering a specific health topic, e.g. the psychological impact of the condition
			Too short/no follow-on
			20 responses: nothing to improve on
Question 7: can you think of ways in which the programme can be improved?	47	40	More carer input/involvement/carers meeting/separate session for carer without person with Parkinson's present
			Local health-care integration
			Ongoing programme (some suggested telephone helpline/one-stop clinic)
			19 responses: no way to improve
Question 14: do you have any other comments about the treatment or study overall?	50	49	Positive experience
			Learnt new things
			Health-care professionals very helpful and co-ordinated
			Needed earlier, would be useful soon after diagnosis
			Follow-up would be helpful

Selected quotes:

There is no doubt that the success of this programme can be attributed to the individual interests paid to the person with PD by the health-care specialists. These are one-to-one discussion, with a shared interest and professional concern which have been both supportive and stimulating, and have allowed an up to date programme to be developed on an individual basis. As a carer, I can see how encouraging this has been as my wife grasps on to the new ideas

The fact of home visits meant that there was no rush and we had their individual attention in our own environment

Knowing that there is help out there if [name] problem gets worse, and knowing what to look for with books and all the information that was left with us

Very professional. Ticked all the boxes. Well worth the cost to the NHS

Absolutely brilliant cost effective way of incorporating the well-being of Parkinson's sufferers and their families therefore making people feel cherished and important within the vast NHS system

PD, Parkinson's disease.
Total number of questionnaires sent: 70; total number received: 58.

TABLE 31 Qualitative analysis of responses to question on continuing benefit from MDT treatments, groups A and B only, cohorts 4–10, at assessment 3 (24 weeks)

When the 6-week multidisciplinary rehabilitation intervention ended, did you/person with Parkinson's continue to benefit from the treatment? If yes, please explain	
Group A (MDT only): themes emerging from data	**Group B (MDT + PCA): themes emerging from data**
Person with Parkinson's: 150 questionnaires sent (100% response rate)	
63 responses received to question: 58 relevant and legible	65 responses received to question: 62 relevant and legible
Continued with advice from health-care professionals	Continued with advice from health-care professionals
Aware of what help was available for Parkinson's sufferers and sought it out	More confidence
22 mentioned exercises	30 mentioned exercises
	Nine specifically mentioned PCA input, for motivation
Live-in carers: 86 questionnaires sent (85 received completed)	
32 responses received to question: 30 relevant and legible	34 responses received to question: 33 relevant and legible
Continued with advice from health-care professionals	Continued with advice from health-care professionals
More positive outlook	More positive outlook
	Greater understanding and knowledge of Parkinson's
	No mention of PCA

Economic evaluation

Intervention costs

Analysis of the data contained in the CRFs revealed that most participants received 500 minutes of direct patient-facing contact time (almost exclusively from home visits, median of six) from members of the MDT in weeks 1–6. The contact time was the same for both groups A and B. Participants in group B received, on average, an additional 418 minutes of patient-facing contact time from the PCA (median of seven home visits and five telephone calls) in weeks 7–24. The PCA asked for input from the MDT for a small number of patients. The contribution of the MDT during the PCA period (weeks 7–24) was a mean 17 minutes per patient (median 0 minutes) (*Table 32*).

The mean cost per patient of the MDT (2011 GBP) was £445 (SD £60 group A; £52 group B). This includes both the patient-facing time spent in home visits and telephone calls, and an allowance for non-patient-facing follow-up (referral letters, case notes, MDT meetings, etc.) of 30 minutes per visit and 15 minutes per telephone call. Travel costs, based on mileage, added a further £338 (£275 for professional time in transit, £63 for the cost of running a car). There was no difference in MDT costs between groups A and B (*Table 33*). The mean cost of the PCA for group B was £579 [£310 (SD £109) for patient-related work, and £269 (SD £89) for travel]. There was a small additional MDT cost during the 6–24-week PCA support period of £21 (SD £38) per patient, arising when the PCA identified issues that needed further professional input. The cost of the PNS providing comprehensive feedback to GPs about all patients at the end of the trial was a further £50. The grand total cost per patient was £833 for the MDT (both groups A and B), and an additional £600 for the extra PCA input (group B).

Service use

Service use was collected at three assessment points and is reported descriptively (*Table 34*). Baseline data refer to the 3-month period prior to recruitment to the study. Service use collected at assessment 3 (24 weeks) relates to the period after the end of the MDT, but does not include the PCA input being

TABLE 32 Staff resources used in the delivery of the MDT interventions

Item	Group A, cohort 2–10, $n = 87$					Group B, cohort 2–10, $n = 83$					Difference group A vs. B, p-value
	Frequency	Mean per patient	SD	Median	IQR	Frequency	Mean per patient	SD	Median	IQR	
Week 0–6											
PNS											
Total visits	172	1.98	0.15	2	0	161	1.94	0.24	2	0.0	0.229[a]
Duration (minutes)	13,445	154.54	30.71	155	35	12,769	153.84	27.60	160	37.5	0.876[b]
Duration/visit		78.17		77.5			79.31		80		
Total telephone calls	3	0.03	0.18	0	0	2	0.02	0.15	0	0.0	0.690[a]
Duration (minutes)	20	0.23	1.30	0	0	10	0.12	1.10	0	0.0	0.554[b]
Duration/call		6.67		0			5.00		0		
PT[c]											
Total visits	174	2.00	0.00	2	0	164	1.98	0.15	2	0.0	0.159[a]
Duration (minutes)	15,483	177.97	41.11	180	25	14,593	175.82	28.18	180	20.0	0.691[b]
Duration/visit		88.98		90			88.98		90		
OT[c]											
Total visits	87	1.00	0.00	1	0	83	1.00	0.00	1	0.0	1.000[a]
Duration (minutes)	7784	89.47	24.09	90	25	7450	89.76	23.39	90	27.5	0.937[b]
Duration/visit		89.47		90			89.76		90		
SLT[c]											
Total visits	98	1.13	0.43	1	0	100	1.20	0.46	1	0.0	0.253[a]
Duration (minutes)	6835	78.56	38.04	75	30	6729	81.07	39.99	75	30.0	0.675[b]
Duration/visit		69.74		75			67.29		75		
MDT total											
Total visits	531	6.10				508	6.12				
Duration (minutes)	43,547	500.54				41,541	500.49				
Duration/visit		82.01					81.77				
Total telephone calls	3	0.03				2	0.02				
Duration (minutes)	20	0.23				10	0.12				

continued

TABLE 32 Staff resources used in the delivery of the MDT interventions (*continued*)

Item	Group A, cohort 2–10, *n* = 87					Group B, cohort 2–10, *n* = 83					Difference group A vs. B, *p*-value
	Frequency	Mean per patient	SD	Median	IQR	Frequency	Mean per patient	SD	Median	IQR	
Duration/call		6.67					5.00				
Total contacts[d]	**534**	**6.14**	**0.49**	**6**	**0**	**510**	**6.14**	**0.52**	**6**	**0.0**	**0.932[a]**
Total duration of contacts (minutes)	**43,567**	**500.77**	**89.55**	**495**	**87.5**	**41,551**	**500.61**	**75.92**	**490**	**102.5**	**0.9902[b]**
Week 7–24											
MDT total											
Total visits						20	0.24	0.48	0	0	
Duration (minutes)						1305	15.72	34.76	0	0	
Duration/visit							65.25		0	0	
Total telephone calls						15	0.18	0.45	0	0	
Duration (minutes)						121	1.46	3.80	0	0	
Duration/call							8.07		0		
Total contacts[d]						**35**	**0.42**	**0.72**	**0**	**1**	
Total duration of contacts (minutes)						**1426**	**17.18**	**35.43**	**0**	**10**	
PCA total											
Total visits						567	6.83	2.37	7	2	
Duration (minutes)						32,246	388.51	161.37	400	179.5	
Duration/visit							56.87		57.1		
Total telephone calls						400	4.82	2.17	5	3.5	
Duration (minutes)						2467	29.72	16.62	29	23	
Duration/call							6.17		5.8		
Total contacts[d]						**967**	**11.65**	**3.66**	**12**	**5**	
Total duration of contacts (minutes)						**34,713**	**418.23**	**163.13**	**427**	**191**	

IQR, interquartile range.
a Mann–Whitney *U* test.
b *t*-test (unequal variance, two-sided).
c There were no telephone calls reported for PT, OT and SLT.
d Total contacts = home visits + telephone calls.

TABLE 33 Intervention costs per patient (£, 2011)[a]

Item	Group A cohort 2–10, $n = 83$				Group B cohort 2–10, $n = 83$			
	Mean per patient	SD	Median	IQR	Mean per patient	SD	Median	IQR
Weeks 1–6								
MDT total (PNS, PT, OT, SLT)	445.05	59.91	441.33	65.67	444.61	51.97	436.83	65.83
Travel (staff time and mileage)	338.19	23.84	333.50	0.00	338.35	26.41	333.50	0.00
Total	**783.24**				**782.96**			
Weeks 7–24								
MDT (support of PCA)	–	–	–	–	20.74	38.30	0.00	25.00
PCA	–	–	–	–	310.56	109.43	324.48	140.60
Travel (staff time and mileage)	–	–	–	–	268.67	89.85	275.07	75.90
End								
GP letter	50.00		50.00		50.00		50.00	
Grand total	**833.24**	**74.00**	**831.00**	**82.17**	**1432.92**	**227.75**	**1461.89**	**274.48**

IQR, interquartile range.
a Unit costs used in the calculation are shown in *Appendix 19*.
–, not applicable to weeks ≥ 24.

provided to group B at that time. The data collected at assessment 4 (36 weeks) cover the 3-month follow-up period when no participants were receiving treatment within the study.

Small numbers of participants reported the use of hospital and overnight respite services in care/nursing homes. Between one-third and half reported outpatient neurology appointments. Overall, the participants are relatively high users of GP and community therapy services. About one-third of physiotherapy contacts, and half of alternative therapy contacts, were reportedly organised and paid for privately. Most participants were over 60 years of age and exempt from paying prescription charges. Of those reporting expenditure on medications bought over the counter, the average monthly spend, over the three periods, was £9.90, mostly for pain relief and anti-acid preparations. Of the 75 tests reported, 27 were for brain scans {magnetic resonance imaging, DaTSCAN™ [Ioflupane (^{123}I) Injection, a radiopharmaceutical agent used for dopamine transmitter imaging], computed tomography, unspecified}, and the rest were blood tests.

Almost half of participants reported receiving paid home help (cleaning and gardening), usually for a small number of hours per week and privately financed. Small numbers (higher in group B) stated that they received personal care packages through social services. Similar numbers reported unpaid help from family and friends, including transportation (as driving can be a problem for people with Parkinson's disease).

The NHS costs of the health service use were calculated on a per-participant basis for each 3-month period, by study group (*Table 35*). Self-paid services were excluded from the calculations. Tests, social and informal care could not be calculated owing to insufficient details on the type and frequency of use. The per-patient costs are driven by small numbers of high users of relatively expensive services (mostly overnight hospital stays). The costs vary accordingly within and between groups, the SDs are very high, and tests reveal only one significant difference, which was in the community care costs at 36 weeks, with group A higher than group C ($p = 0.022$). However, no significant differences were observed in total per-patient costs between any pair of groups at any time point.

TABLE 34 Use of other health and social services by people with Parkinson's

	Baseline 1						Assessment 3 (24 weeks)						Assessment 4 (36 weeks)					
	A, *N* = 88		B, *N* = 88		C, *N* = 93		A, *N* = 76		B, *N* = 73		C, *N* = 85		A, *N* = 80		B, *N* = 72		C, *N* = 85	
Events = visits/contacts	*n*	E	*n*	E	*n*	E	*n*	E	*n*	E	*n*	E	*n*	E	*n*	E	*n*	E
A&E and overnight																		
A&E	5	5	10	10	10	11	10	10	10	10	8	10	12	12	6	9	3	5
Hospital day cases	0	0	2	3	1	1	5	7	1	1	3	5	2	2	2	2	2	2
Hospital overnight occasions	4	6	4	4	3	3	12	17	7	7	8	11	9	9	7	7	4	4
Hospital overnight, total number of nights	4	7	4	17	3	7	12	188	7	75	8	35	9	219	7	36	4	30
Day hospital/care centre	1	1	3	5	5	5	1	1	7	8	0	0	1	1	4	6	2	2
Care home, number of nights	0	0	1	7	0	0	0	0	1	58	0	0	0	0	1	8	0	0
Nursing home, number of nights	0	0	0	0	0	0	0	0	1	7	0	0	0	0	1	7	0	0
Outpatient and community																		
Hospital neurologist	28	31	34	49	35	36	33	41	35	42	38	45	33	47	28	33	32	37
Hospital geriatrician	3	3	3	3	7	7	5	5	1	1	7	8	1	1	0	0	0	0
GP (home and surgery)	33	46	32	46	36	60	29	56	28	45	27	41	28	41	22	33	25	37
GP telephone	6	6	5	5	5	7	7	10	3	3	5	7	3	3	0	0	0	0
GP out of hours	0	0	0	0	1	2	1	1	1	1	4	5	1	1	0	0	0	0
PNS	29	30	41	46	32	36	28	37	21	26	28	33	27	33	15	17	25	39
District/practice nurse	3	11	5	5	3	3	5	23	4	14	5	6	4	7	5	19	1	2
PT	11	50	21	71	17	59	13	50	13	45	13	46	13	54	12	33	11	21
OT	5	8	7	9	4	4	8	13	2	3	8	12	8	11	0	0	6	6
SLT	7	17	4	23	4	9	6	14	1	1	9	29	7	14	3	6	6	26
Psychiatrist	0	0	0	0	0	0	1	1	0	0	0	0	1	2	1	2	1	1
Psychologist	0	0	0	0	1	2	0	0	0	0	0	0	0	0	0	0	0	0
Alternative therapist	3	30	1	1	2	8	4	27	3	11	10	41	0	0	2	3	2	6
Social worker	0	0	1	1	0	0	1	1	0	0	1	1	1	1	0	0	0	0
Health-care assistant	0	0	2	36	0	0	0	0	2	18	1	10	0	0	0	0	0	0

	Baseline 1						Assessment 3 (24 weeks)						Assessment 4 (36 weeks)					
	A, *N* = 88		B, *N* = 88		C, *N* = 93		A, *N* = 76		B, *N* = 73		C, *N* = 85		A, *N* = 80		B, *N* = 72		C, *N* = 85	
Events = visits/contacts	*n*	E	*n*	E	*n*	E	*n*	E	*n*	E	*n*	E	*n*	E	*n*	E	*n*	E
Parkinson's UK support worker	3	3	4	4	1	1	3	3	0	0	1	1	0	0	0	0	0	0
NHS Direct	0	0	0	0	0	0	1	1	0	0	2	2	0	0	0	0	0	0
Other																		
Tests	11	11	7	7	11	11	6	6	6	6	3	3	16	16	8	8	7	7
Private spend medicines, £ per month	28	183.1	19	176	37	275.49	28	312.4	13	223.5	33	354	21	180	16	160	23	294.5
Social services	***42***	**–**	***50***	**–**	***49***	**–**	***38***	**–**	***42***	**–**	***39***	**–**	***40***	**–**	***46***	**–**	***45***	**–**
Personal care	1	–	16	–	4	–	4	–	12	–	4	–	5	–	11	–	5	–
Home help	35	–	44	–	45	–	36	–	40	–	41	–	33	–	41	–	39	–
Nursing	0	–	0	–	0	–	1	–	0	–	0	–	1	–	0	–	1	–
Transport	4	–	5	–	5	–	5	–	3	–	5	–	1	–	3	–	3	–
Care alarm	18	–	25	–	13	–	17	–	20	–	13	–	21	–	22	–	14	–
Meals on wheels	0	–	2	–	2	–	1	–	1	–	1	–	1	–	1	–	2	–
Unpaid/informal care	***35***	**–**	***45***	**–**	***40***	**–**	***47***	**–**	***27***	**–**	***47***	**–**	***31***	**–**	***24***	**–**	***24***	**–**
Personal care	6	–	7	–	10	–	25	–	3	–	20	–	1	–	1	–	1	–
Home help	27	–	28	–	27	–	43	–	18	–	34	–	23	–	17	–	15	–
Transport	13	–	21	–	22	–	31	–	11	–	33	–	8	–	8	–	11	–
Other	6	–	14	–	7	–	21	–	5	–	16	–	11	–	7	–	9	–

–, not applicable; E, number of events.

TABLE 35 Summary of costs of other health service utilisation, per patient (£, 2011)[a]

	Group A				Group B				Group C				Significance tests			
													Unpaired comparisons: two-sided *t*-test, ANOVA multiple comparison of variance A vs. B vs. C			
	Mean	SD	Median	IQR	Mean	SD	Median	IQR	Mean	SD	Median	IQR	A vs. B, *p*-value	A vs. C, *p*-value	B vs. C, *p*-value	A vs. B vs. C, *p*-value
Baseline 1 (group A,* n = *88; group B,* n = *88; group C,* n = *93)																
Hospital care	**60.98**	258.01	0	0	**129.03**	364.29	0	0	**97.01**	309.97	0	0	0.155	0.396	0.526	0.356
Community care	**61.44**	79.02	40	45	**76.47**	78.47	55	73	**63.73**	72.62	40	57	0.207	0.840	0.259	0.375
Total, per patient	**122.42**	285.67	40	55	**205.50**	387.53	65	141.5	**160.74**	336.26	40	87	0.108	0.409	0.409	0.268
Assessment 3 (24 weeks) (group A,* n = *76; group B,* n = *73; group C,* n = *85)																
Hospital care	**385.11**	870.18	0	0	**351.00**	1110.51	0	0	**192.55**	558.83	0	0	0.836	0.102	0.272	0.317
Community care	**96.12**	123.74	62	97.5	**69.56**	80.75	55	69	**81.53**	93.89	60	75	0.122	0.405	0.390	0.277
Total, per patient	**481.22**	923.49	65	234	**420.56**	1116.39	70	127	**274.08**	608.30	65	118	0.719	0.099	0.319	0.318
Assessment 4 (36 weeks) (group A,* n = *80; group B,* n = *72; group C,* n = *85)																
Hospital care	**251.34**	684.31	0	0	**236.83**	656.09	0	0	**127.69**	486.68	0	0	0.894	0.186	0.246	0.368
Community care	**75.73**	91.65	40	69	**54.81**	78.38	40	70	**48.81**	49.63	40	70	0.132	0.022	0.576	0.057
Total, per patient	**327.06**	726.86	52.5	159	**291.64**	664.91	48.5	163.5	**176.51**	502.54	40	82	0.754	0.126	0.230	0.283

IQR, interquartile range.
a Unit costs are shown in *Appendix 20*.

Evaluation

Short-term benefits from the MDT were identified at the end of the intervention period for people with Parkinson's in terms of reduced anxiety, and marginally improved non-motor symptom control and health-related quality of life and reduced disability. Live-in carers in the intervention groups A and B also recorded significant improvements in psychological well-being (SF-36 MCS) at the end of the MDT input. Following the continuing PCA support for group B, people with Parkinson's in group A (no PCA support) worsened significantly for non-motor symptoms and posture, and marginally for health-related quality of life and self-efficacy, while scores on these measures for group B did not change. In addition, carer strain at the end of the 18-week period over which the PCA support was provided tended to be lower in group B than in group A. However, few sustained effects from the interventions were observed.

Inspection of outcomes at the 6-month trial end point revealed no effect in either the patients' or carers' primary outcome measure, or in EQ-5D scores, and so no formal cost-effectiveness analysis was undertaken. The MDT intervention was delivered at a cost of £833 per patient, with an extra £600 per patient for the PCA input (group B). The cost of the MDT was uniform between cohorts, but the PCA costs were more variable. The treatment protocol focused on providing input tailored to individual needs, and some participants had more complex issues than others. In addition, some individuals were hospitalised, or did not complete the PCA component for other reasons, affecting the mean costs of their cohorts. No significant differences were observed between groups in utilisation or costs of other health and social services over the trial period.

The qualitative analysis suggests that patients and carers may benefit from the intervention in less tangible ways, including improved knowledge and understanding of Parkinson's disease, appreciation of the individual care and attention they received, and gratitude for signposting to services. Such effects may not be captured by the trial outcome measures, or in the data on use of other services, but are nonetheless of importance in a comprehensive analysis of the costs and consequences and consideration of value for money.

Conclusion

There are some caveats and limitations to the costing study. As this is a domiciliary intervention, the travel costs are about 40% of the total intervention cost (largely resulting from professional time in transit). The calculation of the travel costs was based on the median distance from the MDT base to the homes of participants in the trial, and assumptions about the speed of travel in the local area. However, differences in the size of catchment areas, and local geography, could affect the travel costs (either way). The service use costs did not include the costs of tests, social services or informal care, owing to missing and incomplete information on the nature of the services received. The unit cost of inpatient care was banded, and the cost of long stays may have been underestimated (although using a pro rata cost would have increased the variability further).

The trial provides evidence of costs and consequences of one particular programme of specialist rehabilitation, and PCA follow-up protocol, on the basis of which commissioners can assess the balance between its resource implications and the improvements in the quality of care that it delivers. Some 40% of participants who answered the question on the value for money of the intervention on the acceptability questionnaire stated that they thought the 6-week specialist rehabilitation would be good value for money for the NHS at £835 (see *Table 28*). However, the limitations of hypothetical questions of this nature are well known, and many participants had problems understanding the purpose of the question and chose not to answer it.

Chapter 5 Feedback from the multidisciplinary team

Introduction

Feedback from the MDT about their experience of team working and delivering the intervention was obtained from various sources. Nine members of the MDT (two PNSs, two PTs, two SLTs, one OT and two PCAs) were interviewed at the end of the intervention phase (December 2011–January 2012). In addition, 14 written reflections were available for analysis (four provided at the end of cohort 2, three at the end of cohort 6 and seven at the end of cohort 8). Eight structured feedback forms were completed at the end of the project, and the content of the open-comment sections was integrated into the qualitative analysis of the MDT feedback. In addition, as part of the project analysis phase, the lead PNS provided written reflection of the development and benefits of interdisciplinary working, illustrated by three patient case studies.

Findings

Analysis of the responses to structured items on the feedback revealed that all eight professionals rated all aspects of team working (communication; use of shared documents and joint care planning including patient/carer involvement; mutual support; delegation of responsibilities; and administrative support from project office) as good or very good (vs. satisfactory or poor).

Verbal and written feedback from various sources were collated and subjected to a thematic analysis.[98] A summary of the findings is given below, organised around the topics used in the exit interview. Quotes are attributable to participants by number, but no further information is given about the participants in order to preserve confidentiality.

The multidisciplinary team

Structure and roles

Both of the PNSs perceived themselves as having a leadership role: one qualified this as relating to the supervision of the PCAs only, and the other (who had the wider remit in the study) recognised herself as having overall team leadership responsibilities. All respondents were positive about the team and all ascribed leadership to the one PNS who was centrally involved in the project and had a role in MDT recruitment. When issues arose with one PCA, the lead PNS arranged for additional training and supervision, and the reallocation of duties. The role of this nurse was seen as ‘co-ordinator of provision’ and as a ‘troubleshooter’ (Participant 8).

The lead nurse appeared comfortable with her role, although she commented that during very busy phases of the trial she had insufficient time to keep up with administrative tasks.

The allied health professionals (i.e. PTs, OTs and SLTs) did not consider themselves to have a leadership role in the team and stated that they all felt equally part of the team:

> *. . . all at the same level and all equally responsible.*
>
> *Participant 8*

All of the MDT members felt well supported, with the team described as 'small, focused, supported' (participant 7).

Despite joining the project as experts in their field, all commented that they had learned a lot during the project:

> *. . . able to collaborate and really understand each other's roles.*
>
> *Participant 5*

The SLT and PT respondents felt that having a fellow professional to work with in the team was a benefit to both them and the team as a whole:

> *. . . perfect with the other physio there.*
>
> *Participant 8*

> *[X] and I thought the same way.*
>
> *Participant 3*

All of the respondents reported that the team was very well served by the project management and administrative assistant, who arranged visits and travel expenses, as required. Back-up of this nature played an important role in the smooth delivery of the intervention, and enabled the health professionals to concentrate on patient care.

Formation and evolution

Only two of the team members (the OT and one of the PTs) had worked together previously. The professionals initially appointed to the project were involved in the development of the intervention, and this helped to secure 'ownership'. The process of agreeing the implementation of the intervention protocol and the details of integrating all members was largely seen as smooth, leading to a perception that the team gelled rapidly:

> *. . . no major hiccups.*
>
> *Participant 1*

Teams need time to operationalise a protocol and to resolve practical issues. The initial cohort (subsequently deemed the pilot) was perceived by team members as a development phase (storming and forming):

> *. . . sorting out practicalities.*
>
> *Participant 2*

> *. . . the MDT was finding its feet and getting to grips with the requirements of patients and the project.*
>
> *Participant 1*

> *Everything seemed to come together in the second cohort . . . the paperwork . . . team working well together.*
>
> *Participant 3*

Initially, team meetings were described as 'a bit stilted' (Participant 5), but at all points in the project, there was an appreciation that the team was multidisciplinary, with all staff being both appreciative and respectful of the roles of others.

Role of team meetings

Team meetings were valued by all respondents in terms of contributing to the high quality of the service given to patients, as well as enhancing their own satisfaction with working in the team, and improving knowledge and understanding of other disciplines.

Patient care was the prime focus of team meetings, enabling clinical judgements to be discussed, plans to be refined and the need for referrals to be agreed.

> *The MDT meetings are an important part of the process. Discussing patients with the team helps highlight issues that may not have come up in my visit and also helps me to know what everyone wants reinforcing.*
>
> *Participant 2*

> *Patient care is discussed in depth at team meetings . . . excellent opportunity to share ideas and expertise and prepare a realistic and relevant care plan.*
>
> *Participant 2*

Meetings were also used to present information on the roles and working practices of team members in relation to Parkinson's disease, and these regular teaching sessions increased the understanding of what each professional could offer, and resulted in an improved holistic approach to care.

> *I feel I have a much deeper understanding of the role of other members of the team, and am more able to give advice and reinforce.*
>
> *Participant 3*

> *As the study progressed, the team became more cohesive and team working became even stronger: 'bonded'.*
>
> *Participant 4*

> *. . . more insight into what each of us is advising.*
>
> *Participant 7*

All respondents were very complimentary about being in the team: 'best team I have ever worked with' (Participant 8).

The intervention (treatment)

Value of home visits

The entire MDT reported that working with patients in their homes was one of the most positive aspects of the study:

> *. . . make it realistic in situ . . . much better than the day hospital . . . travel time is worthwhile.*
>
> *Participant 1*

Two participants mentioned that some homes could be difficult to work in:

> *. . . hectic houses with family in and out.*
>
> *Participant 7*

Balance of professionals

The SLT team members and the PCAs reported some issues about the amount of SLT time available. This appeared to relate to more patients presenting with communication and swallowing difficulties than had been anticipated by the project team, who had been working from incidence figures. A second SLT was subsequently employed. One PT stated that many patients had not previously had access to SLT before and this might have affected the demand.

The SLTs themselves did report that a small number of patients would ideally have had more SLT input, but generally they were satisfied that they could meet patient needs within the trial protocol. They particularly appreciated the emphasis on communication, which contrasts to many NHS settings where attention is given to swallowing difficulty, with communication needs having a secondary priority:

> *. . . focus on communication is great.*
>
> *Participant 4*

Culture change

The lead PNS felt that seeing patients at all stages of the disease highlighted the importance of education and a preventative approach, in order to help people maintain independence for as long as possible. The PTs felt that the trial intervention offered a major advantage to patients, in that they are seen at an earlier stage than would generally be the case in the NHS and this allowed preventative work to occur:

> *. . . getting in early . . . prevention of bad habits.*
>
> *Participant 3*

The contrast with more crisis-driven NHS input was mentioned by four of the team. All participants felt that the NHS should offer such a service:

> *. . . people need it.*
>
> *Participant 5*

Project related

Workload

As the project got under way, the amount of paperwork and the scheduling of work emerged as issues, although the team coped with these and were immensely supportive to each other. Once multiple cohorts were in progress, the teams had no breaks in their work schedule between cohorts and this relentless scheduling with no 'down time' was seen as 'very tiring' by several team members. There were also comments from five of the team on the structure of the working day being too intensive. Four patient visits in a day was perceived as very demanding of staff and there were comments about travel time estimates between visits occasionally being unrealistic, especially in the later cohorts when patients were more geographically dispersed.

Problems of research environment

All members of the MDT had limited prior experience of a research trial and were initially daunted by the idea of working to a trial protocol, thinking that it limited their autonomy:

> *. . . hard to get your head around.*
>
> *Participant 3*

> *. . . very different to follow a protocol in its entirety.*
>
> *Participant 4*

However, it was also recognised that the protocol was flexible and allowed the team to identify and focus on the needs of patients:

> *. . . were able to tailor input.*
>
> *Participant 5*

> *. . . information that is tailored to their issues.*
>
> *Participant 3*

Several members of the MDT expressed some frustration with randomisation in that, on occasions, participants who could clearly benefit from follow-up would not be randomised to that arm of the trial. The MDT understood and accepted the inevitability of this but nevertheless expressed frustration:

> *. . . you wish you could swap the randomisation when you can see someone really needs support.*
>
> *Participant 3*

Two of the team members referred to a very small number of patients who were randomised to follow-up but who were perceived to have fewer needs, or for whom the follow-up was inconvenient. One case cited was a younger patient who was still in the workplace.

Care assistant role

The PCAs were trained using the materials developed by the team[68] and by spending a day with the lead PNS. They then shadowed the other professionals on their visits. While the PCAs felt that they benefited from the training, they commented that they wanted more contact with the team in the early stages, and that they had learnt more from each subsequent cohort of patients.

> *From the start I felt supported by each of the specialists. This enabled me to expand my knowledge base as each individual patient query allowed me to learn more about the condition and the effects on individual patients.*
>
> *Participant 6*

The lead nurse felt that the training could have been enhanced further. She took action to do this by initially visiting participants with the PCAs but, for reasons of time, this was not possible later in the project. As was the case with the professional staff, the PCAs found the team meetings very helpful:

> *. . . team discussion and overview very useful.*
>
> *Participant 6*

The quality of the PCAs was seen as crucial to the success of the intervention. Leaving aside the team member who left in the early stages of the project, the PCAs were regarded by the other team members as providing good quality follow-up for patients within their agreed role:

> *. . . set high standards.*
>
> *Participant 9*

> *Both fantastic, open and ask questions.*
>
> *Participant 3*

The PCAs both commented that their remit was clear and that they had no difficulties in staying within it. They identified their role as mainly reinforcing the advice given by the team and particularly in encouraging patients to complete their exercises, or in some cases to make an attempt at the exercises:

> *. . . getting into a routine of exercises is difficult.*
>
> *Participant 6*

Other members of the team also commented on the value of the PCAs reinforcing their advice:

> *. . . good to be able to tell her to reinforce things.*
>
> *Participant 1*

> *. . . PCAs used the team well.*
>
> *Participant 1*

The PCAs were able to give specific examples of interventions from the OT, PTs and SLTs as being directly helpful to participants.

The PCAs were clear that there was a social element to the visits for some participants, but they did not think that this was the only purpose:

> *. . . not just social.*
>
> *Participant 6*

The PCAs felt that they had a particularly valuable role for participants who did not have a partner at home. Again, they related this specifically to the effect of the participant's ability to manage the exercise programme supplied. This was noted in relation to speech exercises, and was also mentioned by the SLTs:

> *. . . no one to prompt them.*
>
> *Participant 7*

One PCA noted that participants tended to expect more of them as the follow-up visits progressed:

> *Patients have increased expectations and ask more questions as they get to know you.*
>
> *Participant 6*

The PCAs felt that access to the MDT in the follow-up phase was sufficient. Different models of access were evident, with one PCA relying on the MDT lead to liaise with other team members and the other being able to contact team members directly. One MDT member was critical of the first model. The PCAs reported that they felt comfortable going into people's homes; the trial procedures included mechanisms to ensure that staff whereabouts were known and monitored when they were working alone. One of the PCAs felt that telephone calls to follow-up participants were not always satisfactory:

> *. . . a limit to what you can do: if you were worrying it could be hard to visit quickly.*
>
> *Participant 7*

The PCAs reported that participants were largely positive about their visits:

> *. . . they have openly said how much they value my time spent with them.*
>
> *Participant 6*

Potential use of the care package in the NHS

Barriers and facilitators

The integrated team was viewed by members as having worked well. The main barriers perceived were the workload and resources, and the constraints imposed by the research environment.

Facilitators to successful working of the team were identified as strong leadership; involvement of team members in the development of the intervention; regular case review meetings; administrative support from the project office; and the underlying preventative philosophy. In particular, the team meetings not only improved patient care, but also were a vehicle for delivering mutual support, team cohesion, staff development (improved knowledge and understanding), and hence enhancing job satisfaction.

Implications for the NHS

All members of the team felt that the NHS could, and should, offer this type of intervention: one commented that it:

> *. . . sits comfortably with the NHS role.*
>
> *Participant 9*

In terms of benefits to patients, members of the MDT were unanimous in agreeing that, from their perspective, the programme was beneficial to patients. Making a difference to patients was seen as crucial:

> *. . . clinically making a difference.*
>
> *Participant 9*

> *. . . saw benefits in someone who looked hopeless.*
>
> *Participant 7*

Improvements in more general well-being were cited also:

> *. . . well-being . . . didn't realise there were positives.*
>
> *Participant 9*

The only major barrier to this was considered to be funding:

> *If the money was there yes.*
>
> *Participant 1*

All members of the team stated that there was a need to improve care for people with Parkinson's disease, with greater recognition of the need for preventative care:

> *. . . getting in early, putting them on the right path.*
>
> *Participant 3*

They stated that the specific contribution to improving care for people with Parkinson's would be increased access to SLTs, more time with patients and a structured MDT approach. They also felt that the approach was better organised and less crisis driven than much of the NHS input:

> *. . . well organised compared to the NHS.*
>
> *Participant 5*

One of the staff felt that the project offered a model for ongoing intervention for people with Parkinson's:

> *. . . got the blueprint [for the NHS].*
>
> *Participant 9*

Some MDT members identified possible improvements to the intervention: greater inclusion of GPs in the intervention and support; more selectivity with regard to who would benefit from the programme; increased access to ear, nose and throat and neurology follow-up; and the inclusion of a counsellor for patients with long-term conditions.

Reflections of the lead Parkinson's nurse specialist about team development and working

Overview

At the start of the project and commencement of the first cohort of participants, the MDT members were still settling into the project and establishing best working practice methods in order to optimise interdisciplinary working. The cohesiveness of the team grew stronger as the study progressed and there was increased awareness of what each team member was able to offer the participants. Seeing clients at all stages of the disease highlighted the importance of education and preventative work, thus enabling clients to maintain their level of function for as long as possible. The documentation for the intervention became well tried and tested and very familiar with use.

Benefits of integrated team working

Professional development and job satisfaction

The team developed a great deal of respect for each other over time and the regular teaching sessions held at team meetings led to an enhanced interdisciplinary knowledge and understanding, and an improved holistic approach to care. All members of the MDT became more informed about all aspects of managing a client with Parkinson's disease and providing a holistic package of care.

Example: the PNSs gained confidence in giving patients basic advice on physiotherapy techniques, such as balance and posture exercises, and strategies for improving communication, such as breathing and vocal exercises. They also gained greater knowledge of equipment and simple tips to help clients with daily activities (e.g. raising the level of a washing-up bowl in the sink to avoid backache by putting it on top of an upturned bowl, putting a mug in the sink before pouring boiling water from the kettle to avoid lifting a heavy kettle and spilling water over themselves, sitting to shave with elbows on the table to steady the razor). The PTs, OTs and SLTs reported a far greater knowledge and understanding of Parkinson's medication by the end of the intervention period. All members of the team experienced high levels of job satisfaction as they felt that they were able to deliver a very high standard of holistic care supported by a strong back-up team.

Improved standard of care and patient benefit

It proved beneficial for participants that therapists were able to advise them that another member of the MDT would be able to help them with a particular problem.

As time progressed, the MDT found that integrated team working provided an invaluable opportunity to share knowledge of individual clients with other health professionals who were also experts in the field. It enabled clinical judgements to be questioned and discussed.

Example 1: individual therapists felt that a diagnosis of Parkinson's disease was in question for three participants. Each therapist was able to discuss her concerns with other team members at the team meeting. Further visits by therapists to these clients confirmed the findings and these clients were referred back to their GP or consultant for further investigations. It was confirmed at a later date that, in all three cases, the diagnosis of Parkinson's disease was indeed incorrect.

Example 2: it was also found that participants often imparted different information to each member of the MDT. The 6-week intervention period and regular team meetings, therefore, provided an opportunity for a true picture of a participant and their carer to be created. For example, one participant admitted to having an impulse control disorder which took the form of cross-dressing, but this information was not revealed to the team until week 3 when confidence and trust in the team had been established. The cross-dressing itself was not a problem for the participant, but the financial burden it imposed in buying the outfits was great. The problem was discussed by the team and a management plan was put in place. This symptom would almost certainly not have been identified at a routine clinic appointment.

Participant case studies

Three case studies (*Tables 36–38*) were selected to illustrate the methodology of the MDT method of working, the focus on prioritising patients' concerns, and the holistic approach to care that this generated. The case studies provide an indication of the challenging motor and non-motor problems faced by people living with Parkinson's on a daily basis, and the complex issues involved in the management of the condition. The MDT approach enables the full range of symptoms to be addressed by professionals with expertise in their particular fields, cross-disciplinary issues to be discussed, and patient-centred care planning and delivery to be undertaken in a co-ordinated way. The 6-week intervention enables the team to get to know the patient better, and the patient to feel sufficiently comfortable with therapists to be able to 'open up' about their problems and fears. Regular contact between team members provides the opportunity for each to reinforce the messages of the other, which is to the benefit of patients and carers and provides job satisfaction for professionals.

TABLE 36 Patient case study 1 (group A: MDT)

Male; aged 67 years; lives alone, no carer; no current services or support

Hoehn and Yahr stage 3; 13 years since diagnosis

Comorbidity: arthritis in wrists

Medication: pramipexole (Mirapexin®, Boehninges Ingelheim Ltd) 0.7 mg t.d.s.; Mirapexin® 0.18 mg × 2 t.d.s.; cocareldopa (Sinmet®, Merk Sharp & Dohme) 110 mg × 2 t.d.s.; Entacapone 200 mg × 1 t.d.s.

Week	MDT member	Problems identified	Actions taken
One	PNS (assessment)	• Motor fluctuations • Poor medication compliance • Urinary incontinence/UTI • Drooling • Apathy and fatigue • Social isolation • Still driving but DVLA not aware of diagnosis • OPD appointments at local PD clinic have lapsed	• Reviewed medication and explained importance of taking medication at correct time(s) • Advised PwP to take urine sample to GP surgery for analysis • Strategies for management of drooling discussed • Strategies for management of apathy and fatigue discussed • Information supplied on local support groups (PD UK, Age Concern) • Advised PwP of legal requirement to inform DVLA of diagnosis (PD UK information brochure 'Driving and Parkinson's disease' supplied) • New OPD appointment arranged at local PD clinic • Care plan commenced and agreed with PwP
Two	SLT (assessment)	• Mild/moderate dysarthria • Decreased volume and articulation • Increased rate of speech • Poor syllabification	• Advised on strategies to maximise communicative effectiveness and encouraged to practise simple exercises daily in chair including reading aloud for 20 minutes per day • Care plan updated and agreed with PwP

continued

TABLE 36 Patient case study 1 (group A: MDT) (*continued*)

Week	MDT member	Problems identified	Actions taken
Three	PT (assessment)	• Stooped posture (camptocormia) • Difficulty turning in bed	• Posture exercises while sitting, stretching and back exercises when lying down • Taught and practised strategies for turning in bed • Care plan updated and agreed with PwP
Three	Team meeting: all MDT members present	• Poor medication compliance • Communication difficulties • Posture and mobility issues • Driving issues • Urinary problems	• Importance of medication compliance to be reinforced by all MDT members • Encourage continuation of exercises taught by speech therapist (to improve volume and clarity of speech) • Encourage continuation of exercises taught by PT (to improve posture and bed mobility) • Remind PwP to notify DVLA of diagnosis of PD • Ensure PwP has taken urine sample to GP as advised • Review care plan
Four	OT (assessment)	• Handwriting issues • Has difficulty reaching up due to stooped posture	• Handwriting practice • Wooden clothes hanger with finger stall to manage light switches; use step at kitchen sink to reach taps • Care plan updated and agreed with PwP
Five	PNS (follow-up visit)	• Poor medication compliance • Urine sample required for analysis • Speech difficulties • Posture and mobility issues • Handwriting difficulties • Driving issues • Non-motor symptoms assessed	• Confirmed with PwP that medications are mostly now being taken at correct times • No urine sample provided for analysis as yet; encouraged to obtain sample as soon as possible • Encouraged PwP to continue with speech exercises • Encouraged PwP to continue with physiotherapy exercises • Encouraged PwP to continue with handwriting exercises • Reminded PwP of legal requirement to inform DVLA of diagnosis of PD • Strategies for management of drooling discussed and general advice given regarding management of the non-motor symptoms of Parkinson's disease • Care plan reviewed
Six	PT (follow-up visit)	• Poor medication compliance • Urine sample required for analysis • Speech difficulties • Posture and mobility issues • Handwriting difficulties • Driving issues	• Reinforced to PwP importance of correct timings of medication • Confirmed urine sample has now been taken to GP surgery for analysis • Encouraged PwP to continue with speech exercises • Checked bed exercises, sit to stand technique and posture in chair; advice given about not doing too much resistance work on exercise bike but increase time to help with endurance • Encouraged PwP to continue with handwriting exercise(s) • PwP has now informed DVLA of diagnosis of PD • Care plan reviewed
Six	Team meeting: all MDT members present	• Medication compliance issues • Urinary problems • Speech difficulties • Posture and mobility issues • Handwriting problems	• PNS to make referral to community PNS for ongoing support and reinforcement of established speech, physiotherapy and occupational therapy exercise regimes • Future appointment at outpatient department PD clinic confirmed for ongoing review of medication • PNS to make referral to community district nurse/continence nurse team for follow-up of urinary issues • GP informed of MDT input

DVLA, Driver and Vehicle Licensing Agency; OPD, outpatient department; PD, Parkinson's disease; PwP, person with Parkinson's; UTI, urinary tract infection.

TABLE 37 Patient case study 2 (group B: MDT + PCA)

Male; aged 84 years; wife is main carer (aged 82 years and has her own health problems); agency carers attend twice per week to shower PwP, and provide 4 hours respite per week

Hoehn and Yahr stage 4 (complex stage); 19 years since diagnosis

Comorbidities: myocardial infarctions × 2; prostate problems (has indwelling catheter which district nurses attend to every 3 months); hypotension

Medication: Co-beneldopa (Madopar®, Roche) 250 mg q.d.s.; Rotigotine (Neupro®, UCB) 8 mg daily

Week	MDT member	Problems identified	Actions taken
One	PNS (assessment)	• Poor mobility (walks with two sticks short distances only, wheelchair for longer distances) • Drooling • Swallowing difficulties • Postural hypotension • Hallucinations (sees objects on floor) • Carer strain	• Advice given on safe mobility • Strategies for management of drooling discussed (letter to GP requesting prescription for atropine drops or scopolamine patch) • Advice given regarding pureed diet; full assessment of swallowing problems to be carried out by project SLT • Blood pressure checked; advised to increase fluid intake and add extra salt to diet • Advice given on management of hallucinations; explained the importance of comforting PwP during hallucinations rather than denying their existence • Further opportunities for respite to relieve carer strain considered and discussed • Care plan commenced and agreed with PwP and carer
Two	SLT (assessment)	• Hypokinetic dysarthria • Decreased range of movement of articulators and decreased facial expression • Oral-stage dysphagia, difficulty initiating swallow reflex; at risk of aspiration and undernutrition • Drooling	• Advice and instructions given to perform simple exercise programme to maintain range of movement of articulators (lip, tongue and jaw stretches) and encouraged to talk more • Facial exercises given • Encouragement to swallow; verbal prompts for set periods in the day • Letter to GP for prescription of Fortisips (three per day); wife does not need further help from dietician as she is already very knowledgeable about how to fortify PwP's food • Continue with thickener in all fluids • Soft/moist, puree and thickened drinks leaflets provided • Educated regarding the nature of swallowing disorders and their links with chest infections • Awaiting prescription for treatment to ease drooling, as organised by PNS • Care plan updated and agreed with PwP and carer
Three	PT (assessment)	• Balance problems and falls • Posture	• Tends to cross sticks when walking (unsafe); encouraged to focus on delta frame (already supplied); strengthening exercises taught and practised (to maintain strength in all lower limb muscles) • Postural exercises taught and practised • Care plan updated and agreed with PwP and carer
Three	Team meeting: all MDT members present	• Mobility issues • Drooling • Swallowing difficulties • Dysarthria • Postural hypotension • Carer strain	• All team members to encourage PwP to walk with delta frame rather than two walking sticks (unsafe) and to remind PwP to perform leg-strengthening exercises and postural exercises as taught by PT • All team members to monitor treatment programme for drooling as prescribed by GP • All team members to ensure that verbal prompting for swallowing is still practised

continued

TABLE 37 Patient case study 2 (group B: MDT + PCA) (*continued*)

Week	MDT member	Problems identified	Actions taken
			• Check Fortisips have been received and fluids are still being thickened • Encourage PwP to continue with facial exercises to improve articulation • Encourage to maintain fluid intake and apply extra salt to meals to maintain blood pressure • Review level of carer strain and consider possible respite options (respite at hospice considered; PNS to discuss with PwP and wife at follow-up visit) • Review care plan
Four	OT (assessment)	• Difficulty mobilising around bungalow • Difficulty shaving	• Encouraged to use delta frame for mobilisation • Use electric shaver and sit in chair • Known to social services • Requires respite three times per year • Care plan updated and agreed with PwP and carer
Five	PNS (follow-up visit)	• Drooling • Swallowing difficulties • Speech difficulties • Posture and mobility issues • Carer strain • Discussion of non-motor symptoms and general information for PD	• GP has prescribed scopolamine patches; checked proper application of patches • GP has prescribed Fortisips as requested • PwP encouraged to continue with facial exercise programme • Ensured PwP continues to use delta frame rather than two walking sticks • PwP continues with leg-strengthening exercises and postural exercises when he feels able • Discussed with wife and PwP the prospect of respite care at local hospice; request sent to GP to refer to hospice • Care plan reviewed
Six	PT (follow-up visit)	• Balance problems and falls • Posture • Drooling • Swallowing difficulties • Speech difficulties • Carer strain	• Checked use of delta frame; wife reported that he has been practising walking outside with delta frame and has been doing leg-strengthening exercises in the kitchen as instructed • Posture exercises have been regularly practised; good technique confirmed • Drooling has improved slightly with scopolamine patches • Fortisips now taken three times daily as instructed by SLT • Encouraged to continue with facial exercise programme • Awaiting confirmation for respite from hospice • Care plan reviewed
Six	Team meeting: all MDT members present, including PCA	• Mobility, balance and postural issues • Drooling • Swallow difficulties • Speech difficulties • Carer strain	• Over ensuing 4 months PCA will ensure that PwP continues to use delta frame for safe mobility • Over ensuing 4 months PCA will encourage PwP to continue with leg-strengthening and postural exercises and report back to PT • Over ensuing 4 months PCA will monitor the level of drooling following initiation of scopolamine patch and will report any untoward side effects to the PNS • Over ensuing 4 months PCA will continue to encourage verbal prompting of swallow reflex and encourage continuation of Fortisip drinks reporting back to the SLT • Over ensuing 4 months PCA will encourage PwP to continue with facial exercise programme reporting back to the SLT • PCA will ensure that the hospice contacts PwP and his wife regarding the possibility of respite care (confirmed 4 weeks after handover)

PD, Parkinson's disease; PwP, person with Parkinson's.

TABLE 38 Patient case study 3 (group A: MDT)

Male; aged 68 years; wife is carer; no current services or support

Hoehn and Yahr stage 3; 10 years since diagnosis

Comorbidity: hypertension

Medication: Ropinirole 24 mg extended release; Madopar® 125 mg q.d.s.; Madopar® 62.5 mg q.d.s.

Week	MDT member	Problems identified	Actions taken
One	PNS (assessment)	• Motor fluctuations with unpredictable 'off' periods • Freezing episodes • End of dose wearing off • Recent bereavements have caused low mood, self-imposed social isolation and relationship problems with wife • Constipation • Urinary problems (prone to urgency and frequency) • Fatigue • Sleep problems	• Timings of medications reviewed and discussed; general review of medications needed by specialist consultant (outpatient appointment arranged) • Strategies for management of freezing discussed • Timings of medication reviewed to reduce wearing off • Discussed support groups available to help with low mood; contact details given for PD UK; discussed possibility of antidepressant therapy at PD specialist clinic • Management of constipation discussed (increase fluid intake in particular) • Patient education regarding possible causes of urinary urgency and frequency; consider possibility of urinary tract infection • Strategies for management of fatigue discussed (PwP needs to 'pace himself') and information booklet supplied • Discussed ways to improve sleep pattern and information sheet supplied • Care plan commenced and agreed with PwP and carer
Two	SLT (assessment)	• Decreased volume of speech and monotone • Decreased facial expression	• Taught daily breathing and speech exercises • Control over breathing explained • Functional phrases for volumes practiced • Facial expression exercises practised • Care plan updated and agreed with PwP and carer
Three	PT (assessment)	• Freezing leading to frequent falls • Small-stepped shuffling gait • Difficulty turning in bed • No longer socialising or going on holiday due to low mood	• Advice regarding freezing strategies and information sheet supplied • Gait re-education (increase step length and slow down) • Balance exercises taught • Physiotherapy tips sheet provided • Discussed mood lifting strategies; need to have a daily walk explained • Care plan updated and agreed with PwP and carer

continued

TABLE 38 Patient case study 3 (group A: MDT) (*continued*)

Week	MDT member	Problems identified	Actions taken
Three	Team meeting: all MDT members present	• Motor fluctuations with unpredictable 'off' periods • Freezing episodes • Small-stepped shuffling gait • Decreased volume of speech • Decreased facial expression • Bereavement issues leading to low mood	All MDT members to: • Check timings of medications as discussed with PNS • Remind PwP to attend PD specialist clinic appointment for review of medications • Remind PwP of strategies to overcome freezing • Reinforce importance of pacing out and reducing speed • Encourage PwP to continue with speech and facial expression exercises • Discuss bereavement issues with PwP and his wife and make aware of local support groups (e.g. Cruise, PD UK) • Encourage PwP to go for a walk each day to help lift mood • Review care plan with PwP and carer
Four	OT (assessment)	• Dressing issues; difficulty putting socks on • Eating issues; difficulty cutting food • Difficulty extracting bank cards from wallet	• Try using sock aid; pegs on string to assist with clothing while toileting • Use steak knife for cutting food • Use handybar® (NRS Healthcare, Coalville, UK) to assist with getting out of car • Ribbon round credit card to assist with removing bank cards from wallet • Care plan updated and agreed with PwP and carer
Five	PNS (follow-up visit)	• Motor fluctuations, unpredictable 'off' periods • Freezing episodes and gait issues • Decreased volume of speech • Decreased facial expression • Eating/dressing issues • Low mood • Constipation • Urinary problems (frequency and urgency) • Sleep issues and fatigue	• Non-motor symptoms assessed and general information regarding PD discussed • Reminded PwP of forthcoming PD specialist clinic appointment and further discussions on timing of medication • Practised strategies for overcoming freezing and gait practice • Encouraged PwP to continue with speech exercises • Encouraged PwP to continue with facial exercises • Confirmed use of sock aid and steak knife to assist with dressing and eating • Discussed issues surrounding psychological well-being • Assessed constipation and reminded of need to increase fluid intake; urinary issues remain the same; advised to contact GP if symptoms deteriorate • Reassessed and discussed concerns over sleep pattern and fatigue • Care plan reviewed
Six	SLT (follow-up visit)	• Low volume of speech • Decreased facial expression	• PwP reported trying to speak up, and friends have noticed an improvement • Practised speech exercises • Practised facial expression exercises • Discussed 'freezing' in speech; try yawning to alleviate • Care plan reviewed

TABLE 38 Patient case study 3 (group A: MDT) (*continued*)

Week	MDT member	Problems identified	Actions taken
Six	PT (follow-up visit)	• Freezing episodes and gait issues (had a fall in previous week caused by freezing) • Decreased volume of speech and limited facial expression • Low mood • Constipation	• Further discussions of freezing strategies and gait re-education • Encouraged continuation of speech and facial exercises • PwP has been going out for a walk each day and is finding this has lifted his mood a little; antidepressant treatment to be discussed at forthcoming PD clinic • Ensured PwP continues to maintain a good fluid intake • Care plan reviewed
Six	Team meeting: all MDT members present	• Motor fluctuations • Speech problems • Mobility issues • Constipation and urinary problems • Psychological issues	• PNS to write referral letter to local PNS for ongoing support and reinforcement of exercises initiated by speech therapist and PT • Future appointment at local PD outpatient clinic confirmed • Letter to GP

PD, Parkinson's disease; PwP, person with Parkinson's.

Chapter 6 Discussion

Overview of findings

The findings show that people with Parkinson's receiving a 6-week MDT intervention in their own homes experienced an immediate reduction in anxiety, and their carers recorded improved psychological well-being (on the MCS of SF-36). Additionally, people with Parkinson's in the MDT groups had marginally reduced disability and improved non-motor symptoms and health-related quality of life (on the EQ-5D Index). In contrast, depression increased and psychological well-being deteriorated among people with Parkinson's in the control group.

The comparisons of groups A and B (both of who received the MDT input) at the end of the subsequent 4-month period of PCA support for group B revealed some benefits for people with Parkinson's in group B, compared with group A (no PCA). There were significant differences in change scores between week 6 (end of MDT) and week 24 (end of PCA for group B) in favour of group B in non-motor symptoms and posture and marginally in health-related quality of life (measured by EQ-5D Index) and self-efficacy. In each measure, this was due to a significant worsening in group A, suggesting that the PCA input may have helped to maintain benefits derived from the MDT in group B. There was also a tendency for carer strain to be lower in group B than in group A at the 24-week assessment point, which was reinforced by qualitative evidence that showed that carers valued the PCA support.

At the final study end point (36 weeks post recruitment and 3 months after the end of PCA support for group B), there were few differences between the groups. There were significant differences between changes in people with Parkinson's in group B (received MDT + PCA) and in groups A (MDT only) and C (control) in the SF-36 MCS and in Speech Self Report due to significant deteriorations in these measures in groups A and C. The SF-36 MCS of carers in group A also declined, compared with group B. Gait (UPDRS item) of people with Parkinson's in group B improved marginally, compared with group A, while mobility (Timed Up and Go[87,88]) in group A improved marginally, compared with control group C. For carers, significant differences in changes between groups were observed in SF-36 PCS due to non-significant trends for improvement in group A and worsening in groups B and C.

The trial involved a large range of outcome measures at four different assessment points and complex patterns were observed. There was an overall general trend to worsening in the condition of people with Parkinson's in many of the main outcomes over the 6-month period of follow-up, including Parkinson's-specific disability, quality of life and non-motor symptoms; ability to perform activities of daily living and participate in social activities; generic health-related quality of life; depression; self-efficacy; and self-assessed speech and voice. The trial included live-in carers, both as subjects for the research and as partners in the intervention. Generally, the carers scored high on functional indicators, but a slight deterioration in general health, and increase in depression, was observed over the 6-month period.

Overall, the 6-week MDT intervention cost £833 per patient, with an extra £600 per patient for the continuing 4-month PCA support (GBP 2011). The cost of travel to participants' homes (staff time and car running expenses) accounted for about 40% of this. Data on other service use by participants revealed large variations but no significant differences between groups in total per-participant costs at any time point. In the absence of evidence of sustained impact on the patient and carer primary outcomes, or on EQ-5D Index scores, no formal cost-effectiveness analysis was undertaken. However, feedback on the acceptability of the interventions from patients and carers suggests that they benefit in less tangible ways. In particular, they report improved understanding of Parkinson's disease, awareness of available support services and confidence in self-management. Analysis of the MDT and PCA treatment notes for individual participants reveals many ways in which the intervention resulted in improved care. Among 176 people with Parkinson's,

the PNS made 51 changes to medications, the OT made multiple recommendations for new aids and equipment and the team made 23 referrals to other professionals. Moreover, five people who had previously received a diagnosis of Parkinson's disease were found not to have that condition.

Discussion of findings

There are several possible reasons why the MDT intervention showed little sustained effect. In line with the commissioning brief, the trial recruited patients at all disease stages, and there is less scope to show improvement in people with few limitations. Around 25% of people with Parkinson's had minimal disability (Hoehn and Yahr[65] stages 1 and 2) at baseline. Similarly, high proportions of the live-in carers in the study had few functional limitations. There is much heterogeneity as to how the disease affects people with Parkinson's and trajectories of decline are known to vary.[102] For some, disease progression is slow, reducing the chances of detecting a reduction in deterioration over a 6-month follow-up period.

In addition, many of the patients recruited to the study were already relatively well managed. Over 80% reported that they had a PNS and 60% of these had seen the nurse within the previous 6 months. Consistent with other evidence,[103] prior access to other professionals was less good; of those who had been diagnosed for more than 2 years, 20% reported that they had never seen a PT, and 60% stated that they had never seen an OT or a SLT.

Another consideration is that the PCA 'dose' may not have been sufficient to generate a treatment effect on people with Parkinson's. Over an 18-week period, participants received a mean of 7 hours, 12 contacts (five by telephone, seven home visits). Feedback from the PCAs was that they felt that the telephone calls were not very useful as patients often said that they were 'fine' when in fact they had fallen or been unwell.

Therapy outcomes rely on the practice of rehabilitative exercises.[104] No measure of compliance was included in the study, so we do not know if those who engaged fully with the study gained more. Anecdotally, PCAs reported that they observed very different levels of motivation among participants. Patients dealing with other health issues alongside Parkinson's, or with pain, found it more difficult to practise exercises. Those with cognitive impairments struggled to remember the movements and follow written instructions. Some were hampered by a general lethargy that made them procrastinate, and left them unable to perform even essential tasks unless prompted by others. This often led to relationship difficulties. Loving carers became frustrated in their attempts to help the person with Parkinson's, and needed support and reassurance from the PCA. The need for emotional support for carers, as well as for patients, was a common theme reported by PCAs as cohorts progressed, and may underlie the marginally significant beneficial effects on carer strain observed to arise from the PCA component of the intervention.

In general, patients were more motivated to practise movement exercises than speech or writing, which they found boring, or embarrassing as a result of the odd noises involved in speech exercises. Hence other ways of encouraging practice had to be found, such as writing shopping lists or reading aloud to carers. While the OTs' suggestions of simple aids (such as kitchen gadgets) or adaptations (such as grab rails) made a big difference to the quality of life of some participants, others were resistant to change. Some patients and carers were unwilling to reduce the risk of falls by reorganising furniture or moving rugs and low tables.

Drug compliance was another problem for some patients, impairing their ability to practise exercises. This particularly affected people who lived alone, but sometimes even live-in carers (despite timed drug boxes) did not appreciate the importance of timing and the impact of missed doses. PCAs also recognised that for some participants, especially those who lived alone, the visits fulfilled a social function, and it was sometimes difficult to focus on the therapeutic aspects.

Benefits identified from patient feedback (such as improved knowledge and confidence, learning where to go for help, and feeling that someone is taking an interest) were not directly measured, and were not

picked up in the self-efficacy outcome instrument that was used in the trial. Consideration should be given as to how to capture such effects in future trials. Evaluative research exploring the impact of community interventions targeting older and frail people face methodological challenges, and new approaches to capturing patient and carer outcomes are required.[105]

Comparison with other studies

There is little prior evidence on the impact of multidisciplinary rehabilitation for Parkinson's disease.[14] In demonstrating some short-term benefits, and very limited effects at 6-month follow-up, the SPIRiTT findings correspond to those of the other available studies,[21,23,27] and with evidence on the effectiveness of (single-discipline) physiotherapy for Parkinson's disease.[106–109] A study set in a specialist Parkinson's centre found that 70% of patients undergoing multidisciplinary treatment improved over 12 months, but the nature of the intervention (which involved neurology, psychiatry, psychology, functional diagnostic testing, medication review, home exercise and support) is not directly comparable with a domiciliary rehabilitation service.[19]

Conclusive evidence is still needed to confirm the effectiveness of occupational therapy[110,111] and speech and language therapy[112–114] for Parkinson's disease, although their value in clinical practice is recognised through their inclusion in treatment guidelines.[12] Equally, PNSs play a central role in providing local specialist services, and are highly valued by patients and carers,[115] although evaluations have not shown conclusive improvements in patient outcomes.[31,32] The advantages of a cross-disciplinary collaborative approach to rehabilitation involving all these professions are widely accepted,[3,10–13] but clear evidence of effectiveness is elusive.

Evidence from evaluations of general geriatric assessments and support in the community show inconsistent effects on outcomes and costs,[46,51,52] dependent on the nature and scope of the intervention and methodology of the study. A systematic review of co-ordinated and integrated interventions to frail elderly people found only nine RCTs, seven of which reported at least one favourable outcome for patients. Only two studies included carers, and neither found an effect on carer burden. The reviewers report a reliance on measures with poor psychometric properties, and a need for more robust evidence.[116]

Comparison with day-hospital rehabilitation

One objective of SPIRiTT was to compare the results of domiciliary delivery of the specialist rehabilitation intervention with those obtained from a previous trial conducted by the research team that was set in a day hospital. People with Parkinson's (with carers) attended in groups of six on 1 day per week for 6 weeks. They received individual treatments from the PNS, PT, OT and SLT, and group education and relaxation.[26] The day-hospital protocol formed the basis for the design of the SPIRiTT intervention.

SPIRiTT succeeded in delivering a comparable intervention to that provided in the day-hospital trial, comprising around 9 hours of patient-centred multidisciplinary rehabilitative care for each person with Parkinson's.[26] In showing some short-term patient benefit, it also confirmed the findings of the day-hospital study, which was an uncontrolled (pre–post) design.[21] A marginal impact on mobility (measured by Timed Up and Go[87,88]) was also the only longer-term benefit in both studies.[23] SPIRiTT additionally tested if continuing benefit from a PCA could help to sustain immediate improvements from treatment. Some evidence was found that the PCA component, while it was being provided, generated some benefits for people with Parkinson's [non-motor symptom control, posture and (marginally) quality of life and self-efficacy] and carers (tendency towards reduced strain).

Domiciliary rehabilitation was tested in SPIRiTT because the day-hospital trial had incurred facilities overhead costs, and transport difficulties for those patients without independent means of reaching the treatment setting.[27] In SPIRiTT, expenses associated with professionals travelling to patients' homes (which accounted for some 40% of the costs) are substituted for the expense of patient transport, but the use of NHS premises for treatment is avoided. Much of the cost of professional travel is associated with the time it takes, and, thus, depends on the catchment area of the team and local geography. In this respect, the travel costs in SPIRiTT may not be widely generalisable.

The pros and cons of domiciliary rehabilitation were identified in feedback from patients and carers, and from members of the MDT. Home visits enable professionals to assess safety issues and gain an understanding of the context of patients' daily lives, and recommend accordingly. On the other hand, group activities cannot be provided, and any benefits from group interaction are lost. In particular, some carers value the opportunity to get out of the home and exchange experiences with other carers, and also to have individual time with professionals. The feelings of patients about group interventions are more mixed and some do not want to encounter people with more advanced disease.

A recent trial that directly compared rehabilitation of older people in a day hospital and at home produced equivocal results and concluded that the costs were the same.[117] These findings were based on a limited clinical sample, and the authors recognised the need for condition-specific evaluations. The evidence now available from Parkinson's disease confirms the more general findings, that both types of provision confer benefits and that relative costs will vary by location.

Strengths and limitations of the study

Although the trial involved a complex design with a difficult patient group, the study ran to time, achieved the required patient sample size and delivered the intervention without any delays. This was facilitated by assembling a large pool of interested patients prior to the launch of the intervention, so that several cohorts could be treated consecutively, during which period the remaining patients were recruited. The trial experienced a low rate of drop-out through good liaison with participants by the research office, and the incentive for those in the control group of a full assessment from a member of the MDT if they completed all of the research assessments. It was a pragmatic study that aimed to reflect realistic service delivery and provide messages that would be useful in practice. The primary outcome measures (Parkinson's disability and carer strain) were chosen to be of importance to people with Parkinson's and carers in their everyday lives, and were successful at picking up marginal effects at the end of the MDT intervention and PCA support, respectively. The intervention was delivered safely, with no observed increases in fall rates, or unexpected serious adverse events.

The study has several limitations. Recruitment, which took place largely through GPs (via the PCRN) or local PNS or hospital outpatient clinic lists, did not reach ethnic minorities in the area. This might be because GPs serving ethnic groups were not involved in the mailing of invitations to their patients, or because people from these communities are less inclined to volunteer for research. Parkinson's disease is more common in men,[118] and this was reflected in the study recruitment, which was 60% male. Although the study reached the planned sample size of 270 people with Parkinson's, carers were under-recruited. Based on the previous day-hospital study,[21,23] sample size calculations assumed that 79% of patients would have live-in carers and that they would take part in the research. While this proportion was largely accurate (77% of the SPIRiTT sample had live-in carers), carers in this study displayed a greater reluctance to be involved in the research than the carers of the patients in the day-hospital study. There are several possible reasons for this. Many did not see themselves in a caring role, particularly if their partner was relatively independent and not requiring assistance. Some carers were out at work, others were frail themselves and not capable of filling in the forms, and others were just not interested.

The randomisation process resulted in uneven groups at baseline, with group B (which received the MDT + PCA intervention) containing people with higher levels of disability, who had received more physiotherapy recently and who had lower BMIs than the participants in the other groups. This imbalance was adjusted for in the analysis through change scores, but the group suffered higher attrition. Although an ITT analysis was planned, some people had dropped out prior to treatment and others missed later assessments due to illness, death, withdrawal or loss to follow-up. Such attrition is expected in a trial involving this patient group, but it led to a decision to prioritise a PPA over the ITT approach.

All research data were collected through research nurse visits to participants' homes. Although the instrument battery had been discussed and piloted within the PPI group, in practice it proved quite onerous for participants to complete. To minimise the length of the research nurse visit, items suitable for self-completion were mailed in advance. Some participants struggled with the assessments, depending on cognitive abilities, and required help from the research nurse. In these circumstances, answers were taken directly from the participant, and never 'led'.

Questionnaires were checked for completeness before the end of the visit and on return to the research office, and this resulted in minimal missing data. Instruments were excluded if there were more than two missing items and remaining items were filled using established procedures for the relevant instrument (when available). Alternatively, missing values were set to zero (or normal), i.e. the most favourable value. This occurred in a very small number of instances (0.40% for people with Parkinson's, 0.06% for live-in carers; see *Appendix 18*), and we do not believe that this affected the results in any way. There were a few circumstances where the research nurses could not conduct the Timed Up and Go,[87,88] and participants experienced difficulties with the pain VAS, meaning that the sample sizes for those instruments were reduced.

As the trial progressed, the load of research assessments was too great for one nurse, and two assistants were employed. Owing to problems recruiting on a temporary and part-time basis, the two assistant research nurses were employed from within the project team (a PNS and a PCA). Most instruments were self-reported by participants, but to ensure inter-rater reliability in items requiring judgement (gait, posture and some speech scales), the nurses were trained and observed in early visits. However, we cannot rule out the possibility that differences in judgement affected results. In particular, several significant differences were found in nurse-rated scales involving the 24-week assessment, which was largely (58%) conducted by one of the supplementary assessors (see *Table 4*).

All reasonable precautions were taken to keep all of the research nurses blinded to the group allocation of the people they were assessing. The PNS was assigned to baseline assessments (before group assignment is determined) and the PCA did not assess people she was treating. To avoid unblinding, research nurses had no access to study databases and did not answer the telephone in the research office, as patients often called in to alter MDT appointments. Participants were constantly reminded not to give away their group allocation, but they frequently did mention, during the second assessment (immediately after the MDT intervention), that they had seen a member of the team. Many were confused by the study processes and did not understand the importance of the distinction between the treatment team and the research assessors. Unblinding occurred anyway at the end of the third assessment when the research nurses collected the feedback questionnaires from participants who had received treatment, enabling them to distinguish control participants but not the allocation of others between groups A and B. The main research nurse carried out over 750 assessments and was visiting people in several cohorts at any point in time, and reported that, generally, she was not able to recall group allocations, if they had been disclosed to her.

It had been planned to collect feedback from the patients and carers about the acceptability of the intervention at the third (24-week) assessment point, after both the MDT and the PCA components were completed. However, it became apparent that participants suffered recall problems about the MDT intervention, which had ended 4 months earlier. Hence, from the fourth cohort onwards, acceptability questionnaires were additionally mailed to participants after the second assessment (at 6 weeks).

Feedback was still collected at 24 weeks to elicit views about continuing benefit from the MDT, and specifically about the PCA component (group B only).

Study instruments

The trial contained a large number of outcome measures, and experience with using these may be of relevance to the NHS outcomes framework.[119] Trends across the assessments were not consistent, making interpretation difficult. Most instruments selected for the study are widely used and validated for older people, and for people with Parkinson's in particular (including Parkinson's Disability,[69,70] Barthel ADL[76] and Frenchay Activities Index[77–79]). The disease-specific (Parkinson's Disease Questionnaire-8,[72,73] Non-Motor Symptom Questionnaire[74,75]) and generic (EQ-5D,[80,81] SF-36[82]) health-related quality-of-life instruments that were included are recommended for use in Parkinson's disease.[120]

Problems were encountered in the administration of some instruments, which may render the results they provided less reliable and reduce their utility. Many participants were unable to grasp the concept of rating using VASs, and did not have the fine motor skills required to complete them accurately. This resulted in non-response for the pain VAS measure, the validity of which has, in any case, been questioned for use in Parkinson's disease.[90] In line with other studies,[93] the measures collected confirmed that patients rate pain worse during 'off' periods, because dopamine drugs alleviate discomfort. However, Parkinson's patients' experiences of pain are complex,[93] and the large fluctuations reported by patients from one assessment to the next rendered this measure difficult to analyse. Similar problems were experienced with the data generated by the EQ-5D Thermometer,[80,81] which varied markedly for some patients over time. Difficulties with using this measure with older people has also been recorded by other researchers.[121]

Some participants who were frequent fallers had trouble remembering the number of falls they had, and the data available for analysis were severely skewed (a small number of participants reported over 100 falls), so this outcome was explored in binary form only (i.e. whether or not a participant said they had fallen in the assessment period). In addition, further data on falls were accumulated from a variety of different sources for the adverse events log, and this information correlated poorly with participants self-report during assessments. The adverse events log, which was analysed for safety reasons and reported to the external advisory group on an ongoing basis, showed no significant differences between treatment groups in number of falls at any point in the trial.

The single-item nurse-rated gait, posture and speech scales are well validated,[89,96,97] but have only four or five points on the scales and are thus relatively blunt instruments, most often used in clinical situations rather than for research purposes. Speech assessments were conducted at the visit and relied on judgement. Although nurses followed closely the official guidance for raters, recording voice or conversation for later independent assessment would have been more reliable and avoided any concerns about inter-rater reliability. Though unvalidated, the speech self-report measure used in the study proved sensitive. In contrast to many instruments which focus on breathing and articulation, this measure asks respondents to report the frequency of speech and conversational problems and is thus relevant to everyday functional communication. It is routinely used in clinical practice by therapists involved in the study, and deserves to be tested further for its psychometric properties.

Research nurses reported difficulties arising from 'on/off' fluctuations experienced by people with Parkinson's affecting performance on some outcome measures, such as the Timed Up and Go,[87,88] and nurse-assessed posture, gait and speech items. In a small number of cases when the participant was experiencing a serious 'off' phase, these measures were not conducted. No record was taken of whether a participant was 'on' or 'off' at the time of assessments, and this could have varied between data collection visits and may account for large individual fluctuations in some measures observed during the analysis. Although notes were made about the chair used for the Timed Up and Go assessment (with or without arms, and height of seat), it was not always possible to ensure consistency in the home setting, and this is

another reason why the marginally significant findings on this measure at the final 36-week follow-up point should be interpreted with caution. At around 18 seconds, the mean (and SD) values for Timed Up and Go recorded in SPIRiTT were higher than those recorded in more controlled environments (13.7 for 'on', 17.2 for 'off'[87]), but lower than those in the day-hospital study.[23]

The Yale Depression Screen[84,85] was administered in the study to assess its effectiveness for use with people with Parkinson's. Although the proportions screening positive fluctuated a lot, the instrument correlated closely at baseline, for both people with Parkinson's and carers, with both the HADS depression subscale[83] and the SF-36 MCS[82] ($p < 0.0005$ in all comparisons).

Although psychometrically sound, and probing (among other things) levels of confidence in self-management, the six-item Self-Efficacy Scale used in the study[86] did not pick up the improved confidence that, in feedback, patients and carers reported feeling that they had gained from the interventions. This may be because the instrument used was designed for chronic conditions in general and was not sufficiently tailored to the particular problems of people with Parkinson's. Other research has suggested that self-efficacy in Parkinson's disease is mediated by family support.[122] Of importance is the need to focus on outcomes that matter to patients rather than clinicians,[123] and most instruments in the study were selected with that in mind. However, the diversity of symptoms, and variability in the way that these affect people with Parkinson's, makes measurement of outcomes challenging.[124]

Multidisciplinary team intervention

Increasing numbers of people are living longer, often with multiple long-term conditions. It is recognised that no single discipline or professional can provide complete care for this group,[29,30] and emphasis is being placed on interprofessional working.[125] In the context of long-term neurological conditions, the role of nurse specialists is seen as pivotal to provide support and continuity of care across disciplinary boundaries and longitudinally.[126] Debate exists around the definition of the term 'interprofessional working', which is closely linked to the concept of 'co-ordinated care'.[127] Different models of interprofessional working have been identified: integrated teams, case management and collaborative networks.[128] The interprofessional working within SPIRiTT fits the definition of an integrated team. A range of external factors facilitate or inhibit team formation, and influence team structure, working processes and evolution. Important among these are management and financial arrangements, the historical organisation of service delivery, local geography and power relations.[125,129,130] Team effectiveness is enhanced by diversity of expertise, alignment of professional goals, good communication, strong leadership and access to a broad network of other organisations.[129,131]

The SPIRiTT team was formed for the purposes of the research, and worked parallel to existing community services. Through its emphasis on prevention, and providing more time for professionals to get to know individual patients, the SPIRiTT intervention differed from usual care within the NHS, which has increasingly become crisis driven.[53] This holistic approach to care, and the strength of the interprofessional working relationships, contributed to reported high levels of job satisfaction.

The MDT professionals identified that a key factor in the success of the intervention was that they were closely involved in its design and development, both prior to starting treatment and through the process of reappraisal after the first cohort, in which unanticipated practical issues were addressed and more effective processes were put in place. Consolidated by strong leadership, the team bonded over time. Good communication, regular team meetings and mutual respect between all team members, including the PCAs, ensured that patients received a co-ordinated package of care. Individual professionals taught and learnt from the other disciplines, and, by gaining a better understanding about what others do, they were each able to advise and reinforce the messages to patients. The team could concentrate on patient care and function efficiently because of strong managerial and administrative back-up in the project office.

The use of trained assistants to provide therapy and monitor patients is consistent with NHS workforce policy that seeks to develop roles for non-registered support workers.[60,61] This approach offers a potentially flexible and low-cost means of providing ongoing care for patients. Support workers are widely used within different models of care throughout the NHS,[132] and have been shown effective in team-working in community settings.[133,134] The quality of care assistants is crucial for safety and efficacy reasons,[57] and so training and supervision are of paramount importance.[58] The PCAs in SPIRiTT were trained using materials developed for the purpose by the research team,[68] and through shadowing professionals from each discipline within the MDT. They were monitored by the lead PNS, but liaised, as needed, with other professionals regarding patient care. They were fully embedded in the MDT, attending meetings and contributing to discussions around care planning. Despite concerns about demarcations when skills are mixed, no such issues were encountered. The PCAs reported working within their competencies, feeling fully supported by professional members of the MDT, and gaining knowledge and confidence as the intervention progressed.

Chapter 7 Conclusions

In 2006, the NICE guidelines for Parkinson's disease recommended early referral and regular access to a broad range of medical and allied health professionals, but gave no recommendations as to how to organise the multidisciplinary care.[12] The All Party Parliamentary Group inquiry on Parkinson's Disease (APPGPD) was carried out in 2009 amid growing concerns about variations in access to the comprehensive services and expert multidisciplinary care needed by people with this complex condition.[33] The inquiry found evidence of significant inequalities in service access across the whole of England, Wales and Northern Ireland to all aspects of care. It concluded that the value of therapy and social care services in the management of Parkinson's disease is not being recognised by many health and social care professionals, resulting in early decline in an individual's condition and adverse impact on the carer's health.

A clear picture of the key components of high-quality services for people with Parkinson's disease and their carers was provided to the APPGPD inquiry through evidence from professionals working in health and social services and those directly affected by the condition. The report highlighted the importance of integrated MDTs delivering care to people with Parkinson's and carers; provision of information about all aspects of living with the condition and the range of services and sources of support available; and guidance on how to access these services.[33]

The SPIRiTT intervention incorporates key aspects of interdisciplinary team working (shared goal setting and care planning, effective communication channels and appropriate referrals to other specialities) and a client-centred approach that invited participants to prioritise their concerns. It also addressed the needs of carers who have a crucial role to play in assisting clients in their daily activities. Feedback from participants suggested that it was effective at increasing their understanding of the condition and providing signposting to other services. Results from the RCT show that people with Parkinson's experienced reduced anxiety, a tendency for improved symptom control and health-related quality of life, and reduced disability after the MDT intervention. There is also evidence that ongoing PCA input helped to maintain some of the benefits, while it continued. Similarly, carers recorded improved psychological well-being and a trend towards reduced strain from the MDT and PCA contributions, respectively. Support for carers is a high policy priority[135] because it improves their ability to cope with complex situations and protects their health, and hence has the potential to avert a breakdown in care and the need to introduce expensive external assistance. The overall SPIRiTT intervention represented an improvement in quality of care at a cost (2011 GBP) of around £1433 per participant (£833 for the 6-week MDT specialist rehabilitation; £600 for 4 months of PCA support).

The National Service Framework for long-term conditions was introduced in 2005 to improve services for people with neurological conditions,[30] and, since then, spending in this area has increased. However, a recent report by the National Audit Office (which focused on Parkinson's disease, multiple sclerosis and motor neurone disease) has reported poor implementation and worsening in key indicators of quality of care.[136] Particular problems identified were variable quality of the diagnosis process, fragmented and poorly co-ordinated ongoing care and poor information and advice to patients. With changes in the structure of decision-making in the NHS, local clinical commissioning groups will be responsible for purchasing services.[137] This provides both opportunities for innovation and quality improvement, and risks of perpetuating existing variability in access. Information on alternative specialist community rehabilitation models (structures, processes, impacts and costs), such as that provided by the SPIRiTT trial, is important to enable evidence-based decisions to be made by service planners and commissioners.

Further research

The findings from this study point to the need for further research on the relative benefits and costs of alternative models of specialist multidisciplinary rehabilitation for people with Parkinson's in the community to provide evidence for local service commissioners and providers. While this and other studies[20,21] have confirmed that patients can benefit from multidisciplinary rehabilitation in the short term, the means by which the improvements gained can be sustained need further investigation. One possibility, suggested in feedback from participants, is to spread the professional input over a longer period of time, and this deserves to be explored.

The use of PCAs for extended support beyond the end of a 6-week MDT intervention produced some benefits for patients, compared with those without ongoing PCA support. Carers also reported some reduced strain during the PCA intervention. More research is required on the potential of PCA support by exploring how the nature and 'dose' might affect outcomes, both for people with Parkinson's and carers, and whether or not support provided over an extended period could be effective at avoiding costly hospitalisations.

Future research should select outcome measures carefully and focus on those that are patient and carer centred, and are relevant to their daily functioning and quality of life. Methods need to be found to incorporate intangible benefits from interventions into evaluations of their effectiveness, such as improved understanding of the condition and confidence in self-management. In addition, studies should be powered to enable subgroup analysis according to disease stage because issues important to patients and carers change with disease progression, and incorporating those with few limitations in the analysis may conceal effects occurring in other groups.

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- Alan Kimber, Reader in Statistics, University of Southampton.
- Tricia Macnair, Specialty Doctor in Medicine for the Elderly, NHS Surrey.
- Jane Renshaw, Parkinson's UK area manager.

Contributions of authors

Heather Gage was the principal investigator, contributed to the study design, oversaw the running of the project and completed the draft final report.

Linda Grainger was the project research manager from May 2012 and contributed to the draft final report.

Sharlene Ting was the project research manager until April 2012 and contributed to the set-up of the project.

Peter Williams provided statistical advice throughout the project and undertook the statistical analysis.

Christina Chorley was the lead research nurse who undertook the majority of the research assessments and contributed to the set-up of the project and draft final report.

Gillian Carey was the co-ordinator of the MDT and contributed to the draft final report.

Neville Borg was a administrative assistant for the MDT and research team and contributed to the draft final report.

Karen Bryan was a member of the core research team, responsible for the qualitative interviews of the MDT members and contributed to the draft final report.

Beverly Castleton member of the core research team and provided expert clinical input.

Patrick Trend contributed to the study design, member of the core research team and provided expert clinical input.

Julie Kaye contributed to the study design, member of the core research team and co-ordinator of the PPI group.

Jake Jordan undertook the economic analysis.

Derick Wade contributed to the study design, advice on the analysis and contributed to the draft final report.

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Appendix 1 Information leaflet

Flyer (Appendix B), version 1, 101209, REC ref no.: 10/H1109/1

This is a unique opportunity to take part in a leading research study, which can affect services for people with Parkinson's

If you would like further information, please complete the form on the other side

The treatment team comprises:

Specialist doctors
Parkinson's nurse specialist
Physiotherapists
Occupational therapists
Speech and language therapist
Other health professionals as required
Care assistants

SPIRiTT is a collaboration between:

University of Surrey
NHS Surrey
Royal Surrey County Hospital
Guildford Parkinson's Research Group

SPIRiTT
Specialist Parkinson's Integrated Rehabilitation Team Trial

NHS Research on Parkinson's in Surrey

Opportunities to take part in a trial of specialist rehabilitation in your home

SPIRiTT
Specialist Parkinson's Integrated Rehabilitation Team Trial

GPDRG

NHS National Institute for Health Research

UNIVERSITY OF SURREY

Do you have Parkinson's?

Do you know someone who has Parkinson's?

We are looking for volunteers to take part in a research study

The study is funded by the NHS

It is investigating whether specialist team treatment is helpful to people with Parkinson's and their carers

The findings will be used in the planning of future services

If you are interested in taking part, or would like more information about the study, please contact the research team

By Mail

Complete the form on the right and post to:

FREEPOST xxxx
SPIRiTT, Department of Economics
University of Surrey, Guildford
GU2 7XH

You do not need to put a stamp on the envelope

By Telephone

01483 684611
or
01483 686219

Please leave your name and number and we will call you back

By Email

spiritt@surrey.ac.uk

I would like further information about the Parkinson's rehabilitation trial

Name.....
.....

☐ *I am a person with Parkinson's*

☐ *I am a carer of a person with Parkinson's*

☐ **Telephone landline** .....
.....

☐ **Mobile telephone**.....
.....

☐ **E-mail**.....
.....

☐ **Address**.....
.....
.....
.....

Please indicate your preferred method of contact, by ticking the appropriate box

Appendix 2 Poster

Poster (Appendix A), version 1, 101209, REC ref no.: 10/H1109/1

Do you have **Parkinson's?**

SPIRiTT
Specialist Parkinson's Integrated Rehabilitation Team Trial

Do you know someone with **Parkinson's?**

We are looking for **volunteers** to take part in a **research** study

It is investigating whether
specialist team treatment
is helpful to
people with Parkinson's and their carers

The study is funded by the NHS

If you are interested in taking part, or would like to know more about the study, please contact the research team by:

Mail: FREEPOST xxxx, SPIRiTT, Department of Economics, University of Surrey, Guildford, Surrey, GU2 7XH
(*You do not need to put a stamp on the envelope*)

Telephone: 01483 684611 or 01483 686219

E-mail: spiritt@surrey.ac.uk

www.spiritt.surrey.ac.uk

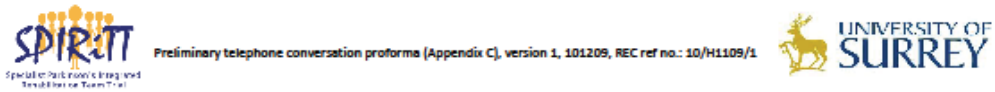
UNIVERSITY OF SURREY

GPDRG

SPIRiTT is a collaboration between the University of Surrey, NHS Surrey, Royal Surrey County Hospital NHS Trust, Guildford Parkinson's Disease Research Group. The study is funded by the NIHR Service Delivery and Organisation (SDO) Programme

NHS National Institute for Health Research

Appendix 3 Telephone-screening pro forma



Specialist Parkinson's Integrated Rehabilitation Team Trial (SPIRiTT)

Preliminary telephone conversation proforma

(researcher script in italics)

Please complete as appropriate using checkmarks/ticks √ or circles.

Date:	__/ ___ / 20 __			
Time:	__:__ AM PM			
Location:				
Name of researcher receiving call:				
Thank you for your interest in our study				
Please tell me how you heard about this study?				
Do you have Parkinson's or are you the carer of someone with Parkinson's?	**Person with Parkinson's**	**Carer**		**Other:**
		Live-in	**Does not live-in**	
For this conversation, I will follow a set procedure. Would you like me to tell you some more about the study, and then you can ask me any questions you may have?				
o *This study is being funded by the Department of Health. There are local Parkinson's specialists/doctors in the research team*				
o *The aim is to see whether people with Parkinson's would benefit from receiving specialist treatment in their own homes, so services can be planned for the future*				
o *If the person has a live-in carer, they will also be invited to take part*				
o *If you agree to take part, there will be four assessments over a period of nine months conducted by a researcher, who is a qualified nurse, in your own home, to see if the treatment is effective*				
o *The normal care of the person with Parkinson's will not be affected in any way, if they decide to take part in the study*				
Do you have any questions you would like to ask me? *(Supplementary information from Participant Information Sheets will be provided)*				
Are you interested in continuing?	**YES** *(Great, I need to ask some more questions to check whether you are eligible)*		**NO** *(Thank you for your time. Should you change your mind, please feel free to contact us again)*	
If caller is person with Parkinson's	**Do you have a live-in carer?**		*If yes, mention that they will be sent separate information about the study.* Go to next page	
	No	**Yes**		
If caller is carer	**Explain:** *1) The study is recruiting people with Parkinson's first, and if they have a live-in carer, he or she will also be invited to take part. We cannot recruit carers without the person with Parkinson's* *2) We need verbal consent of the person with Parkinson's to allow the carer to talk further about participation in and eligibility for the trial.* **Ask:** *Would it be possible to speak to the person with Parkinson's?* ☐ *If yes, confirm person with Parkinson's is willing for carer to speak on their behalf* ☐ *If no, ask when it would be possible to speak to them and arrange to call back*			

Preliminary telephone conversation proforma (Appendix C), version 1, 101209, REC ref no.: 10/H1109/1

Eligibility screening, information provided by:	**Carer**	**Person with Parkinson's**	**Other:** _____
Has the person with Parkinson's been told by a doctor he or she has Parkinson's?		**Yes**	**No**
Is the person with Parkinson's over 18?		**Yes**	**No**
Do you live in Surrey?		**Yes**	**No**
Do you live in your own home? *(that is not in a care home)*		**Yes**	**No**
Have you had an organised programme of rehabilitation in the last 6 months? *(involving coordinated care from physio/OT, including Flo Des/Milford/Haslemere, or taken part in a multidisciplinary rehabilitation research study)*		**Yes**	**No**
Has the person with Parkinson's been diagnosed by a doctor of having dementia?		**Yes**	**No**
If not eligible: *I am sorry from the information you have given me the trial would not be appropriate for you.* Thank caller for interest.			
If eligible: *I am pleased to tell you, from the information you have given me, you appear to be eligible to proceed to the next stage which will be a home evaluation.*			
Are you happy to continue?	☐ **No.** *Ok, thank you. Should you change your mind please feel free to contact us again*		
	☐ **Unsure/would like further information.** *Could you please provide me with your contact details so I can send you the information sheet(s) and consent form(s)? Fix time to call back.* *Name:* _____ *Contact telephone:* _____ *Address:* _____ *E-mail:* _____ *Date and time of call back:* _____		
	☐ **Yes.** *Excellent, the next stage is* *1) I send you written information about the study, which explains further the things we have been talking about. I will also send a consent form that you will need to sign if you agree to take part.* *2) There will be a separate information sheet and consent form for the the carer/person with Parkinson's (as appropriate).* *3) We would like to make an appointment for our research nurse to visit you in about one week time. She will go through the information sheet with you and answer any questions you may have. If you are willing to take part, she will ask you to sign the consent form. She will then collect some information about you, and your health. This initial visit will take up to two hours. Please can I book a convenient time for the research nurse to come visit you.* *Appointment with research nurse: Date:* _____ *Time:* _____ *Name of person with Parkinson's:* _____ *Name of live-in carer:* _____ *Address:* _____ *Postcode* _____ *Telephone (home):* _____ *Mobile:* _____ *E-mail:* _____		

Appendix 4 Information leaflets, consent forms and letters to participants

Information leaflet: person with Parkinson's

UNIVERSITY OF SURREY

version 1, 101209, REC ref no.: 10/H1109/1

SPIRiTT

Specialist Parkinson's Integrated Rehabilitation Team Trial (SPIRiTT)

Participant Information Sheet for Person with Parkinson's

You are invited to take part in a research study. Before you decide, please take the time to carefully read the information below. This explains why the research is being done and what it will involve for you. You may find it helpful to discuss the study with your friends, relatives and anyone involved in your care. Thank you.

What is the purpose of the study?
This study is investigating whether specialist treatment provided by a team of healthcare professionals is helpful to people with Parkinson's and their carers. The purpose is to help with the planning of services for people with Parkinson's in the future.

Why have I been invited?
The study is for people with Parkinson's, living in the community in their own homes, who could benefit from a programme of rehabilitation.

Do I have to take part?
It is up to you to decide whether or not you would like to take part. If you decide not to take part, the medical care you receive will not be affected in any way.

What will happen to me if I take part?
A researcher, who is a qualified nurse, will make an appointment to visit you in your home at a time convenient to you. During this visit, she will go through this information sheet with you and answer any questions you may have. If you decide to take part, she will ask you to sign the consent form. She will provide you with a copy of this for your records. She will then complete some questionnaires with you about your background, health and use of health services. This visit may take up to two hours. She may leave some of the questionnaires for you to fill out, and return by freepost to the research team. Once all of this information has been gathered, the research team will check to make sure that you meet all of the study's inclusion criteria.

Once your eligibility has been confirmed, you will be assigned randomly, to one of three groups. You will have an equal chance of being assigned any one of the groups.

- People in Group A will receive treatment in their homes, from a specialist Parkinson's team, over six weeks. The team has a Parkinson's specialist nurse, physiotherapist, occupational therapist, and can call in other professional as required. The team will form a care plan, in discussion with yourself and anyone who helps with your care. You will receive visits from the healthcare professionals over the six week period, according to your assessed needs.

- People in Group B will receive the same treatment as those in Group A, and additional visits and follow up telephone calls from a care assistant for another four months.

- People in Group C will be given information about Parkinson's from the Parkinson's Disease Society booklets, and an assessment from a member of the specialist team at the end of the study.

Throughout the study, people in each group will also receive three further home visits from the research nurse, at 6, 24 and 36 weeks after group assignment. You will be asked to complete similar questionnaires to those used in the first home visit. Some questionnaires will be sent for you to fill out in advance of these follow up visits. The purpose of these additional home visits is to see what effect the treatment is having.

Whilst you are in the study, all of your normal treatment will continue as usual.

GPDRC

Page 1 of 2

NHS National Institute for Health Research

Will my General Practitioner (GP) be involved?
The consent form will ask for your permission, to inform your GP that you taking part in this study, and the group you are in.

What are the possible benefits of taking part?
There may be no obvious personal benefit to you, but your participation will enable us to improve the care of people with Parkinson's, and in particular to help design future services.

Will my taking part in the study be kept confidential?
Yes. All the information collected about you during this study will be kept strictly confidential as required by the Data Protection Act (1998). All questionnaires will have a unique identification number, specific to you. No names or personal information will be kept on or stored with these questionnaires. Information will be kept in locked filing cabinets and password protected computers, in a room with restricted access at the University of Surrey. The information collected will be analysed to meet the aims of the study. Under no circumstances will any of your personal details be passed onto third parties, or appear in any reports on this study.

What will happen if I do not want to carry on with the study?
You can withdraw from the study at any time, without giving any reason, and this will in no way affect the usual care that you receive. Any information that has already been collected will be kept and used in the study's analysis.

What happens when the research study ends?
The treatment input is for a set amount of time only. At the end of the allocated time, participants will have the opportunity to reflect on their involvement during a short semi-structured interview with the researcher.

What will happen to the results of the research study?
The results of this study will be presented to the funder of the study as a report. The research team will write papers for publication in journals and make presentations at conferences, to help influence the development of future services for people with Parkinson's. Summaries of the study's results will be available from the project's website www.spiritt.surrey.ac.uk or the research team.

Who is funding the research?
The research is funded by the Department of Health (National Institute for Health Research, Service Delivery and Organisation Programme).

Who has reviewed the study?
All research in the National Health Service (NHS) is reviewed by a Research Ethics Comittee, which is responsible for protecting your interests and safety. This study has received favourable opinion by the Surrey Research Ethics Committee.

What if there is a problem?
If you have a concern about any aspect of this study, you should speak to the researchers who will do their best to answer your questions. You can contact the principal investigator, Dr Heather Gage or the project manager, Sharlene Ting, using the details provided below. If you would like to make a formal complaint, you can do this through the University of Surrey complaints procedure. Details can be obtained from the research team.

Contact details for further information
FREEPOST GI197, SPIRiTT, Department of Economics, University of Surrey, Guildford, Surrey, GU2 7XH
Telephone: 01483 684 611 or 01483 686 219
E-mail: spiritt@surrey.ac.uk
Website: www.spiritt.surrey.ac.uk

Information leaflet: live-in carer

UNIVERSITY OF SURREY

version 1, 101209, REC ref no.: 10/H1109/1

SPIRiTT

Specialist Parkinson's Integrated Rehabilitation Team Trial (SPIRiTT)

Participant Information Sheet for Live-in carer of people with Parkinson's

You are invited to take part in a research study. Before you decide, please take the time to carefully read the information below. This explains why the research is being done and what it will involve for you. You may find it helpful to discuss the study with your friends, relatives and anyone involved in your care. Thank you.

What is the purpose of the study?
This study is investigating whether specialist treatment provided by a team of healthcare professionals is helpful to people with Parkinson's and their carers. The purpose is to help with the planning of services for people with Parkinson's in the future.

Why have I been invited?
The study is for people with Parkinson's, living in the community in their own homes, who could benefit from a programme of rehabilitation. You have been invited because you are a live-in carer of a person with Parkinson's. You will be able to take part, if the person you care for agrees and is eligible to participate in the study.

Do I have to take part?
It is up to you to decide whether you would like to take part. If you decide not to take part, the medical care you, or the person with Parkinson's receive, will not be affected in any way.

What will happen to me if I take part?
A researcher, who is a qualified nurse, will make an appointment to visit you and the person you care for, in your home at a time convenient to you. During this visit, she will go through this information sheet with you and answer any questions you may have. If you decide to take part, she will ask you to sign the consent form. She will provide you with a copy of this for your records. She will then ask you to complete some questionnaires about your background, health and caring role. The nurse will assist you as necessary. This visit may take up to two hours. She may leave some of the questionnaires for you to complete and return by freepost to the research team. Once all of this information has been gathered, the research team will check to make sure that you meet all of the study's inclusion criteria.

Once your eligibility has been confirmed, you will be assigned to the same group as the person you care for. The person you care for will have equal chances of being allocated into any of the three study groups. The groups are:

- People with Parkinson's in **Group A** will receive treatment in their homes, from a specialist Parkinson's team, over six weeks. The team has a Parkinson's specialist nurse, physiotherapist, occupational therapist, and can call in other professional as required. The team will form a care plan, in discussion with the person with Parkinson's and yourself. The person with Parkinson's will receive visits from the healthcare professionals over the six week period, according to his/her assessed needs.

- People with Parkinson's in **Group B** will receive the same treatment as those in Group A, and additional visits and follow up telephone calls from a care assistant for another four months.

- People with Parkinson's in **Group C** will be given information about Parkinson's from the Parkinson's Disease Society booklets, and an assessment from a member of the specialist team at the end of the study.

You will receive three further home visits from the research nurse at 6, 24 and 36 weeks after the person you are caring for has been assigned to his/her group. You will be asked to complete similar questionnaires to those used in the first home visit. Some questionnaires will be sent for you to fill out in advance of these follow up visits. The purpose of these follow up visits is to see what effect the treatment is having on the person with Parkinson's and on your wellbeing.

GPDRG

Page 1 of 2

NHS National Institute for Health Research

Will my General Practitioner (GP) be involved?
The consent form will ask for your permission, to inform your GP that you taking part in this study, and the group you are in.

What are the possible benefits of taking part?
There may be no obvious personal benefit to you, but your participation will enable us to improve the care of people with Parkinson's, and in particular to help design future services.

Will my taking part in the study be kept confidential?
Yes. All the information collected about you during this study will be kept strictly confidential as required by the Data Protection Act (1998). All questionnaires will have a unique identification number, specific to you. No names or personal information will be kept on or stored with these questionnaires. Information will be kept in locked filing cabinets and password protected computers, in a room with restricted access at the University of Surrey. The information collected will be analysed to meet the aims of the study. Under no circumstances will any of your personal details be passed onto third parties, or appear in any reports on this study.

What will happen if I do not want to carry on with the study?
You can withdraw from the study at any time, without giving any reason, and this will in no way affect the usual care that you receive. Any information that has already been collected will be kept and used in the study's analysis.

What happens when the research study ends?
The treatment input is for a set amount of time only. At the end of the allocated time, participants will have the opportunity to reflect on their involvement during a short semi-structured interview with the researcher.

What will happen to the results of the research study?
The results of this study will be presented to the funder of the study as a report. The research team will write papers for publication in journals and make presentations at conferences, to help influence the development of future services for people with Parkinson's. Summaries of the study's results will be available from the project's website www.spiritt.surrey.ac.uk or the research team.

Who is funding the research?
The research is funded by the Department of Health (National Institute for Health Research, Service Delivery and Organisation Programme).

Who has reviewed the study?
All research in the National Health Service (NHS) is reviewed by a Research Ethics Comittee, which is responsible for protecting your interests and safety. This study has received favourable opinion by the Surrey Research Ethics Committee.

What if there is a problem?
If you have a concern about any aspect of this study, you should speak to the researchers who will do their best to answer your questions. You can contact the principal investigator, Dr Heather Gage or the project manager, Sharlene Ting, using the details provided below. If you would like to make a formal complaint, you can do this through the University of Surrey complaints procedure. Details can be obtained from the research team.

Contact details for further information
FREEPOST GI197, SPIRiTT, Department of Economics, University of Surrey, Guildford, Surrey, GU2 7XH
Telephone: 01483 684 611 or 01483 686 219
E-mail: spiritt@surrey.ac.uk
Website: www.spiritt.surrey.ac.uk

Consent form: person with Parkinson's

Consent form – Person with Parkinson's (Appendix F1), version 1, 101209, REC ref no.: 10/H1109/1

SPIRiTT Unique Identification Number: _____

Consent Form for Person with Parkinson's

Title of project: Specialist Parkinson's Integrated Rehabilitation Team Trial (SPIRiTT)

Name of principal investigator: Dr Heather Gage

		Please initial boxes
1	I voluntarily agree to take part in the study.	
2	I confirm that I have read and understood the information sheet dated _____ (version __). I have had the opportunity to ask questions on all aspects of the study, and have had these answered satisfactorily.	
3	I understand that I will be randomly assigned to receive either treatment with or without additional care support in my own home, or usual care. I understand that the treatment is only for a limited period of time.	
4	I understand that I will be visited and assessed by the research nurse in my own home on four occasions.	
5	I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.	
6	I agree that if I withdraw from the study for any reason, all of my data collected up to that point may be retained and used.	
7	I agree to my General Practitioner (GP) being informed about my participation in the study.	
8	I consent to my personal data being used for the study as detailed in the information sheet. I understand that all personal data relating to volunteers is held and processed in the strictest confidence, and in accordance with the Data Protection Act (1998).	
9	I confirm that I have read and understood the above and freely consent to participating in this study. I have been given adequate time to consider my participation and agree to comply with the instructions of the study.	

_____	_____	_____
Name of Participant	Signature	Date and Time
_____	_____	_____
Name of Person taking consent	Signature	Date and Time
_____	_____	_____
Name of Witness (*optional*)	Signature	Date and Time

(Copies: 1 for participant, 1 for researcher site file, 1 [original] for GP to be kept in medical notes)

Consent form: live-in carer

Consent form – Live-in carer (Appendix F2), version 1, 101209, REC ref no.: 10/H1109/1

SPIRiTT Unique Identification Number: _____

Consent Form for Live-in carer of person with Parkinson's

Title of project: Specialist Parkinson's Integrated Rehabilitation Team Trial (SPIRiTT)

Name of principal investigator: Dr Heather Gage

		Please initial boxes
1	I voluntarily agree to take part in the study.	
2	I confirm that I have read and understood the information sheet dated _____ (version __). I have had the opportunity to ask questions on all aspects of the study, and have had these answered satisfactorily.	
3	I understand that I will be assigned to the same study group as the person that I care for. I understand that the treatment is only for a limited period of time.	
4	I understand that I will be visited and assessed by the research nurse in my own home on four occasions.	
5	I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected, or those of the person that I care for.	
6	I understand that if the person I care for leaves the study, I will automatically be withdrawn.	
7	I agree that if I leave the study for any reason, all of my data collected up to that point may be retained and used.	
8	I consent to my personal data being used for the study as detailed in the information sheet. I understand that all personal data relating to volunteers is held and processed in the strictest confidence, and in accordance with the Data Protection Act (1998).	
9	I confirm that I have read and understood the above and freely consent to participating in this study. I have been given adequate time to consider my participation and agree to comply with the instructions of the study.	

_____	_____	_____
Name of Participant	Signature	Date and Time
_____	_____	_____
Name of Person taking consent	Signature	Date and Time
_____	_____	_____
Name of Witness (*optional*)	Signature	Date and Time

(Copies: 1 for participant, 1 for researcher site file, 1 [original] for GP to be kept in medical notes)

Baseline visit confirmation letter

Faculty of Arts and Human Sciences

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Department of Economics
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Research Nurse BSc RN

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spiritt@surrey.ac.uk
www.spiritt.surrey.ac.uk

Name
Address

Date

Dear _____,

Confirmation of first home research visit

Thank you for your interest in our research study on Parkinson's (SPIRiTT). Further to our telephone conversation on _____, I am writing to confirm that I will be making the first visit to your home:

on ***Date***

at ***Time***

As mentioned on the telephone, I enclose the information sheet about the study and the consent form for you to review. During my visit I will go through these documents with you, and answer any questions you may have. If you wish to join the study, I will ask you to complete and sign the consent form, and you will be provided with a copy. I will then conduct the baseline assessments for the study.

I am looking forward to meeting you. If you have any questions in advance to our meeting, please do not hesitate to contact me by telephone on 01483 684 611 or email spiritt@surrey.ac.uk.

Yours sincerely,

Christina Chorley
Research Nurse (BSc RN)

SPIRITT is a collaboration between the University of Surrey, NHS Surrey, Royal Surrey County Hospital NHS Trust, Guildford Parkinson's Disease Research Group, University of Hertfordshire and the Nuffield Orthopaedic Centre NHS Trust.
The study is funded by the NIHR Service Delivery and Organisation (SDO) Programme

Appendix 5 Background information collected at baseline

Nurse-collected from the person with Parkinson's

version 1, 101209, REC ref no.: 10/H1109/1

SPIRiTT Unique Identification Number: ___ Assessment time-point 1

Specialist Parkinson's Integrated Rehabilitation Team Trial (SPIRiTT)

Background questionnaire for Person with Parkinson's

THIS SECTION TO BE COMPLETED BY THE RESEARCHER

We would be grateful if you could provide as much information as possible
All information collected is treated with complete confidentiality

Date: __/___/____ **Time:** __:__ AM PM **Location:** ☐ Home ☐ Other _____

Person completing form: ☐ Carer ☐ Person with Parkinson's ☐ Researcher ☐ Other (please specify): _____

ABOUT YOUR CONDITION

1) How long ago were you diagnosed with Parkinson's?
☐ Less than 2 years ☐ 2 to 4.99 years ☐ 5 to 9.99 years ☐ 10 to 14.99 years ☐ 15 years and more

2) Please indicate which statement below best describes you
☐ The main symptoms such as tremor, muscle stiffness, slowness of movement and problems with posture, are only on one side of the body. Problems with balance may be noticed
☐ Parkinson's affects both sides of the body and problems with swallowing, talking and "facial masking" (loss of facial expression) may be noticed
☐ Parkinson's affects both sides of the body and problems with swallowing, talking and "facial masking" (loss of facial expression) are worse. Person is independent
☐ Person is now less independent and needs help with some or all activities of daily living
☐ Person is confined to a wheelchair or bed and needs total assistance

3) Have you had an organised programme of rehabilitation in the last 6 months? *(involving coordinated care from physio/OT, including Flo Des/Milford/Haslemere, or taken part in a multidisciplinary rehabilitation research study)* ☐ Yes ☐ No ☐ Don't know

4) How many times A YEAR do you usually visit the hospital as an outpatient with a doctor for Parkinson's?
☐ Never ☐ About 2 times a year ☐ Less than one time a year
☐ About one time a year ☐ About 3 to 4 times a year ☐ More than 4 times a year

5) Do you have a Parkinson's nurse specialist? ☐ Yes ☐ No

6) If yes, you do have a Parkinson's nurse specialist, when did you last see him/her?
☐ Less than 6 months ago ☐ Between 6 months and 1 year ☐ 1 to 2 years ago ☐ Not relevant

7) When did you last see a physiotherapist?
☐ Less than 6 months ago ☐ Between 6 months and 1 year ☐ 1 to 2 years ago ☐ Don't know

8) When did you last see an occupational therapist?
☐ Less than 6 months ago ☐ Between 6 months and 1 year ☐ 1 to 2 years ago ☐ Don't know

9) When did you last see a speech and language therapist?
☐ Less than 6 months ago ☐ Between 6 months and 1 year ☐ 1 to 2 years ago ☐ Don't know

This study is funded by the Department of Health
Favourable ethical opinion has been granted by Surrey Research Ethics Committee
Page 1 of 4

version 1, 101209, REC ref no.: 10/H1109/1

SPIRiTT Unique Identification Number: ___ Assessment time-point 1

FALLS QUESTIONNAIRE

Please place a tick √ in the box that is most appropriate to you.

1)	In the LAST 3 MONTHS, have you fallen?	☐ Yes	☐ No	
2)	If you have fallen in the LAST 3 MONTHS, roughly how many times have you fallen?	___ times		
3)	Did you hurt yourself on any of these occasions?	☐ Yes	☐ No	
4)	Were you able to get up from the floor/ground?	☐ Yes	☐ No	
5)	Did you see a doctor?	☐ Yes, A&E	☐ Yes, GP	☐ No
6)	Are your falls related to freezing?	☐ Yes	☐ No	☐ Don't know

This study is funded by the Department of Health
Favourable ethical opinion has been granted by Surrey Research Ethics Committee

version 1, 101209, REC ref no.: 10/H1109/1

SPIRiTT Unique Identification Number: ___ **Assessment time-point 1**

Modified Hoehn & Yahr

Please indicate which statement below best describes you

- ☐ **0** No sign of disease
- ☐ **I** Unilateral disease (mild symptoms on one side of body only)
- ☐ **II** Bilateral disease (both sides of body affected), minimal disability
- ☐ **III** Bilateral disease with some postural instability (balance problems). Significant slowing of movement, and generalised functional problems, but the person is physically independent
- ☐ **IV** Severe symptoms and disability, and no longer able to live alone
- ☐ **V** Wheelchair or bed ridden unless has help, and requires constant nursing care

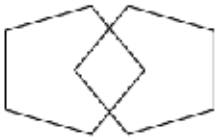
This study is funded by the Department of Health
Favourable ethical opinion has been granted by Surrey Research Ethics Committee

version 1, 101209, REC ref no.: 10/H1109/1

SPIRiTT Unique Identification Number: ___ Assessment time-point 1

MINI-MENTAL STATE EXAMINATION QUESTIONNAIRE

Using the instructions for administering and scoring this questionnaire, please ask the participant the following questions in the order listed and record his/her score on the column on the right.

Questions	Score
1) What is the year? Season? Date? Day of the week? Month?	/5
2) Where are we now: County? Town/city? Street? House number?	/5
3) Researcher name three unrelated objects (*monitor, slippers, car*) clearly and slowly, then asks the participant to name all three of them. The researcher repeats them until the participant learns all of them, if possible. Number of trials: ___ Please remember these three items as I will ask you for them later.	/3
4) I would like you to count backward from 100 by 7s (*100, 93, 86, 79, 72, 65, 58, 51, 44, 37, 30, 23, 16, 9, 2*). Stop after 5 answers. Alternatively, spell "world" backwards (D L R O W)	/5
5) Earlier I told you the names of three things. Can you tell me what those were? _____	/3
6) Show the participant two simple objects (*mobile phone, pen*) and ask the participant to name them _____	/2
7) Repeat the phrase "No ifs, ands or buts"	/1
8) Researcher gives the participant a piece of blank paper and instructs him/her to "Take the paper in your right hand, fold it in half and put it on the floor"	/3
9) Please read this and do what it says (*Written instructions are "Close your eyes"*)	/1
10) Make up and write a sentence about anything. Sentence must contain a noun and a verb _____	/1
11) Researcher gives the participant a blank piece of paper and instructs him/her "Please copy this picture". (*All 10 angles must be present and two must intersect*) 	/1
TOTAL:	/30

If score is <24, please complete ABOUT YOU section in Participant Booklet ONLY

This study is funded by the Department of Health
Favourable ethical opinion has been granted by Surrey Research Ethics Committee

Self-reported background information from person with Parkinson's

SPIRiTT

version 1, 101209, REC ref no.: 10/H1109/1

UNIVERSITY OF SURREY

SPIRiTT Unique Identification Number: **Assessment time-point 1**

ABOUT YOU

In answering the questions below, please place checkmarks/ticks √ in the relevant boxes.

1) Are you ☐ Male? ☐ Female?

2) When were you born? Day _ _ Month _ _ _ Year 19_ _

3) What is your height? *(please specify centimetres or feet)* _ _ _ centimetres (cm) or _ feet _ _ inches

4) What is your weight? *(please specify kilograms or pounds)* _ _ _ kilograms (kg) or _ _ stones _ _ pounds (lbs) or _ _ _ lbs

5) Have you ever smoked? ☐ Yes ☐ No

6) If yes (you have smoked), are you ☐ A current smoker? ☐ An ex-smoker? ☐ Not relevant

7) If you are a current or an ex-smoker, how long have (did) you smoke(d) for in years? _____ years ☐ Not relevant

8) Has the doctor ever told you that you have any of the following conditions: *(please tick all that applies)*

☐ Heart attack?	☐ Stroke?	☐ Dementia or Alzheimer's?
☐ Joint problems (such as arthritis, osteoarthritis, rheumatoid arthritis)?	☐ Problems with blood vessels (such as thrombosis, embolism, claudication, aneurysm, blood clots)?	☐ Visual problems (such as cataracts, glaucoma, age related macular degeneration)?
☐ Heart trouble (such as angina, valve disease, palpitations, chest pains)?	☐ High blood pressure or hypertension?	☐ Neurological problems (such as multiple sclerosis)?
☐ Bone problems (such as osteoporosis)?	☐ Emotional or psychiatric problems?	☐ Chest problems (such as bronchitis, asthma, wheeze)?
☐ Depression?	☐ Broken bones or fractures?	☐ Hearing problems?
☐ Cancer?	☐ Diabetes?	☐ Other (please specify): _____

9) Please tell us about your living situation (Tick all that apply)

☐ I live with my husband/wife/ partner ☐ I live with other family member e.g. child ☐ Other (please specify): _____

☐ I live with a paid live-in carer ☐ I live with a friend ☐ I live alone

This study is funded by the Department of Health
Favourable ethical opinion has been granted by Surrey Research Ethics Committee

version 1, 101209, REC ref no.: 10/H1109/1

SPIRiTT Unique Identification Number: **Assessment time-point 1**

10) What kind of accommodation do you live in?

☐ Owner occupied flat or house ☐ Rented flat or housing association ☐ Other (please specify): _____

11) Do you live in a warden assisted or sheltered accommodation? ☐ Yes ☐ No

12) Which ethnic group best describes you?

☐ White ☐ Chinese ☐ Asian ☐ Black ☐ Mixed ☐ Other (please specify): _____

13) What is the highest level of education that you have completed?

☐ Primary level up to age 12 years ☐ Vocational/further education

☐ Secondary level up to age 16 years ☐ University

☐ Secondary level up to age 18 years ☐ Other (please specify): _____

14) What is your employment status?

☐ In paid full-time employment ☐ In paid part-time Employment ☐ Not in work due to ill health ☐ Other (please specify): _____

☐ Home maker ☐ Retired ☐ Seeking work ☐ Volunteer

15) If you are currently in paid employment, what job do you do?

_____

16) If you are in paid employment, how many days of work have you missed in the LAST 3 MONTHS because of your Parkinson's?

_____ days ☐ Not relevant

17) If you are not currently employed, what was the last job that you did?

_____

18) What is your household income EACH YEAR before tax?

☐ Less than £12,000 ☐ £12,000 to £20,000 ☐ £20,001 to £30,000 ☐ £30,001 to £45,000 ☐ More than £45,001

19) Do you receive any benefits (not including child benefit or state pension)? ☐ Yes ☐ No

20) If yes (you are receiving benefits), please tick all those relevant to you to below:

☐ Attendance allowance ☐ Carer's allowance ☐ Disability living allowance ☐ Housing benefit

☐ Council tax benefit ☐ Social fund ☐ Other (please specify): _____ ☐ Other (please specify): _____

This study is funded by the Department of Health
Favourable ethical opinion has been granted by Surrey Research Ethics Committee

version 1, 101209, REC ref no.: 10/H1109/1

SPIRiTT Unique Identification Number: Assessment time-point 1

21) In the LAST 3 MONTHS, have you received direct payments or a personal budget?

☐ Yes ☐ No

22) If yes, which of these following were received?

☐ Direct payment (means tested cash payment made in place of regular social services provision)

☐ Personal budget (funding received is managed by the individual)

☐ Other (please specify): _____

☐ Not relevant

23) If yes, how much do you receive EVERY WEEK?

£_____

☐ Not relevant

24) ABOUT YOUR SOCIAL NETWORK (Lubben)

Considering your family/relatives, the people to whom you are related either by birth or marriage, and your friends, including those who live in your neighbourhood, please answer the following questions by placing a checkmark/tick √ in the appropriate box. Please select only one box for each question.

Questions	none	1	2	3 or 4	5 to 8	9 or more
1) How many relatives do you see or hear from at least once a month?						
2) How many relatives do you feel at ease with that you can talk about private matters?						
3) How many relatives do you feel close to such that you could call on them for help?						
4) How many of your friends do you see or hear from at least once a month?						
5) How many friends do you feel at ease with that you can talk about private matters?						
6) How many friends do you feel close to such that you could call on them for help?						

This study is funded by the Department of Health
Favourable ethical opinion has been granted by Surrey Research Ethics Committee

Self-reported background information from live-in carer

version 1, 101209, REC ref no.: 10/H1109/1

SPIRiTT Unique Identification Number: ___C Assessment time-point 1

ABOUT YOU

In answering the questions below, please place checkmarks/ticks √ in the relevant boxes.

1) **Are you** ☐ Male? ☐ Female?

2) **When were you born?** Day __ Month ___ Year 19__

3) **What is your height?** ***(please specify centimetres or feet)*** ___ centimetres (cm) or _ feet __ inches

4) **What is your weight?** ***(please specify kilograms or pounds)*** ___ kilograms (kg) or __ stones __ pounds (lbs) or ___ lbs

5) **Have you ever smoked?** ☐ Yes ☐ No

6) **If yes (you have smoked), are you** ☐ A current smoker? ☐ An ex-smoker? ☐ Not relevant

7) **If you are a current or an ex-smoker, how long have (did) you smoke(d) for in years?** _____ years ☐ Not relevant

8) **Has the doctor ever told you that you have any of the following conditions:** ***(please tick all that applies)***

☐ Heart attack?	☐ Stroke?	☐ Dementia or Alzheimer's?
☐ Joint problems (such as arthritis, osteoarthritis, rheumatoid arthritis)?	☐ Problems with blood vessels (such as thrombosis, embolism, claudication, aneurysm, blood clots)?	☐ Visual problems (such as cataracts, glaucoma, age related macular degeneration)?
☐ Heart trouble (such as angina, valve disease, palpitations, chest pains)?	☐ High blood pressure or hypertension?	☐ Neurological problems (such as multiple sclerosis)?
☐ Bone problems (such as osteoporosis)?	☐ Emotional or psychiatric problems?	☐ Chest problems (such as bronchitis, asthma, wheeze)?
☐ Depression?	☐ Broken bones or fractures?	☐ Hearing problems?
☐ Cancer?	☐ Diabetes?	☐ Other (please specify): _____

9) **Which ethnic group best describes you?**

☐ White ☐ Chinese ☐ Asian ☐ Black ☐ Mixed ☐ Other (please specify): _____

This study is funded by the Department of Health
Favourable ethical opinion has been granted by Surrey Research Ethics Committee

version 1, 101209, REC ref no.: 10/H1109/1

SPIRiTT Unique Identification Number: ___C Assessment time-point 1

1) What is the highest level of education that you have completed?

☐ Primary level up to age 12 years
☐ Secondary level up to age 16 years
☐ Secondary level up to age 18 years
☐ Vocational/further education
☐ University
☐ Other (please specify): _____

2) What is your household income EACH YEAR before tax?

☐ Less than £12,000 ☐ £12,000 to £20,000 ☐ £20,001 to £30,000 ☐ £30,001 to £45,000 ☐ More than £45,001

3) Do you receive any benefits (not including child benefit or state pension)? ☐ Yes ☐ No

4) If yes (you are receiving benefits), please tick all those relevant to you to below:

☐ Attendance allowance ☐ Carer's allowance ☐ Disability living allowance ☐ Housing benefit
☐ Council tax benefit ☐ Social fund ☐ Other (please specify): _____ ☐ Other (please specify): _____

5) In the LAST 3 MONTHS, have you received direct payments or a personal budget? ☐ Yes ☐ No

6) If yes, which of these following were received?

☐ Direct payment (means tested cash payment made in place of regular social services provision)
☐ Personal budget (funding received is managed by the individual)
☐ Other (please specify): _____
☐ Not relevant

7) If yes, how much do you receive EVERY WEEK?

£_____ ☐ Not relevant

THANK YOU for taking the time to complete this questionnaire.

Please check through to ensure that you have answered all of the questions.

Your input is extremely valued and very much appreciated.

This study is funded by the Department of Health
Favourable ethical opinion has been granted by Surrey Research Ethics Committee

Page 2 of 2

Appendix 6 Baseline exclusion letter

Faculty of Arts and Human Sciences

SPIRITT
Department of Economics
University of Surrey
Guildford, Surrey, UK, GU2 7XH

Sharlene Ting
Trial Manager

T: +44 (0)1483 686 219
F: +44 (0)1483 689 548

spiritt@surrey.ac.uk
www.spiritt.surrey.ac.uk

Name
Address

Date

Dear _____,

Re: Parkinson's Rehabilitation Trial

Thank you very much for your interest and taking the time to participate in our research study on Parkinson's (SPIRiTT).

Further to your first home visit with the research nurse, _____ on _____, please find enclosed copies of your consent forms. As was explained to you at this visit, the collected baseline information would be used to determine final eligibility into the study. In addition, as you know, (LiC's name) will need to be eligible before (PwP's name) can also take part in the study. Unfortunately, having evaluated the baseline information, _____ is not eligible to proceed onto the study, as s/he scored ___ out of 30 on the memory test. In order to participate in the study, volunteers need to score at least 24.

As per the consent form, we have written to your GP informing him that you are not eligible to take part in the trial. I am sorry to relay the disappointing news but would like to thank you very much for taking part.

If you have any questions, please do not hesitate to contact me by telephone on 01483 686 219 or email spiritt@surrey.ac.uk.

Yours sincerely,

Sharlene Ting
Trial Manager

SPIRITT is a collaboration between the University of Surrey, NHS Surrey, Royal Surrey County Hospital NHS Trust, Guildford Parkinson's Disease Research Group, University of Hertfordshire and the Nuffield Orthopaedic Centre NHS Trust.
The study is funded by the NIHR Service Delivery and Organisation (SDO) Programme

Appendix 7 Eligibility confirmation and randomisation letters

SPIRiTT
Specialist Parkinson's Integrated Rehabilitation Team Trial

Name
Address

UNIVERSITY OF SURREY
Faculty of Arts and Human Sciences

SPIRITT
Department of Economics
University of Surrey
Guildford, Surrey, UK, GU2 7XH

Sharlene Ting
Research Fellow/Trial Manager

T: +44 (0)1483 686 219
F: +44 (0)1483 689 548

spiritt@surrey.ac.uk
www.spiritt.surrey.ac.uk

Date

Dear _____,

Re: Parkinson's Rehabilitation Trial – eligibility confirmation and random allocation to study groups

Further to the baseline assessment conducted by the research nurse, _____ on _____, please find enclosed a copy of your consent form. I am pleased to confirm your eligibility and tell you that the statistician has randomly allocated you to **Group A** and you will be receiving 6 weeks of rehabilitation from the study's specialist multidisciplinary team.

As arranged by telephone on _____, please find below the initial schedule of home visits by the team:

On:	At approximately:	With:

In advance of the first home visit, we would be grateful if you could complete the enclosed questionnaire (tick boxes only). Gillian will collect this form from you when she visits and use it as part of her assessment. Please do contact us if you would like to alter your appointment slot.

For your convenience, I have set out below a rough time estimate of the calendar of events for the rest of the trial. Research nurse visits will be much shorter than the initial one and all appointments will be made in advance.

Date	Event
	Start of 6 week multidisciplinary rehabilitation
	Research nurse visit #2
	Research nurse visit #3
	Final research nurse visit #4

Thank you once again for taking part in the study. Your contribution is greatly valued. Please do not hesitate to contact me should you have any queries.

Yours sincerely,

Sharlene Ting (Research Fellow/Trial Manager)

SPIRITT is a collaboration between the University of Surrey, NHS Surrey, Royal Surrey County Hospital NHS Trust, Guildford Parkinson's Disease Research Group, University of Hertfordshire and the Nuffield Orthopaedic Centre NHS Trust.
The study is funded by the NIHR Service Delivery and Organisation (SDO) Programme

SPIRITT
Specialist Parkinson's Integrated Rehabilitation Team Trial

UNIVERSITY OF SURREY
Faculty of Arts and Human Sciences

SPIRITT
Department of Economics
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Sharlene Ting
Research Fellow/Trial Manager

T: +44 (0)1483 686 219
F: +44 (0)1483 689 548

spiritt@surrey.ac.uk
www.spiritt.surrey.ac.uk

Name
Address

Date

Dear _____,

Re: Parkinson's Rehabilitation Trial – eligibility confirmation and random allocation to study groups

Further to the baseline assessment conducted by the research nurse, _____ on _____, please find enclosed copies of your consent forms. I am pleased to confirm your eligibility and tell you that the statistician has randomly allocated you to **Group B** and you will be receiving 6 weeks of rehabilitation from the study's specialist multidisciplinary team, followed by 18 weeks of care assistant support.

As arranged by telephone on _____, please find below the initial schedule of home visits by the team:

On:	At approximately:	With:

In advance of the first home visit, we would be grateful if you could complete the enclosed questionnaire (tick boxes only). Geraldine will collect this form from you when she visits and use it as part of her assessment. Please do contact us if you would like to alter your appointment slot.

For your convenience, I have set out below a rough time estimate of the calendar of events for the rest of the trial. Research nurse visits will be much shorter than the initial one and all appointments will be made in advance.

Date	Event
	Start of 6 week multidisciplinary rehabilitation
	Research nurse visit #2
	Start of 18 week care assistant support
	Research nurse visit #3
	Final research nurse visit #4

Thank you once again for taking part in the study. Your contribution is greatly valued. Please do not hesitate to contact me should you have any queries.

Yours sincerely,

Sharlene Ting (Research Fellow/Trial Manager)

SPIRITT is a collaboration between the University of Surrey, NHS Surrey, Royal Surrey County Hospital NHS Trust, Guildford Parkinson's Disease Research Group, University of Hertfordshire and the Nuffield Orthopaedic Centre NHS Trust.
The study is funded by the NIHR Service Delivery and Organisation (SDO) Programme

SPIRITT
Specialist Parkinson's Integrated Rehabilitation Team Trial

UNIVERSITY OF SURREY
Faculty of Arts and Human Sciences

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spiritt@surrey.ac.uk
www.spiritt.surrey.ac.uk

Name
Address

Date

Dear _____,

Re: Parkinson's Rehabilitation Trial – eligibility confirmation and random allocation to study groups

Further to the baseline assessment conducted by the research nurse, _____ on _____, please find enclosed a copy of your consent form. I am pleased to confirm your eligibility and tell you that the statistician has randomly allocated you to Group C. Please find enclosed the information booklet from Parkinson's UK for you.

For your convenience, I have set out below a rough time estimate of the calendar of events for the rest of the trial. Research nurse visits will be much shorter than the one you have just completed and all appointments will be made in advance at times convenient to you.

Date	Event
	Research nurse visit #2
	Research nurse visit #3
	Final research nurse visit #4
	Visit by member of the multidisciplinary specialist team

Thank you once again for taking part in the study. Your contribution is greatly valued. Please do not hesitate to contact me should you have any queries.

Yours sincerely,

Sharlene Ting (Research Fellow/Trial Manager)

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Appendix 8 General practitioner notification letter

Faculty of Arts and Human Sciences

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Heather Gage
Principal Investigator

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Name
Address

Date

Dear Dr_____,

Re: PwP Name Date of birth: _____

This is to notify you that your patient above is participating in our research trial, and has been randomised to Group ___. Please find enclosed the original signed consent form to be kept with the patient's medical notes. The study is evaluating the effects of a specialist multidisciplinary rehabilitation programme (with or without additional care assistant support) on people with Parkinson's, in their own homes. Assessment time-points are at baseline, 6, 24 and 36 weeks post-randomisation. All normal treatment will continue as usual during the study.

There are three study groups:

- People in Group A will receive rehabilitation in their own homes, from a specialist Parkinson's team, over six weeks. The team comprises a Parkinson's specialist nurse, physiotherapist, occupational therapist and speech and language therapist. They can call on other professionals as required. The team will form a tailored care plan, in discussion with the patient and anyone who helps with his/her care. They will receive visits from the healthcare professionals over the six week period, according to their assessed needs.
- People in Group B will receive the same treatment as those in Group A, and additional visits and follow up telephone calls from a care assistant for another four months.
- People in Group C will be given information about Parkinson's from the Parkinson's Disease Society booklets, and an assessment from a member of the specialist team at the end of the study.

For further details about the study, please refer to the information sheet enclosed. Please do not hesitate to contact me should you have any queries.

Thank you for your attention in this matter.

Yours faithfully,

Heather Gage
Principal Investigator

Sharlene Ting
Research Fellow/Project Manager

SPIRITT is a collaboration between the University of Surrey, NHS Surrey, Royal Surrey County Hospital NHS Trust, Guildford Parkinson's Disease Research Group, University of Hertfordshire and the Nuffield Orthopaedic Centre NHS Trust.
The study is funded by the NIHR Service Delivery and Organisation (SDO) Programme

Appendix 9 Fact sheets for multidisciplinary team participants (educational component of the intervention)

Parkinson's UK information sheets on:

- Parkinson's and diet
- drug treatments for Parkinson's
- constipation and Parkinson's
- looking after your bladder and bowels in Parkinsonism
- foot care and Parkinson's
- fatigue and Parkinson's
- sleep and night-time problems in Parkinson's
- speech and language therapy
- general information about benefits.

Fact sheets developed by the SPIRiTT team:

- physiotherapy general tips
- relaxation.

Appendix 10 Generic information for control group participants

(Also provided to intervention groups.)

Parkinson's UK. *Parkinson's and You*. London: Parkinson's UK; 2010.

Parkinson's Disease Society. *The Carer's Guide*. London: Parkinson's Disease Society; 2008.

Appendix 11 Multidisciplinary team roles and intervention protocols

Parkinson's nurse specialist

Role

- To provide expert Parkinson's management to maintain maximum independence for patients.
- To act as a reliable source of information about clinical and social issues that were of concern to people with Parkinson's and their carers.
- To ensure appropriate timely referral to essential services such as therapy or social care.
- To empower and educate people with Parkinson's and their carers.
- To identify the tolerance and efficacy of medication.
- To complete adverse event forms as per the project protocol.
- To reinforce all MDT treatment programmes.

Protocol

Initial assessment (1.5 hours):

- collection and collation of baseline information including data of diagnosis, medical history, current support services and falls history
- completion of MDS-UPDRS
- review of Parkinson's medication
- review of current problems as identified by the person with Parkinson's
- provision of leaflets and advice as appropriate
- blood pressure checking and recording.

Follow-up visit (1.5 hours):

- discussion of non-motor symptoms including drooling, swallowing, constipation, urinary problems, sexual and relationship pain, apathy, fatigue, depression, hallucinations, anxiety, dizziness, sleep problems, dyskinesias, motor fluctuations, end of dose 'wearing off' and nausea
- reinforcement of all MDT treatment programmes
- provision of an agreed care plan reflecting the needs and wishes of the participant and their carer.

Physiotherapist

Role

- To improve the quality of life for people with Parkinson's by improving/maintaining levels of function and independence.
- To increase awareness of Parkinson's and its effect on functional ability including posture, mobility and transfers.
- To give advice and education on preventative strategies/measures.
- To provide an agreed care plan reflecting the needs and wishes of the participant and their carer.
- To complete adverse event forms as per the project protocol.
- To reinforce all MDT treatment programmes.

Protocol

Initial assessment:

If during the initial assessment there were problems with poor posture, transfers including bed mobility, balance and falls, mobility including freezing and turning, then a further in-depth assessment followed which could include, as appropriate, the Lindop Parkinson's Assessment Scale or the Berg Balance 7-item short-form version.

All participants received a physiotherapy tips information leaflet covering transfers, freezing, posture and mobility information and strategies.

A patient-specific programme tailored to the participant's individual needs was provided.
This programme included:

- Yale balance exercises (levels 1–5)
- Roche exercises for people with Parkinson's disease
- posture handout including specific exercises and posture advice
- Keep Moving booklet (PD UK)
- handwritten individual tailored exercises as appropriate.

Physiotherapy interventions included treatment for improving:

- functional activities including bed transfers and bed mobility
- posture
- balance and prevention/reduction of falls
- mobility problems including freezing and turning.

Speech and language therapist

Role

- To give advice on the speech and swallowing disorders that could arise with Parkinson's disease. To explain how these disorders come about and educate as to the importance of targeted exercise programmes. Use of diagrams, etc., where needed, to explain swallow function.
- To provide advice regarding how to access local speech and language therapy services and to refer on to these services if appropriate.
- To ensure that individuals knew how to recognise dysphagia that may be associated with Parkinson's disease and to seek appropriate support.
- To improve the patient's quality of life through structured exercise programmes designed to maintain and improve function.
- To advise on modified food/fluid consistencies where these might improve swallow function and reduce the risk of aspiration and to refer to videofluoroscopy where appropriate. To engage carers/family members as to the role they could play in support.

Protocol

All participants received an initial assessment (1.5 hours):

- understanding the individual's perception of their own speech/swallowing problem through discussion with them and their family and with the use of rating scales
- understanding if they have previously undergone speech and language therapy and what form this has taken
- evaluation of posture, breath capacity and control, i.e. their ability to support speech

- evaluation of their habitual and possible optimum volume for speech
- evaluation of diadochokinetic movements for speech and possible impact on articulation
- evaluation of any swallowing disorder
- if swallowing difficulties were present, assessment of cranial nerve function and Sydney Swallow questionnaire
- completion of adverse event forms as per the project protocol
- reinforcement of all MDT treatment programmes.

Following their assessment, individuals were advised as appropriate on suitable exercises/strategies to help with their specific difficulties. These exercises were provided in written form and could have included:

- a facial exercise programme to maintain muscle flexibility
- breathing and phonation exercises to maximise volume
- functional phrases to incorporate volume work into meaningful task
- poetry/pacing exercises to work on rate and intonation
- tongue twisters/reading aloud to work on articulatory imprecision.

Further written leaflets were available to provide advice on a number of modified food and fluid consistencies.

Where appropriate, individuals were offered a second appointment to follow-up on the exercise programme. Onward referral to the local speech and language therapy service or for videofluoroscopy assessment was made if required.

Occupational therapist

Role

A single assessment (1.5 hours) was carried out for each individual:

- to assess an individual's ability to perform day-to-day activities
- to advise on appropriate aids, equipment or adaptations to help the individual maintain independence
- to provide information and explanations about the various resources, services and benefits which are available to help maintain family life, work and leisure interests
- to advise on coping strategies to help with Parkinson's symptoms such as fatigue, handwriting and communication difficulties
- to refer to other services and organisations that offer support or help
- to ensure completion of adverse event forms as per the project protocol
- to reinforce all MDT intervention programmes.

Care assistant

Role

- Provide ongoing support to patients and their carers using agreed care plans as formulated by therapists and nurse specialists for a period of up to 18 weeks.
- Attend MDT meetings at start of intervention phase for detailed handover of designated individuals from team therapists/nurses.
- Clarify the role of the project care assistant with the participant and their carer and their importance for the project outcomes.
- Emphasise the importance of doing prescribed exercises and the long-term benefits which could be gained.

- Demonstrate the exercises to the participant and their carer and encourage regular practice.
- Keep detailed and legible records of progress made by the participant at each visit and document any identified problems or changes required during the participant/carer review process.
- Report any identified problems to the appropriate member of the MDT and provide regular feedback to the therapist/nurse until the problem is resolved.
- Meet regularly with the PNS to discuss individual participant progress and issues which have arisen.
- Ensure completion of adverse event forms as per the project protocol.

Appendix 12 Client record form

SPIRiTT UIN: Group: Participant's name: DOB:

MULTIDISCIPLINARY TEAM CONTRIBUTIONS

No.	Name (please print)	Signature	Initials	Position	Date	Time of arrival	Time of leaving	Participant Consent (initials)

CURRENT MAIN PROBLEMS

No.	Description of main problems

REFERRALS MADE

Service	Reason	By whom

RECOMMENDATIONS AND CHANGES

Recommendation for changes to medication	Reason	By whom	Imple-mented?	Aids/adaptations			Who paid?	Amount (£)
				Recommendations	By whom	Obtained?		

Page 1 of 21

SPIRiTT UIN: Group: Participant's name: DOB:

GENERAL INFORMATION

Title:		Surname:		Forenames:		Preferred name:	
Date of birth:		Gender:		Ethnic origin:		Language:	
Address:							
Telephone (home):				Work:		Mobile:	

GP DETAILS					
GP Name:		Practice Name:			
Practice address:					
Telephone:					
SOCIAL ASSESSMENT					
House:	Detached Semi-detached Terraced Bungalow Upstairs flat Sheltered housing				
Steps inside:	Yes/No	Steps outside:	Yes/No	Stair lift:	Yes No
Bathroom:	Upstairs Downstairs	Toilet:	Upstairs Downstairs	Pets:	Yes No
Lives:		Comments:			
Support from family/carer:		Main Carer's Name:			
Carer's address:	As above				
Telephone:	As above				
Next of kin:	Same as Main Carer				
Next of kin's address:					
Telephone:					

SERVICES								
Services and Support	M	T	W	T	F	S	S	Comments
Home care (personal)								
Home care (domestic)								
Meals on wheels								
Day centre								
District nurse								
Community psychiatric nurse								
Other (state):								

Driving:	Yes No	DVLA aware:	Yes No

MEDICAL HISTORY			
Date of diagnosis:		Diagnosis made by:	Consultant GP
Date of noticing symptoms:		Duration of condition:	
Falls:	Never Occasionally (1-2 a month) Frequently (weekly basis or more)		
Explanation for falls if able:			
Other medical/health problems:			

SPIRiTT UIN: Group: Participant's name: DOB:

MDS-UPDRS SCORE SHEET

Assessment Date:		Investigator ID:		Consent given:	
PART I: Non-Motor Aspects of Experiences of Daily Living *(completed by health care professional)*					
1A: Source of information:	Patient	Caregiver	Patient and Caregiver		
1.1 Cognitive impairment			1.4 Anxious mood		
1.2 Hallucinations and psychosis			1.5 Apathy		
1.3 Depressed mood			1.6 Features of Dopamine Dysregulation Syndrome		
PARTS I & II: PATIENT QUESTIONNAIRE *(completed by patient in advance of first visit)*					
1.6a: Source of information:	Patient	Caregiver	Patient and Caregiver		
1.7 Sleep problems			2.4 Eating tasks		
1.8 Daytime sleepiness			2.5 Dressing		
1.9 Pain and other sensations			2.6 Hygiene		
1.10 Urinary problems			2.7 Handwriting		
1.11 Constipation problems			2.8 Doing hobbies and other activities		
1.12 Light headedness on standing			2.9 Turning in bed		
1.13 Fatigue			2.10 Tremor		
2.1 Speech			2.11 Getting out of bed, a car or a deep chair		
2.2 Saliva and drooling			2.12 Walking and balance		
2.3 Chewing and swallowing			2.13 Freezing		
PART III: Motor Examination *(completed by health care professional)*					
3a Is the participant on medication?			3.9 Arising from chair		
3b Participant's clinical state			3.10 Gait		
3c Is the participant on Levodopa?			3.11 Freezing of gait		
3c1 If yes, minutes since last dose:			3.12 Postural stability		
3.1 Speech			3.13 Posture		
3.2 Facial expression			3.14 Global spontaneity of movement		
3.3b Rigidity – RUE			3.15a Postural tremor – RH		
3.3c Rigidity – LUE			3.15b Postural tremor – LH		
3.3d Rigidity – RLE			3.16a Kinetic tremor – RH		
3.3e Rigidity – LLE			3.16b Kinetic tremor – LH		
3.4a Finger tapping – RH			3.17a Rest tremor amplitude – RUE		
3.4b Finger tapping – LH			3.17b Rest tremor amplitude – LUE		
3.5a Hand movements – RH			3.17c Rest tremor amplitude – RLE		
3.5b Hand movements – LH			3.17d Rest tremor amplitude – LLE		
3.6a Pronation-supination movements – RH			3.17e Rest tremor amplitude – Lip/jaw		
3.6b Pronation-supination movements – LH			3.18 Constancy of rest		
3.7a Toe tapping – RF			Were dyskinesias present?		
3.7b Toe tapping – LF			Did these movements interfere with ratings?		
3.8a Leg agility – RL			Hoehn and Yahr Stage		
3.8b Leg agility – LL					
PART IV: Motor Complications *(completed by health care professional)*					
4.1 Time spent with dyskinesias			4.4 Functional impact of fluctuations		
4.2 Functional impact of dyskinesias			4.5 Complexity of motor fluctuations		
4.3 Time spent in OFF state			4.6 Painful OFF-state dystonia		

LIFE PSYCHOL TOOL *(completed by participant in advance)*

To what level does Parkinson's affect:				
Anger and frustration	Not affected	Mildly affected	Moderately affected	Severely affected
Mood (anxiety and depression)	Not affected	Mildly affected	Moderately affected	Severely affected
Fatigue/energy levels	Not affected	Mildly affected	Moderately affected	Severely affected
Sleep	Not affected	Mildly affected	Moderately affected	Severely affected
Pain	Not affected	Mildly affected	Moderately affected	Severely affected
Mobility and/or physical function	Not affected	Mildly affected	Moderately affected	Severely affected
Finances	Not affected	Mildly affected	Moderately affected	Severely affected
Independence	Not affected	Mildly affected	Moderately affected	Severely affected
Domestic task	Not affected	Mildly affected	Moderately affected	Severely affected
Social life and hobbies	Not affected	Mildly affected	Moderately affected	Severely affected

SPIRiTT UIN: Group: Participant's name: DOB:

PARKINSON'S NURSE ASSESSMENT

Date:		Consent given:	

Subjective main problems:

OBSERVATIONS

Blood pressure:	Lying:		Standing:	
Symptomatic postural hypotension:	Yes No		Pulse:	

ANTI-PARKINSON'S DRUG CHART

Drug	0	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23

Summary of assessment

SPIRiTT UIN: Group: Participant's name: DOB:

Leaflets/advice given:			
Plan for interventions/advice:			
Referrals:			
Additional comments:			
Completed by:		**Designation:**	

Page 5 of 21

SPIRiTT UIN: **Group:** **Participant's name:** **DOB:**

Signature:		**Date:**	

SPIRiTT UIN: Group: Participant's name: DOB:

NON-MOTOR SYMPTOMS			
SYMPTOMS	**PRESENT**	**ABSENT**	**COMMENTS**
Problems with drooling			
Problems with swallowing			
Bowel problems (constipation)			
Bladder problems (incontinence)			
Sexual and relationship problems			
Pain			
Apathy			
Fatigue			
Depression			
Hallucinations			
Anxiety			
Dizziness			
Sleep problems			
SIDE EFFECTS OF MEDICATION			
SIDE EFFECT	**PRESENT**	**ABSENT**	**COMMENTS**
Dyskinesia			
On/off fluctuations			
End of dose "wearing off"			
Nausea			

Completed by:		**Designation:**	
Signature:		**Date:**	

Page 7 of 21

SPIRiTT UIN: Group: Participant's name: DOB:

PHYSIOTHERAPY ASSESSMENT

Date:		**Consent given:**	
Subjective main problem:			
Previous PT? Yes No	**Description:**		
Falls?	Never	Occasionally (1-2 a month)	Frequently (weekly basis or more)
Explanation of falls (if appropriate and able):			
Freezing?		**ON/OFF?**	
OBSERVATIONS			
Posture in standing			
Hips/knees:			
Spine:			
Head position:			
Daily activities			
Getting into bed:			
Getting out of bed:			
Turning over in bed:			
Sitting to standing:			
Turning 180°:	4-6 steps	7-8 steps	9-10 steps / 11 or more steps
Stairs:			
Other physical difficulties:			

SPIRiTT UIN: Group: Participant's name: DOB:

Gait			
Mobility indoors:			
Mobility outdoors:			
Arm swing:			
Size of step:			
Heel strike:	Heel/toe	Flat footed	Toe/heel
Any other relevant information:			
Plan for interventions/advice:			

Completed by:		**Designation:**	
Signature:		**Date:**	

Page 9 of 21

SPIRiTT UIN: **Group:** **Participant's name:** **DOB:**

If during the initial assessment, there were problems with poor posture, transfers including bed mobility, balance and falls, mobility including freezing and turning, then a further in depth assessment would follow which could include as appropriate Lindop Parkinson's Assessment Scale and Berg Balance 7 item short form version. A patient specific treatment programme would be provided and may include as appropriate, the Yale balance sheet exercise (level 1-5), Roche exercises for patients with Parkinson's and handwritten individually tailored exercises.

LINDOP PARKINSON'S ASSESSMENT SCALE

Date:			**Consent given:**			
Time of last medication:				**Walking aid:**		
Gait mobility						
			3=	**2=**	**1=**	**0=**
Score =		**Sit to stand:**	Unaided with ease	Unaided with effort	Help of 1	Help of +2
Score =		**Timed unsupported stand:**	60+ seconds	49-59 seconds	30-44 seconds	0-29 seconds
Score =		**Timed up & go:**	10-20 seconds	21-35 seconds	36-60 seconds	60+ seconds
Score =		**180 turn to right:**	4-6 steps	7-8 steps	9-10 steps	11+ steps
Score =		**180 turn to left:**	4-6 steps	7-8 steps	9-10 steps	11+ steps
Score =		**Walking through doorway:**	No freeze/festination	Some festination	Freezes once	Freezes 2+ times
Total =						
Bed mobility						
			3=	**2=**	**1=**	**0=**
Score =		**Sit to lie (56cm bed):**	Unaided with ease (≤5 seconds)	Unaided with effort (6+ seconds)	Help of 1	Help of 2/unable
Score =		**Turn to left on bed:**	Unaided with ease (≤5 seconds)	Unaided with effort (6+ seconds)	Help of 1	Help of 2/unable
Score =		**Turn to right on bed:**	Unaided with ease (≤5 seconds)	Unaided with effort (6+ seconds)	Help of 1	Help of 2/unable
Score =		**Lie to sit on bed:**	Unaided with ease (≤5 seconds)	Unaided with effort (6+ seconds)	Help of 1	Help of 2/unable
Total =						

BERG BALANCE 7 ITEM SHORT FORM VERSION

1. Sitting to standing Instructions: *Please stand up. Try not to use your hands for support.*			
(4) Able to stand without using hands and stabilise independently		(3) Able to stand independently using hands	
(2) Able to stand using hands after several tries		(1) Needs minimal aid to stand or to stabilise	
(0) Needs moderate or maximal assist to stand		Score =	
2. Standing unsupported with eyes closed Instructions: *Please close your eyes and stand still for 10 seconds.*			
(4) Able to stand 10 seconds safely		(3) Able to stand 10 seconds with supervision	
(2) Able to stand 3 seconds		(1) Unable to keep eyes closed 3 seconds but stays steady	
(0) Needs help to keep from falling		Score =	
3. Reaching forward with outstretched arm while standing Instructions: *Lift arm to 90 degrees. Stretch out your fingers and reach forward as far as you can. (Examiner places a ruler at end of fingertips when arm is at 90 degrees. Fingers should not touch the ruler while reaching forward. The recorded measure is the distance forward that the finger reaches while the subject is in the most forward lean position. When possible, ask subject to use both arms when reaching to avoid rotation of the trunk.)*			
(4) Can reach forward confidently >25cm (10 inches)		(3) Can reach forward >12cm safely (5 inches)	
(2) Can reach forward >5cm safely (2 inches)		(1) Reaches forward but needs supervision	
(0) Loses balance while trying/requires external support		Score =	

SPIRiTT UIN: Group: Participant's name: DOB:

4. Pick up object from the floor from a standing position Instructions: *Pick up the shoe/slipper which is placed in front of your feet*		
(4) Able to pick up slipper safely and easily	(3) Able to pick up slipper but needs supervision	
(2) Unable to pick up but reaches 2-5cm (1-2 inches) from slipper and keeps balance independently	(1) Unable to pick up and needs supervision while trying	
(0) Unable to try/needs assist to keep from losing balance or falling	Score =	
5. Turning to look behind over left and right shoulders while standing Instructions: *Turn to look directly behind you over toward left shoulder. Repeat to the right. Examiner may pick up an object to look at directly behind the subject to encourage better arm twist*		
(4) Looks behind from both sides and weight shifts well	(3) Looks behind one side only other side shows less weight shift	
(2) Turns sideways only but maintains balance	(1) Needs supervision when turning	
(0) Needs assist to keep from losing balance or falling	Score =	
6. Standing unsupported one foot in front Instructions: *(Demonstrate to participant) Place one foot directly in front of the other. If you feel that you cannot place your foot directly in front, try to step far enough ahead that the heel of your forward foot is ahead of the toes of the other foot. (To score 3 points, the length of the step should exceed the length of the other foot and the width of the stance should approximate the subject's normal stride width)*		
(4) Able to place foot tandem independently and hold 30 seconds	(3) Able to place foot ahead of other independently and hold 30 seconds	
(2) Able to take small step independently and hold 30 seconds	(1) Needs help to step but can hold 15 seconds	
(0) Loses balance while stepping or standing	Score =	
7. Standing on one leg Instructions: *Stand on one leg as long as you can without holding*		
(4) Able to lift leg independently and hold >10 seconds	(3) Able to lift leg independently and hold 5-10 seconds	
(2) Able to lift leg independently and hold ≥ 3 seconds	(1) Tries to lift leg unable to hold 3 seconds but remains Standing independently	
(0) Unable to try or needs assist to prevent fall	Score =	
	Total score (Maximum = 28) = ***[Score < 23 is considered at risk for falling]***	

Additional comments:			
Completed by:		**Designation:**	
Signature:		**Date:**	

SPIRiTT UIN: Group: Participant's name: DOB:

OCCUPATIONAL THERAPY ASSESSMENT

Date:		Consent given:	
Subjective main problem:			
Previous OT? Yes No	Description:		

	Independent	Independent with equipment	Needs assistance	Unable	Comments
Falls/ mobility					
Stairs/steps					
Handwriting					
Confusion					
Memory loss					
Housework					
Cooking					
Laundry					
Shopping					
Dressing					
Washing					
Bathing					
Toilet					
Hair					

SPIRiTT UIN: Group: Participant's name: DOB:

	Independent	Independent with equipment	Needs assistance	Unable	Comments
Shaving					
Bed					
Chair					
Communications					
Eating					
Driving					
In/out car					
Gardening					
Read/hold book /paper					
Other hobbies					

Known to Social Services:	Yes No		
Any other relevant information:			
Leaflets/advice given:			
Plan for interventions/advice:			
Completed by:		Designation:	
Signature:		Date:	

Page 13 of 21

SPIRiTT UIN: Group: Participant's name: DOB:

SPEECH AND LANGUAGE THERAPY ASSESSMENT

Date:		**Consent given:**	
Subjective main problem:			
SLT Observations:			
Previous SLT? Yes No	**Description:**		
Do you ever do any practice exercises to improve your speech?		Yes	No
If yes, how much time do you spend a day or week?			
1) Maximum sustained phonation ***"Say 'ahhh' for as loud and as long as you can"*** ..... **seconds** ..... **db**		15-25 Normal 11-24 Good 6-10 Fair 1-5 Poor	
2) Ability to sustain /s/ on exhalation ***"Let your breath out on a hiss 'sssss'. Keep the sound going for as long as you can"*** ..... **seconds**		20-30 Normal 15-19 Good 10-14 Fair 1-9 Poor	
3) Ability to crescendo on /ah/ ***"As you let your breath out on an 'ahhh', begin softly and gradually make the sound louder and louder"***		Good ability Some variation Poor Unable to vary volume	
4) Maximum db – Functional phrase ***"Please read aloud from the card as if you were speaking to someone sitting opposite"***		..... **db**	
DIADOCHOKINESIS			
5) Open and close mouth (5 seconds) ..... **repetitions**		15-20 Normal 10-14 Good 5-9 Fair 1-4 Poor	
6) Tongue in and out (5 seconds) ..... **repetitions**		18-25 Normal 14-17 Good 8-13 Fair 1-7 Poor	
7) "Oo-ee" (5 seconds) ..... **repetitions**		15-20 Normal 10-14 Good 5-9 Fair 1-4 Poor	

SPIRiTT UIN:	Group:	Participant's name:	DOB:

8) "Pa-pa-pa" (5 seconds) **..... repetitions**	20-30 Normal 15-19 Good 8-14 Fair 1-7 Poor
9) "Ta-ta-ta" (5 seconds) **..... repetitions**	20-30 Normal 15-19 Good 8-14 Fair 1-7 Poor
10) "Ka-ka-ka" (5 seconds) **..... repetitions**	20-30 Normal 15-19 Good 8-14 Fair 1-7 Poor
11) "P-T-K" (5 seconds) **..... repetitions**	20-30 Normal 15-19 Good 8-14 Fair 1-7 Poor
Overall, if any, what impact do you feel your speech difficulty is having on your life? **Score .....**	1 Only occasionally (e.g. in company) 2 Moderate (more than once/week) 3 Significant trouble (every day)
Do you feel that you understand why you have speech difficulty and what you can do to improve your speech?	Yes No
Have you had any problems with eating or drinking?	Yes No
If yes, please describe and complete dysphagia assessment and Sydney Swallow Questionnaire	
How often do you experience swallowing problems? **Score .....**	1 Mild (once a week) 2 Moderate (more than once/week) 3 Severe (every day)
How much does your swallowing problem interfere with your enjoyment or quality of life? **Score .....**	1 Only occasionally (e.g. in company) 2 Moderate (more than once/week) 3 Significant trouble (every day)
What strategies have you used that facilitate your eating/drinking?	
How long does it take you to eat an average meal?	Less than 15 minutes 15-30 minutes 30-45 minutes 45-60 minutes more than 60 minutes Unable to swallow at all
Have you modified what you eat/drink to make it easier?	Yes No
If yes, please describe	

SPIRiTT UIN: Group: Participant's name: DOB:

Current eating/drinking

☐ Fluids ☐ Normal ☐ Thickened (specify stage).....

☐ Food ☐ Normal ☐ Modified (specify).....

Do you have any difficulty swallowing your saliva?	Yes	No
If yes, please describe		

Have you had any recent chest infections?	Yes	No
If yes, please explain		

Oral hygiene (please check all that apply)

☐ Clean ☐ Dentures ☐ Dehydrated ☐ Excess secretions ☐ Coated

SYDNEY SWALLOW QUESTIONNAIRE

PLEASE PLACE AN X ON THE LINE TO INDICATE HOW SEVERE YOUR SWALLOWING PROBLEM IS FOR EACH QUESTION BELOW

1) How much difficulty do you have swallowing at present?

No difficulty at all ——— Unable to swallow at all

2) How much difficulty do you have swallowing THIN liquids (e.g. tea, soft drink, beer, coffee)?

No difficulty at all ——— Unable to swallow at all

3) How much difficulty do you have swallowing THICK liquids (e.g. milkshake, soup, custard)?

No difficulty at all ——— Unable to swallow at all

4) How much difficulty do you have swallowing SOFT foods (e.g. scrambled egg, mashed potato)?

No difficulty at all ——— Unable to swallow at all

5) How much difficulty do you have swallowing HARD foods (e.g. steak, raw vegetables, raw fruit)?

No difficulty at all ——— Unable to swallow at all

6) How much difficulty do you have swallowing DRY foods (e.g. bread, biscuits, nuts)?

No difficulty at all ——— Unable to swallow at all

SPIRiTT UIN: Group: Participant's name: DOB:

7) Do you have any difficulty swallowing your saliva?

No difficulty at all — Unable to swallow at all

8) Do you have any difficulty starting a swallow?

Never occurs — Occurs every time I swallow

9) Do you ever have a feeling of food getting stuck in your throat when you swallow?

Never occurs — Occurs every time I swallow

10) Do you ever cough or choke when swallowing solid foods (e.g. bread, meat, fruit)?

Never occurs — Occurs every time I eat

11) Do you ever cough or choke when swallowing liquids (e.g. coffee, tea, water, beer)?

Never occurs — Occurs every time I drink

13) When you swallow, does food or liquid go up behind your nose or come out of your nose?

Never occurs — Occurs every time I swallow

14) Do you ever need to swallow more than once for your food to go down?

Never occurs — Occurs every time I swallow

15) Do you ever cough up or spit out food or liquids DURING a meal?

Never occurs — Occurs every time I eat or drink

16) How do you rate the severity of your swallowing problem today?

No problem — Extremely severe problem

17) How much does your swallowing problem interfere with your enjoyment or quality of life?

No interference — Extreme interference

Page 17 of 21

SPIRiTT UIN: Group: Participant's name: DOB:

OROFACIAL EXAMINATION				
Cranial nerve	Action	WNL	Impaired	Comments
V	Open jaw			
	Close jaw			
	Lateral movement			
VII	Lip protrusion/retraction			
	Alternate			
	Symmetry of smile			
	Lip seal (puff air into cheeks)			
IX	Altered taste			
XII	Tongue protrusion/retraction			
	Elevation			
	Depression			
	Lateral L/R			
	Into cheek L/R			
	Around lips			
X	Palate elevation/depression			
	Voluntary cough			
	Reflexive cough			
	Voice quality and pitch			
Observation of liquid swallow				

SPIRiTT UIN: Group: Participant's name: DOB:

SLT summary of communication and swallowing			
Plan for interventions/advice:			
Leaflets/advice given: (*Tips information leaflet – minimum*)			
Completed by:		**Designation:**	
Signature:		**Date:**	

Page 19 of 21

SPIRiTT UIN: Group: Participant's name: DOB:

AGREED CARE PLAN

No.	Date	Problem	Action	Goal	Review	Review date	Signature

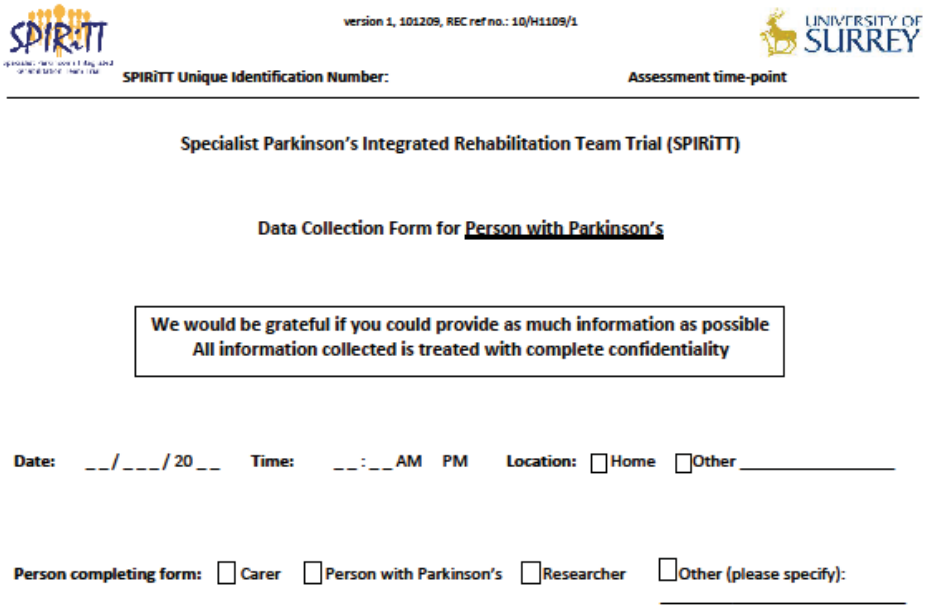
SPIRiTT UIN: Group: Participant's name: DOB:

MULTIDISCIPLINARY NOTES

DATE	NOTES	SIGNATURE (POSITION)

Appendix 13 Outcome measures: self-report questionnaires

Person with Parkinson's self-report questionnaire



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SPIRiTT Unique Identification Number: Assessment time-point

Specialist Parkinson's Integrated Rehabilitation Team Trial (SPIRiTT)

Data Collection Form for Person with Parkinson's

We would be grateful if you could provide as much information as possible
All information collected is treated with complete confidentiality

Date: __/___/ 20__ Time: __:__ AM PM Location: ☐ Home ☐ Other _____

Person completing form: ☐ Carer ☐ Person with Parkinson's ☐ Researcher ☐ Other (please specify): _____

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Page 1 of 17

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SPIRiTT Unique Identification Number: Assessment time-point

SELF ASSESSMENT PARKINSON'S SCALE

For each item below, please tick the box which best describes how easy or difficult it is for you to perform that activity. If you are more able at some times than others, indicate how you are IN GENERAL at the times of day you would normally perform these activities. If you use a frame or walking stick or any special aids to help you, please answer according to how well you would manage WITHOUT the aid.

Activity	Able to do alone without difficulty	Able to do alone with a little effort	Able to do alone with a lot of effort or with a little help	Able to do but only with a lot of help	Unable to do at all
1) Get out of bed					
2) Get up from an armchair					
3) Walk around the house/flat					
4) Walk outside such as to the local shops					
5) Travel by public transport					
6) Walk up stairs					
7) Walk down stairs					
8) Wash face and hands					
9) Get into a bath					
10) Get out of a bath					
11) Get dressed					
12) Get undressed					
13) Brush your teeth					
14) Open tins (not using an electric opener)					
15) Pour milk from a bottle or carton					
16) Make a cup of tea or coffee					
17) Hold a cup and saucer					
18) Wash and dry dishes					
19) Cut food with a knife and fork					
20) Pick up an object from the floor					
21) Insert and remove an electric plug					
22) Dial a telephone					
23) Hold and read a newspaper					
24) Write a letter					
25) Turn over in bed					

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SPIRiTT Unique Identification Number: **Assessment time-point**

EuroQol QUESTIONNAIRE

Please indicate which statement best describes your own health. Please tick only one box in each section.

1) Mobility
- ☐ I have no problems with walking around
- ☐ I have some problems with walking around
- ☐ I am confined to bed

2) Self-care
- ☐ I have no problems with self-care
- ☐ I have some problems with washing or dressing myself
- ☐ I am unable to wash or dress myself

3) Usual activities (e.g. work, study, housework, family or leisure activities)
- ☐ I have no problems with performing my usual activities
- ☐ I have some problems with performing my usual activities
- ☐ I am unable to perform my usual activities

4) Pain/Discomfort
- ☐ I have no pain or discomfort
- ☐ I have moderate pain or discomfort
- ☐ I have extreme pain or discomfort

5) Anxiety/Depression
- ☐ I am not anxious or depressed
- ☐ I am moderately anxious or depressed
- ☐ I am extremely anxious or depressed

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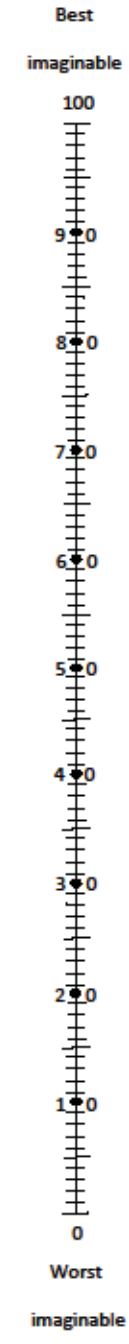
EuroQoL THERMOMETER

To help people say how good or bad a health state is, we have drawn a scale (rather like a thermometer) on which the best state you can imagine is marked 100 and the worst state you can imagine is marked 0.

We would like you to indicate on this scale how good or bad your own health is TODAY, in your opinion. Please do this by drawing a line from the box below to whichever point on the scale indicates how good or bad your health state is TODAY.

Your own health state today



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NON-MOTOR SYMPTOMS QUESTIONNAIRE

From the list below, please tick the box 'Yes' if you have experienced the symptom during the PAST MONTH. You should answer 'No' even if you have had the symptom in the past, but not in the past month.

Have you experienced any of the following in the LAST MONTH?	Yes	No
1) Dribbling of saliva during the daytime		
2) Loss or change in your ability to taste or smell		
3) Difficulty swallowing food or drink or problems with choking		
4) Vomiting or feelings of sickness (nausea)		
5) Constipation (less than three bowel movements a week) or having to strain to pass a stool		
6) Bowel (faecal) incontinence		
7) Feeling that your bowel emptying is incomplete after having been to the toilet		
8) A sense of urgency to pass urine makes you rush to the toilet		
9) Getting up regularly at night to pass urine		
10) Unexplained pains (not due to known conditions such as arthritis)		
11) Unexplained change in weight (not due to change in diet)		
12) Problems remembering things that have happened recently or forgetting to do things		
13) Loss of interest in what is happening around you or in doing things		
14) Seeing or hearing things that you know or are told are not there		
15) Difficulty concentrating or staying focused		
16) Feeling sad, 'low' or 'blue'		
17) Feeling anxious, frightened or panicky		
18) Feeling less interested in sex or more interested in sex		
19) Finding it difficult to have sex when you try		
20) Feeling light-headed, dizzy or weak standing from sitting or lying		
21) Falling		
22) Finding it difficult to stay awake during activities such as working, driving or eating		
23) Difficulty getting to sleep at night or staying asleep at night		
24) Intense, vivid or frightening dreams		
25) Talking or moving about in your sleep, as if you are 'acting out' a dream		
26) Unpleasant sensations in your legs at night or while resting, and a feeling that you need to move		
27) Swelling of the legs		
28) Excessive sweating		
29) Double vision		
30) Believing things are happening to you that other people say are not		

PARKINSON'S QUESTIONNAIRE – 8

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SPIRiTT Unique Identification Number: Assessment time-point

Please tick √ only one box for each question below.

Due to having Parkinson's, how often during the LAST MONTH have you	Never	Occasionally	Sometimes	Often	Always
1) had difficulty getting around in public?					
2) had difficulty dressing yourself?					
3) felt depressed?					
4) felt embarrassed in public due to having Parkinson's?					
5) had problems with your close personal relationships?					
6) had problems with your concentration such as when reading or watching TV?					
7) felt unable to communicate with people properly?					
8) had painful muscle cramps or spasms?					

FRENCHAY ACTIVITIES INDEX

Please answer the following questions by placing a checkmark/tick in one of the boxes.

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SPIRiTT Unique Identification Number: **Assessment time-point**

In the LAST 3 MONTHS, how often have you undertaken:	Never	Less than once a week	1 to 2 times a week	Most days
1) preparing main meals? *(not just making snacks or reheating prepared food)*				
2) washing up? *(not just rinsing or an occasional item)*				

In the LAST 3 MONTHS, how often have you undertaken:	Never	1 to 2 times in 3 months	3 to 12 times in 3 months	At least weekly
3) washing clothes?				
4) light housework? *(such as dusting, polishing, ironing)*				
5) heavy housework? *(such as changing beds, cleaning floors, vacuuming, moving chairs, gardening)*				
6) local shopping?				
7) social outings? *(can include social activities at home such as visits from friends, not for the purpose of providing care)*				
8) walking outside more than 15 minutes? *(includes shopping)*				
9) actively pursuing a hobby *(includes reading)*?				
10) driving a car/going on a bus? *(must travel independently)*				

PAIN VISUAL ANALOGUE SCALE

Please mark, using a 'X' on the visual analogue scales below, what your pain levels have been like, on average, in the LAST 2 WEEKS. 0 represents 'no pain at all' and 10 represents 'worst imaginable pain possible'

1) During your 'on' state:

no pain at all 0 _____ 10 *worst imaginable pain possible*

2) During your 'off' state:

no pain at all 0 _____ 10 *worst imaginable pain possible*

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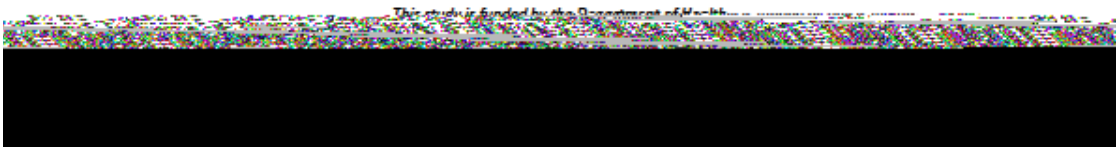
SPIRiTT Unique Identification Number: **Assessment time-point**

SPEECH SELF REPORT QUESTIONNAIRE

Here are 11 statements about speaking. You may feel that some of them are a characteristic of your speech. Read each one carefully and indicate by ticking √ the appropriate box how often they apply to you.

Statements	Never	Rarely	Occasionally	Often	Very often	Always
1) My voice is weak and I have difficulty in raising it to make it louder						
2) I find it difficult to keep speaking at the same speed such that my speech gets faster and faster						
3) My face becomes stiff and this makes speaking difficult						
4) My speech sounds flat and monotonous with little variation in pitch or quality						
5) I have difficulty coordinating my breathing with my speech so that I become "out of breath" in a long conversation						
6) People complain of my voice being too quiet						
7) I find it difficult to start speaking so that I can sound hesitant						
8) My voice sounds husky						
9) My speech does not sound as clear as it used to						
10) Sometimes I cannot remember the name of something						
11) I find food/drink escapes from my lips when eating/drinking						



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SPIRiTT Unique Identification Number: **Assessment time-point**

Here are 15 situations. Please indicate by ticking √ the appropriate box, how often you may AVOID these situations because of your communication.

Situations	Never	Rarely	Occasionally	Often	Very often	Always
1) Making telephone calls						
2) Answering the telephone						
3) Speaking in shops (empty)						
4) Speaking in shops (full)						
5) Buying a train/bus ticket						
6) Speaking to strangers						
7) Asking the way						
8) Speaking to young children						
9) Speaking to friends						
10) Speaking to a group of people						
11) Ordering in a café/restaurant/bar						
12) Introducing myself						
13) Introducing one person to another						
14) Participating in a meeting						
15) Phoning to make an appointment/arrange details						

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SPIRITT Unique Identification Number: **Assessment time-point**

SELF EFFICACY SCALE – 6

We would like to know how confident you are in doing certain activities. For each of the following questions, please choose the number that corresponds to how confident you are that you can do the tasks regularly at the present time.

How confident are you that you can:	Please tick the box which best represents your confidence level
1) keep the fatigue caused by your condition from interfering with the things you want to do?	*Not at all confident* ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ 8 ☐ 9 ☐ 10 *totally confident*
2) keep the physical discomfort or pain of your condition from interfering with the things you want to do?	*Not at all confident* ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ 8 ☐ 9 ☐ 10 *totally confident*
3) keep the emotional distress caused by your condition from interfering with the things you want to do?	*Not at all confident* ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ 8 ☐ 9 ☐ 10 *totally confident*
4) keep any other symptoms or health problems you have from interfering with the things you want to do?	*Not at all confident* ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ 8 ☐ 9 ☐ 10 *totally confident*
5) do the difficult tasks and activities needed to manage your health condition so as to reduce your need to see a doctor?	*Not at all confident* ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ 8 ☐ 9 ☐ 10 *totally confident*
6) do things other than just taking medication to reduce how much your condition affects your everyday life?	*Not at all confident* ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ 8 ☐ 9 ☐ 10 *totally confident*

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SPIRiTT Unique Identification Number: Assessment time-point

WELLBEING QUESTIONNAIRE (Hospital Anxiety and Depression Scale)

Without thinking too much, please place a checkmark/tick √ in the box that applies to you. Please choose only one box for each question.

1) I feel tense or 'wound up'
☐ Not at all ☐ From time to time, occasionally ☐ A lot of the time ☐ Most of the time

2) I still enjoy the things I used to enjoy
☐ Hardly at all ☐ Only a little ☐ Not quite so much ☐ Definitely as much

3) I get a sort of frightened feeling as if something awful is about to happen
☐ Not at all ☐ A little, but it does not worry me ☐ Yes, but not too badly ☐ Very definitely and quite badly

4) I can laugh and see the funny side of things
☐ Not at all ☐ Definitely not so much now ☐ Not quite so much now ☐ As much as I always could

5) Worrying thoughts go through my mind
☐ Only occasionally ☐ From time to time, but not too often ☐ A lot of the time ☐ A great deal of the time

6) I feel cheerful
☐ Not at all ☐ Not often ☐ Sometimes ☐ Most of the time

7) I can sit at ease and feel relaxed
☐ Not at all ☐ Not often ☐ Usually ☐ Definitely

8) I feel as if I am slowed down
☐ Not at all ☐ Sometimes ☐ Very often ☐ Nearly all the time

9) I get a sort of frightened feeling like 'butterflies' in the stomach
☐ Not at all ☐ Occasionally ☐ Quite often ☐ Very often

10) I have lost interest in my appearance
☐ Definitely ☐ I do not take as much care as I should ☐ I may not take quite as much care ☐ I take just as much care as ever

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SPIRiTT Unique Identification Number: Assessment time-point

11) I feel restless as if I have to be on the move

☐ Not at all ☐ Not very much ☐ Quite a lot ☐ Very much indeed

12) I look forward with enjoyment to things

☐ Hardly at all ☐ Definitely less than I used to ☐ Rather less than I used to ☐ As much as I ever did

13) I get sudden feelings of panic

☐ Not at all ☐ Not very often ☐ Quite often ☐ Very often indeed

14) I can enjoy a good book or radio or TV programme

☐ Very seldom ☐ Not often ☐ Sometimes ☐ Often

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SPIRiTT Unique Identification Number: Assessment time-point

SHORT FORM 36 HEALTH SURVEY

Please respond to the questions below, by placing a checkmark/tick √ in the appropriate box.

1) In general, would you say your health is:

☐ Excellent ☐ Very good ☐ Good ☐ Fair ☐ Poor

2) Compared to one year ago, how would you rate your health in general NOW?

☐ Much better now than one year ago ☐ Somewhat better now than one year ago ☐ About the same as one year ago ☐ Somewhat worse than one year ago ☐ Much worse than one year ago

With reference to the activities listed below that you may do during a typical day, does your health NOW limit you in these activities? If so, how much?	No, not limited at all	Yes, limited a little	Yes, limited a lot
3) Vigorous activities such as running, lifting heavy objects, participating in strenuous sports			
4) Moderate activities such as moving a table, pushing a vacuum cleaner, bowling or playing golf			
5) Lifting or carrying groceries			
6) Climbing several flights of stairs			
7) Climbing one flight of stairs			
8) Bending, kneeling or stooping			
9) Walking more than a mile			
10) Walking half a mile			
11) Walking one hundred yards			
12) Bathing or dressing yourself			

During the PAST 4 WEEKS, have you had any of the following problems with your work or other regular daily activities as a result of your PHYSICAL health?	Yes	No
13) Cut down on the amount of time you spent on work or other activities		
14) Accomplished less than you would like		
15) Were limited in the kind of work or other activities		
16) Had difficulty performing the work or other activities (for example, it took extra effort)		

During the PAST 4 WEEKS, have you had any of the following problems with your work or other regular daily activities as a result of any EMOTIONAL problems (such as feeling depressed or anxious)?	Yes	No
17) Cut down on the amount of time you spent on work or other activities		
18) Accomplished less than you would like		
19) Did not do work or other activities as carefully as usual		

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SPIRITT Unique Identification Number: **Assessment time-point**

20) During the PAST 4 WEEKS, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbours or groups?

☐ Not at all ☐ Slightly ☐ Moderately ☐ Quite a bit ☐ Extremely

21) How much bodily pain have you had during the PAST 4 WEEKS?

☐ None ☐ Very mild ☐ Mild ☐ Moderate ☐ Severe ☐ Very severe

22) During the PAST 4 WEEKS, how much did pain interfere with your normal work (including both work outside the home and housework)?

☐ Not at all ☐ A little bit ☐ Moderately ☐ Quite a bit ☐ Extremely

23) During the PAST 4 WEEKS, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting friends, relatives etc)?

☐ All of the time ☐ Most of the time ☐ Some of the time ☐ A little of the time ☐ None of the time

How much of the time during the PAST 4 WEEKS:	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
24) Did you feel full of life?						
25) Have you been a very nervous person?						
26) Have you felt so down in the dumps that nothing could cheer you up?						
27) Have you felt calm and peaceful?						
28) Did you have a lot of energy?						
29) Have you felt downhearted and low?						
30) Did you feel worn out?						
31) Have you been a happy person?						
32) Did you feel tired?						

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SPIRiTT Unique Identification Number: **Assessment time-point**

How TRUE or FALSE is each of the following statements to you?	Definitely true	Mostly true	Don't know	Mostly false	Definitely false
33) I seem to get ill more easily than other people					
34) I am as healthy as anybody I know					
35) I expect my health to get worse					
36) My health is excellent					

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SPIRITT Unique Identification Number: Assessment time-point

ACTIVITIES OF DAILY LIVING QUESTIONNAIRE (BARTHEL)

Please select the statement which best describes your situation. Please tick only one box in each section.

1) Mobility around house

☐ Immobile ☐ Wheelchair independent around corners etc ☐ Walks with verbal or physical help of 1 person ☐ Independent *(but can use walking aid such as a stick)*

2) Stairs

☐ Unable ☐ Needs verbal or physical help *(carrying aid)* ☐ Independent up and down

3) Transfer from bed to chair and back

☐ Unable ☐ Needs major help (1 or 2 people, physical help) ☐ Needs minor verbal or physical help ☐ Independent

4) Bathing

☐ Dependent ☐ Independent

5) Grooming (personal hygiene such as brushing teeth and hair, shaving, washing face)

☐ Needs help ☐ Independent

6) Dressing

☐ Dependent ☐ Needs help but can do half unaided ☐ Independent

7) Feeding (able to eat normal food, not just soft food)

☐ Unable ☐ Needs help cutting, spreading butter etc ☐ Independent

8) Toilet use

☐ Dependent ☐ Needs some help but can do something ☐ Independent

9) Bladder

☐ Incontinent or catheterised and unable to manage ☐ Occasional accident (maximum 1 time in a day) ☐ Continent over 7 days

10) Bowels

☐ Incontinent ☐ Occasional accident (1 per week) ☐ Continent

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SPIRiTT Unique Identification Number: **Assessment time-point**

THANK YOU for taking the time to complete this questionnaire.

Please check through to ensure that you have answered all the questions.

Your input is extremely valued and very much appreciated.

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Live-in carer self-report questionnaire

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SPIRiTT Unique Identification Number: Assessment time-point

Specialist Parkinson's Integrated Rehabilitation Team Trial (SPIRiTT)

Background questionnaire for Live-in carer of person with Parkinson's

We would be grateful if you could provide as much information as possible
All information collected is treated with complete confidentiality

Date: __/___/ 20__ **Time:** __:__ AM PM **Location:** ☐ Home ☐ Other _____

Person completing form: ☐ Carer ☐ Person with Parkinson's ☐ Researcher ☐ Other (please specify): _____

ABOUT YOUR CARING ROLE

In answering the questions below, please place ticks √ in the relevant boxes.

1) On A TYPICAL DAY, how much of the time can you leave the person with Parkinson's at home alone?

☐ Less than 25% of the time ☐ Between 25 to 49% of the time ☐ Between 50 to 74% of the time ☐ Between 75 to 100% of the time

2) In AN AVERAGE WEEK, how many of hours of care or assistance do you provide to the person with Parkinson's?

_____ hours per week

3) What sort of activities do you do? *(Please tick all that applies)*

☐ Communicate/leave reminders	☐ Attending to person's appearance (e.g. help with grooming)	☐ Help with dressing/ undressing etc	☐ Household chores (e.g. minor repairs/ gardening)
☐ Managing money	☐ Cooking/preparing meals/eating	☐ Transport/take out shopping/outings etc	☐ Supervising the person
☐ Shopping	☐ Other (please specify): _____	☐ Other (please specify): _____	☐ Other (please specify): _____

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4) **Other than you, does anyone else (such as friends, relatives, paid carers) provide regular care for the person with Parkinson's?**

☐ Yes, unpaid carer (such as friends or relatives) ☐ Yes, paid carer ☐ No ☐ Other (please specify): _____

5) **Have you given up or cut down on work in order to provide care for the person with Parkinson's?**

☐ Yes, cut down on work ☐ Yes, given up work ☐ No

6) **Do you frequently feel sad or depressed?** ☐ Yes ☐ No

ABOUT YOU AND YOUR HEALTH

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Favourable ethical opinion has been granted by Surrey Research Ethics Committee

version 1, 101209, REC ref no.: 10/H1109/1

SPIRiTT Unique Identification Number: Assessment time-point

MODIFIED CAREGIVER STRAIN INDEX (CSI)

Here is a list of things that other caregivers have found to be difficult. Please place a checkmark/tick √ in the box that applies to you. We have included some examples that are common caregiver experiences to help you think about each item. Your situation may be slightly different, but the item could still apply.

	Yes, on a regular basis	Yes, sometimes	No
1) **My sleep is disturbed** *(for example: the person I care for is in and out of bed or wanders around at night)*	☐	☐	☐
2) **Caregiving is inconvenient** *(For example: helping takes so much time or it's a long drive over to help)*	☐	☐	☐
3) **Caregiving is a physical strain** *(For example: lifting in or out of a chair; effort or concentration is required)*	☐	☐	☐
4) **Caregiving is confining** *(For example: helping restricts free time or I cannot go visiting)*	☐	☐	☐
5) **There have been family adjustments** *(For example: helping has disrupted my routine; there is no privacy)*	☐	☐	☐
6) **There have been changes in personal plans** *(For example: I had to turn down a job; I could not go on vacation)*	☐	☐	☐
7) **There have been other demands on my time** *(For example: other family members need me)*	☐	☐	☐
8) **There have been emotional adjustments** *(For example: severe arguments about caregiving)*	☐	☐	☐
9) **Some behaviour is upsetting** *(For example: incontinence; the person cared for has trouble remembering things; or the person I care for accuses people of taking things)*	☐	☐	☐
10) **It is upsetting to find the person I care for has changed so much from his/her former self** *(For example: s/he is a different person that s/he used to be)*	☐	☐	☐
11) **There have been work adjustments** *(For example: I have to take time off for caregiving duties)*	☐	☐	☐
12) **Caregiving is a financial strain**	☐	☐	☐
13) **I feel completely overwhelmed** *(For example: I worry about the person I care for; I have concerns about how I will manage)*	☐	☐	☐

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EuroQol QUESTIONNAIRE

Please indicate which statement best describes your own health. Please tick only one box in each section.

1) Mobility
- ☐ I have no problems with walking around
- ☐ I have some problems with walking around
- ☐ I am confined to bed

2) Self-care
- ☐ I have no problems with self-care
- ☐ I have some problems with washing or dressing myself
- ☐ I am unable to wash or dress myself

3) Usual activities (e.g. work, study, housework, family or leisure activities)
- ☐ I have no problems with performing my usual activities
- ☐ I have some problems with performing my usual activities
- ☐ I am unable to perform my usual activities

4) Pain/Discomfort
- ☐ I have no pain or discomfort
- ☐ I have moderate pain or discomfort
- ☐ I have extreme pain or discomfort

5) Anxiety/Depression
- ☐ I am not anxious or depressed
- ☐ I am moderately anxious or depressed
- ☐ I am extremely anxious or depressed

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version 1, 101209, REC ref no.: 10/H1109/1

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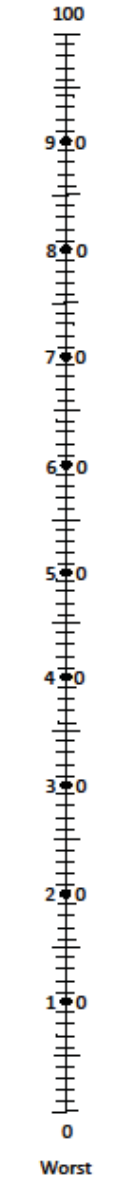
EuroQoL THERMOMETER

To help people say how good or bad a health state is, we have drawn a scale (rather like a thermometer) on which the best state you can imagine is marked 100 and the worst state you can imagine is marked 0.

We would like you to indicate on this scale how good or bad your own health is TODAY, in your opinion. Please do this by drawing a line from the box below to whichever point on the scale indicates how good or bad your health state is TODAY.

Your own health state today



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GENERAL HEALTH QUESTIONNAIRE – 12

Please consider THE LAST FOUR WEEKS and answer the following questions by placing a checkmark/tick in one of the boxes.

In the LAST 4 WEEKS, have you:	much less than usual	less than usual	better than usual	same as usual
1) been able to concentrate on what you're doing?				
2) felt you were playing a useful part in things?				
3) felt capable of making decisions about things?				
4) been able to enjoy your normal day-to-day activities?				
5) been able to face up to your problems?				
6) been feeling reasonably happy, all things considered?				

In the LAST 4 WEEKS, have you:	not at all	no more than usual	rather more than usual	much more than usual
7) lost much sleep over worry?				
8) felt constantly under strain?				
9) felt you couldn't overcome your difficulties?				
10) been feeling unhappy and depressed?				
11) been losing confidence in yourself?				
12) been thinking of yourself as a worthless person?				

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SPIRiTT Unique Identification Number: Assessment time-point

FRENCHAY ACTIVITIES INDEX

Please answer the following questions by placing a checkmark/tick in one of the boxes.

In the LAST 3 MONTHS, how often have you undertaken:	Never	Less than once a week	1 to 2 times a week	Most days
1) preparing main meals? *(not just making snacks or reheating prepared food)*				
2) washing up? *(not just rinsing or an occasional item)*				

In the LAST 3 MONTHS, how often have you undertaken:	Never	1 to 2 times in 3 months	3 to 12 times in 3 months	At least weekly
3) washing clothes?				
4) light housework? *(such as dusting, polishing, ironing)*				
5) heavy housework? *(such as changing beds, cleaning floors, vacuuming, moving chairs, gardening)*				
6) local shopping?				
7) social outings? *(can include social activities at home such as visits from friends, not for the purpose of providing care)*				
8) walking outside more than 15 minutes? *(includes shopping)*				
9) actively pursuing a hobby *(includes reading)*?				
10) driving a car/going on a bus? *(must travel independently)*				

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SPIRiTT Unique Identification Number: Assessment time-point

WELLBEING QUESTIONNAIRE (Hospital Anxiety and Depression Scale)

Without thinking too much, please place a checkmark/tick √ in the box that applies to you. Please choose only one box for each question.

1) I feel tense or 'wound up'

☐ Not at all ☐ From time to time, occasionally ☐ A lot of the time ☐ Most of the time

2) I still enjoy the things I used to enjoy

☐ Hardly at all ☐ Only a little ☐ Not quite so much ☐ Definitely as much

3) I get a sort of frightened feeling as if something awful is about to happen

☐ Not at all ☐ A little, but it does not worry me ☐ Yes, but not too badly ☐ Very definitely and quite badly

4) I can laugh and see the funny side of things

☐ Not at all ☐ Definitely not so much now ☐ Not quite so much now ☐ As much as I always could

5) Worrying thoughts go through my mind

☐ Only occasionally ☐ From time to time, but not too often ☐ A lot of the time ☐ A great deal of the time

6) I feel cheerful

☐ Not at all ☐ Not often ☐ Sometimes ☐ Most of the time

7) I can sit at ease and feel relaxed

☐ Not at all ☐ Not often ☐ Usually ☐ Definitely

8) I feel as if I am slowed down

☐ Not at all ☐ Sometimes ☐ Very often ☐ Nearly all the time

9) I get a sort of frightened feeling like 'butterflies' in the stomach

☐ Not at all ☐ Occasionally ☐ Quite often ☐ Very often

10) I have lost interest in my appearance

☐ Definitely ☐ I do not take as much care as I should ☐ I may not take quite as much care ☐ I take just as much care as ever

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Page 8 of 14

SPIRiTT Unique Identification Number: Assessment time-point

11) I feel restless as if I have to be on the move

☐ Not at all ☐ Not very much ☐ Quite a lot ☐ Very much indeed

12) I look forward with enjoyment to things

☐ Hardly at all ☐ Definitely less than I used to ☐ Rather less than I used to ☐ As much as I ever did

13) I get sudden feelings of panic

☐ Not at all ☐ Not very often ☐ Quite often ☐ Very often indeed

14) I can enjoy a good book or radio or TV programme

☐ Very seldom ☐ Not often ☐ Sometimes ☐ Often

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SHORT FORM 36 HEALTH SURVEY

Please respond to the questions below, by placing a checkmark/tick √ in the appropriate box.

1) In general, would you say your health is:

☐ Excellent ☐ Very good ☐ Good ☐ Fair ☐ Poor

2) Compared to one year ago, how would you rate your health in general NOW?

☐ Much better now than one year ago ☐ Somewhat better now than one year ago ☐ About the same as one year ago ☐ Somewhat worse than one year ago ☐ Much worse than one year ago

With reference to the activities listed below that you may do during a typical day, does your health NOW limit you in these activities? If so, how much?	No, not limited at all	Yes, limited a little	Yes, limited a lot
3) Vigorous activities such as running, lifting heavy objects, participating in strenuous sports			
4) Moderate activities such as moving a table, pushing a vacuum cleaner, bowling or playing golf			
5) Lifting or carrying groceries			
6) Climbing several flights of stairs			
7) Climbing one flight of stairs			
8) Bending, kneeling or stooping			
9) Walking more than a mile			
10) Walking half a mile			
11) Walking one hundred yards			
12) Bathing or dressing yourself			

During the PAST 4 WEEKS, have you had any of the following problems with your work or other regular daily activities as a result of your PHYSICAL health?	Yes	No
13) Cut down on the amount of time you spent on work or other activities		
14) Accomplished less than you would like		
15) Were limited in the kind of work or other activities		
16) Had difficulty performing the work or other activities (for example, it took extra effort)		

During the PAST 4 WEEKS, have you had any of the following problems with your work or other regular daily activities as a result of any EMOTIONAL problems (such as feeling depressed or anxious)?	Yes	No
17) Cut down on the amount of time you spent on work or other activities		
18) Accomplished less than you would like		
19) Did not do work or other activities as carefully as usual		

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Page 10 of 14

version 1, 101209, REC ref no.: 10/H1109/1

SPIRiTT Unique Identification Number: Assessment time-point

20) During the PAST 4 WEEKS, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbours or groups?

☐ Not at all ☐ Slightly ☐ Moderately ☐ Quite a bit ☐ Extremely

21) How much bodily pain have you had during the PAST 4 WEEKS?

☐ None ☐ Very mild ☐ Mild ☐ Moderate ☐ Severe ☐ Very severe

22) During the PAST 4 WEEKS, how much did pain interfere with your normal work (including both work outside the home and housework)?

☐ Not at all ☐ A little bit ☐ Moderately ☐ Quite a bit ☐ Extremely

23) During the PAST 4 WEEKS, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting friends, relatives etc)?

☐ All of the time ☐ Most of the time ☐ Some of the time ☐ A little of the time ☐ None of the time

How much of the time during the PAST 4 WEEKS:	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
24) Did you feel full of life?						
25) Have you been a very nervous person?						
26) Have you felt so down in the dumps that nothing could cheer you up?						
27) Have you felt calm and peaceful?						
28) Did you have a lot of energy?						
29) Have you felt downhearted and low?						
30) Did you feel worn out?						
31) Have you been a happy person?						
32) Did you feel tired?						

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How TRUE or FALSE is each of the following statements to you?	Definitely true	Mostly true	Don't know	Mostly false	Definitely false
33) I seem to get ill more easily than other people					
34) I am as healthy as anybody I know					
35) I expect my health to get worse					
36) My health is excellent					

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SPIRiTT Unique Identification Number: Assessment time-point

ACTIVITIES OF DAILY LIVING QUESTIONNAIRE (BARTHEL)

Please select the statement which best describes your situation. Please tick only one box in each section.

1) Mobility around house

☐ Immobile ☐ Wheelchair independent around corners etc ☐ Walks with verbal or physical help of 1 person ☐ Independent *(but can use walking aid such as a stick)*

2) Stairs

☐ Unable ☐ Needs verbal or physical help *(carrying aid)* ☐ Independent up and down

3) Transfer from bed to chair and back

☐ Unable ☐ Needs major help (1 or 2 people, physical help) ☐ Needs minor verbal or physical help ☐ Independent

4) Bathing

☐ Dependent ☐ Independent

5) Grooming (personal hygiene such as brushing teeth and hair, shaving, washing face)

☐ Needs help ☐ Independent

6) Dressing

☐ Dependent ☐ Needs help but can do half unaided ☐ Independent

7) Feeding (able to eat normal food, not just soft food)

☐ Unable ☐ Needs help cutting, spreading butter etc ☐ Independent

8) Toilet use

☐ Dependent ☐ Needs some help but can do something ☐ Independent

9) Bladder

☐ Incontinent or catheterised and unable to manage ☐ Occasional accident (maximum 1 time in a day) ☐ Continent over 7 days

10) Bowels

☐ Incontinent ☐ Occasional accident (1 per week) ☐ Continent

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THANK YOU for taking the time to complete this questionnaire.

Please check through to ensure that you have answered all of the questions.

Your input is extremely valued and very much appreciated.

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Appendix 14 Outcome measures: nurse assessments

SPIRiTT Unique Identification Number: Assessment time-point

Specialist Parkinson's Integrated Rehabilitation Team Trial (SPIRiTT)

Background questionnaire for Person with Parkinson's

THIS SECTION TO BE COMPLETED BY THE RESEARCHER

We would be grateful if you could provide as much information as possible
All information collected is treated with complete confidentiality

Date: _ _ / _ _ _ / _ _ _ _ **Time:** _ _ : _ _ AM PM **Location:** ☐ Home ☐ Other _____

Person completing form: ☐ Carer ☐ Person with Parkinson's ☐ Researcher ☐ Other (please specify): _____

FALLS QUESTIONNAIRE

Please place a tick √ in the box that is most appropriate to you.

1)	In the LAST 3 MONTHS, have you fallen?	☐ Yes	☐ No	
2)	If you have fallen in the LAST 3 MONTHS, roughly how many times have you fallen?	_ _ _ times		
3)	Did you hurt yourself on any of these occasions?	☐ Yes	☐ No	
4)	Were you able to get up from the floor/ground?	☐ Yes	☐ No	
5)	Did you see a doctor?	☐ Yes, A&E	☐ Yes, GP	☐ No
6)	Are your falls related to freezing?	☐ Yes	☐ No	☐ Don't know

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SPIRiTT Unique Identification Number: **Assessment time-point**

TIMED UP AND GO

The Timed Up and Go test measures in seconds the time taken by an individual to stand up from a standard arm chair, walk a distance of 3 metres, turn, walk back to the chair and sit down again at their own normal walking pace. Please complete the table below.

Chair seat height:	_ _ _cm		**Chair arm height:**	_ _ _cm
Arms used to get out of the chair:	☐ Yes ☐ No			
Use of walking aid:	☐ Yes	☐ No	If Yes, which aid:	
Time taken:	**_ _ _ _ seconds**			
Comments *(please provide details of the chair that was used e.g. dining room chair)*:				

UNIFIED PARKINSON'S RATING SCALE

Please place a tick √ in the box which best describes the participant's posture and gait.

Posture	Gait
☐ Normal erect	☐ Normal
☐ Not quite erect, slightly stooped posture; could be normal for older person	☐ Walks slowly, may shuffle with short steps, but no festination (hastening steps) or propulsion
☐ Moderately stooped posture, definitely abnormal; can be slightly leaning to one side	☐ Walks with difficulty, but requires little or no assistance; may have some festination, short steps or propulsion
☐ Severely stooped posture with kyphosis; can be moderately leaning to one side	☐ Severe disturbance of gait, requiring assistance
☐ Marked flexion with extreme abnormality of posture	☐ Cannot walk at all even if assisted

YALE SINGLE ITEM SCREENING TOOL

Do you frequently feel sad or depressed? ☐ Yes ☐ No

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SPIRiTT Unique Identification Number: **Assessment time-point**

ABRIDGED EMERSON AND ENDERBY RATING SCALE

Please tick √ the most appropriate box that describes the participant's voice and articulation.

Voice	Articulation
☐ No impairment; voice normal for age and sex	☐ No impairment; normal
☐ Slight impairment; slight abnormal nasality, quality or volume, noticeable to trained observer	☐ Slight impairment; a few articulatory substitutions, not usually affecting intelligibility in spontaneous speech
☐ Moderate impairment; abnormal nasality, quality or volume, noticeable to casual observer	☐ Moderate impairment; abnormal articulation is noticeable to the casual observer and sometimes affects intelligibility
☐ Severe impairment; severely abnormal nasality, quality or volume	☐ Severe impairment; many sounds are articulated abnormally and intelligibility is markedly affected

FRENCHAY SUMMARY

Using the instructions and grading system provided, please complete the following table.

		Respiration		Phonation				Intelligibility		
Normal function	A									
	B									
	C									
	D									
No function										
	E									
		Rest	Speech	Time	Pitch	Volume	Speech	Words	Sentences	Conversation

UNIFIED PARKINSON'S RATING SCALE

Please place a tick √ in the box which best describes the participant's speech.

Is the speech:
☐ Normal
☐ Mildly affected; no difficulty being understood
☐ Moderately affected; sometimes asked to repeat statements
☐ Severely affected; frequently asked to repeat statements
☐ Unintelligible most of the time

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SPIRiTT Unique Identification Number: **Assessment time-point**

ABOUT THE SERVICES YOU RECEIVE

Please answer the following questions by placing a tick √ in the appropriate box.

1) In the LAST 3 MONTHS, have you got any new aids/adaptations/equipment (such as bath chair)? ☐ Yes ☐ No

2) If you have got any new aids/adaptations/equipment in the LAST 3 MONTHS, please provide details below

Type of aids/adaptations/equipment	*New aids/adaptations/ equipments or types of changes*	*Who paid for this?*
Special equipment (such as walking stick, bath seats, kitchen ware)		
Changes to home (such as stairlift, shower cubicle)		
Other (please specify): _____		

3) In the LAST 3 MONTHS, because of your Parkinson's

How many TIMES have you visited the:	*What was the reason for your visit?*	*Did you use hospital transport?*		
		Yes, all of the time	*Yes, some of the time*	*No, not at all*
Accident and Emergency (A&E)? ☐☐☐☐☐☐☐☐☐☐☐ 0 1 2 3 4 5 6 7 8 9 10				
hospital as a day case? ☐☐☐☐☐☐☐☐☐☐☐ 0 1 2 3 4 5 6 7 8 9 10				
hospital overnight? ☐☐☐☐☐☐☐☐☐☐☐ 0 1 2 3 4 5 6 7 8 9 10 How MANY NIGHTS IN TOTAL did you stay? _ _ _				

4) In the LAST 3 MONTHS, have you attended a day care centre? ☐ Yes ☐ No

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5) If you do attend a day care centre, please provide details below

How many times a week do you go?

☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7

How long do you stay for each visit?

- ☐ Usually half a day
- ☐ Sometimes half a day
- ☐ Sometimes full day
- ☐ Usually full day

How do you usually get to there?

- ☐ Private transport
- ☐ Private taxi
- ☐ Public transport
- ☐ Local authority transport
- ☐ Hospital transport
- ☐ Other (please specify): _____

6) In the LAST 3 MONTHS, have you lived anywhere else besides your own home? ☐ Yes ☐ No

7) If you have lived elsewhere, what type of accommodation did you stay in at the time and for how long?

- ☐ Care home _____ nights spent in Care home
- ☐ Nursing home _____ nights spent in Nursing home
- ☐ Other (please specify): _____ _____ nights spent

8) In the LAST 3 MONTHS, please provide details of any health services used or received for your Parkinson's below

Service (please tick box if used/received)	*Total number of times*	*Were you visited at home?*		*Did you, your family/ friend pay for the service?*	
		No	*Yes*	*No*	*Yes*
☐ Hospital neurologist					
☐ Hospital geriatrician					
☐ General practitioner (GP)					
☐ Telephoned GP at surgery					
☐ Emergency GP out of hours					
☐ Parkinson's nurse specialist					
☐ District or practice nurse					
☐ Physiotherapist					
☐ Occupational therapist					
☐ Speech and language therapist					
☐ Psychiatrist					
☐ Psychologist					
☐ Alternative therapist					
☐ Social worker					
☐ Health care assistant					
☐ Parkinson's UK information and support worker					
☐ NHS Direct (telephone helpline)					
☐ Other (please specify): _____					

9) In the LAST 3 MONTHS, have you had any tests for Parkinson's (such as brain scan, blood test)? ☐ Yes ☐ No

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SPIRiTT Unique Identification Number: **Assessment time-point**

10) If you have had any tests in the LAST 3 MONTHS, please tell us what they were:

_____

11) How many different prescribed medications do you take each day? _ _ _ medications

12) How many of these prescribed medications are for Parkinson's? _ _ _ medications

13) Do you take any medications for side effects of Parkinson's?

☐ Constipation ☐ Depression ☐ Extra salivation ☐ Overactive bladder ☐ Other (please specify): _____

14) Are you exempt from paying for your prescriptions? ☐ Yes ☐ No ☐ Don't know

15) Over the last month, about how much have you spent on over-the-counter medicines or remedies? £_____

16) Please tell us what over-the-counter medicines or remedies you have bought:

_____

17) Medication profile (to be completed by researcher). Please list below any Parkinson's drugs you currently use

Name of Parkinson's drug	*Dosage*	*Frequency*

SPIRiTT Unique Identification Number: **Assessment time-point**

18) In the LAST 3 MONTHS, please provide information on any of the paid social services you have used or received below (please do not include care from the live-in carer even if paid)

Service (please tick box if used/received)	*Amount/frequency (e.g. hours in a day, number of times in a week)*	*Who has arranged the service?*				*Did you, your family/ friend pay for the service?*	
		Health/ social services	*Participant/ family*	*Voluntary*	*Other*	*Yes*	*No*
☐ Personal care (e.g. dressing, washing)							
☐ Home help (e.g. cleaning, garden)							
☐ Nursing							
☐ Transport (e.g. Dial-a-Ride)							
☐ Community/personal alarm (e.g. Careline)	How many times have you used it in total in the LAST 3 MONTHS? ☐☐☐☐☐☐☐ 1 2 3 4 5 6 7						
☐ Meals-on-Wheels	How many times do you have it A WEEK? ☐☐☐☐☐☐☐ 1 2 3 4 5 6 7						

19) In the past month, have you received unpaid help from family or friends? ☐ Yes ☐ No

20) If yes, you did receive unpaid help from family or friends, please provide details below

Type of help (please tick box if received)	*Who provides the help?*	*Amount/frequency (e.g. hours in a day, number of times in a week)*
☐ Personal care (e.g. dressing, washing)		
☐ Home help (e.g. cleaning, garden)		
☐ Transport		
☐ Other (please specify):_____		

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Appendix 15 Intervention acceptability questionnaire

Person with Parkinson's intervention acceptibility questionnaire

version 1, 101209, REC ref no.: 10/H1109/1

SPIRiTT Unique Identification Number: Assessment time-point 3

Specialist Parkinson's Integrated Rehabilitation Team Trial (SPIRiTT)

Interview schedule for Person with Parkinson's

ACCEPTABILITY OF TREATMENT PROGRAMMES

Date: __/___/____ **Time:** __:__ AM PM **Location:** ☐ Home ☐ Other _____

Name of person completing form: _____

Now that your treatment programme is completed, we would like to ask for your views about it.

1) How helpful did you find the treatment programme overall?				
Not at all helpful	A little helpful	Moderately helpful	Very helpful	Extremely helpful
Please explain:				

2) **Now please tell me, how helpful you found the different aspects of the treatment programme. If you did not see any of these health professionals, please tell me.**

Parkinson's nurse specialist:					
Not at all helpful	A little helpful	Moderately helpful	Very helpful	Extremely helpful	Not relevant
Physiotherapist:					
Not at all helpful	A little helpful	Moderately helpful	Very helpful	Extremely helpful	Not relevant
Occupational therapist:					
Not at all helpful	A little helpful	Moderately helpful	Very helpful	Extremely helpful	Not relevant
Speech and language therapist:					
Not at all helpful	A little helpful	Moderately helpful	Very helpful	Extremely helpful	Not relevant
Care assistants (Group B only):					
Not at all helpful	A little helpful	Moderately helpful	Very helpful	Extremely helpful	Not relevant

This study is funded by the Department of Health
Favourable ethical opinion has been granted by Surrey Research Ethics Committee

Page 1 of 4

SPIRiTT Unique Identification Number: Assessment time-point 3

Other (please specify):					
Not at all helpful	A little helpful	Moderately helpful	Very helpful	Extremely helpful	Don't know
Please explain:					

3) To what extent do you agree or disagree with these statements about the treatment programme.

I learnt new things about Parkinson's and my condition:				
Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
The multidisciplinary team were approachable and friendly:				
Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree

4) How successful has the programme been in helping your relative/friend in his/her caring role (*if applicable*)?

Not successful	A little successful	Moderately successful	Very successful	Extremely successful	Don't know	Not relevant

5) Please explain, in your view, what were the most successful aspects of the programme:

6) Please explain, in your view, what were the least successful aspects of the programme:

7) Can you think of ways in which the programme can be improved?

This study is funded by the Department of Health
Favourable ethical opinion has been granted by Surrey Research Ethics Committee

8) Would you recommend the 6 week multidisciplinary rehabilitation treatment to others?

Yes	No	Don't know

9) Would you like the 6 week multidisciplinary rehabilitation treatment repeated?

Yes	No	Don't know

10) If you would like the 6 week multidisciplinary rehabilitation treatment repeated, how often would you like this?

Not applicable	Once a year	Twice a year	Three times a year

11) When the 6 week multidisciplinary rehabilitation treatment ended, did you continue to benefit from the treatment?

Not at all	Yes, a little	Yes, somewhat	Yes, a lot	Yes, to a great extent
If yes, please explain how you benefitted:				

12) Providing the 6 week multidisciplinary rehabilitation to people with Parkinson's is an expense to the National Health Service (NHS). If the cost is *£235* per patient, do you think that this is good value for money? *Circle if yes, and repeat question for next value until person responds no*.

£235	£435	£635	£835	Don't know
Please explain:				

13) Do you think it would be helpful to have some further assistance or support from care assistants, after the end of the 6 week multidisciplinary rehabilitation treatment?

Yes	No	Don't know

This study is funded by the Department of Health
Favourable ethical opinion has been granted by Surrey Research Ethics Committee

SPIRiTT Unique Identification Number: Assessment time-point 3

8) **Providing continued care assistant support to people with Parkinson's is an expense to the National Health Service (NHS). If the cost is *£645* per patient for one year of support, do you think that this is good value for money? *Circle if yes, and repeat question for next value until person responds no.***

£645	£1245	£1845	£2445	Don't know
Please explain:				

9) **Do you have any other comments about the treatment or study overall?**

This study is funded by the Department of Health
Favourable ethical opinion has been granted by Surrey Research Ethics Committee

Live-in carer acceptibility intervention questionnaire

SPIRiTT Specialist Parkinson's Integrated Rehabilitation Team Trial

version 1, 101209, REC ref no.: 10/H1109/1

UNIVERSITY OF SURREY

SPIRiTT Unique Identification Number: 275 **Assessment time-point 3**

Specialist Parkinson's Integrated Rehabilitation Team Trial (SPIRiTT)

Interview schedule for Live-in carer of person with Parkinson's

We would be grateful if you could provide as much information as possible
All information collected is treated with complete confidentiality

ACCEPTABILITY OF TREATMENT PROGRAMMES

Date: _ _ / _ _ _ / _ _ _ _ **Time:** _ _ : _ _ AM PM **Location:** ☐ Home ☐ Other _____

Name of person completing form: _____

Now that the treatment programme is completed, we would like to ask for your views about it.

1) How helpful did you find the treatment programme overall, for the person you care for?

Not at all helpful	A little helpful	Moderately helpful	Very helpful	Extremely helpful
Please explain:				

2) Now please tell me, how helpful you found the different aspects of the treatment programme, for the person you care for. If he/she did not see any of these health professionals, please tell me.

Parkinson's nurse specialist:					
Not at all helpful	A little helpful	Moderately helpful	Very helpful	Extremely helpful	Not relevant
Physiotherapist:					
Not at all helpful	A little helpful	Moderately helpful	Very helpful	Extremely helpful	Not relevant
Occupational therapist:					
Not at all helpful	A little helpful	Moderately helpful	Very helpful	Extremely helpful	Not relevant
Speech and language therapist:					
Not at all helpful	A little helpful	Moderately helpful	Very helpful	Extremely helpful	Not relevant

version 1, 101209, REC ref no.: 10/H1109/1

SPIRiTT Unique Identification Number: 275 **Assessment time-point 3**

Care assistants (Group B only):					
Not at all helpful	A little helpful	Moderately helpful	Very helpful	Extremely helpful	Not relevant
Other (please specify):					
Not at all helpful	A little helpful	Moderately helpful	Very helpful	Extremely helpful	Don't know
Please explain:					

3) To what extent do you agree or disagree with these statements about the treatment programme.

I learnt new things about Parkinson's:				
Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
The multidisciplinary team were approachable and friendly:				
Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree

4) How successful has the programme been in helping you with your caring role?

Not successful	A little successful	Moderately successful	Very successful	Extremely successful	Don't know

5) Please explain, in your view, what were the most successful aspects of the programme:

_____
_____
_____
_____
_____

6) Please explain, in your view, what were the least successful aspects of the programme:

_____
_____
_____
_____
_____

version 1, 101209, REC ref no.: 10/H1109/1

SPIRiTT Unique Identification Number: 275 **Assessment time-point 3**

7) Can you think of ways in which the programme can be improved?

_____
_____
_____
_____
_____

8) Would you recommend the 6 week multidisciplinary rehabilitation treatment to others?

Yes	No	Don't know

9) Would you like the 6 week multidisciplinary rehabilitation treatment repeated?

Yes	No	Don't know

10) If you would like the 6 week multidisciplinary rehabilitation treatment repeated, how often would you like this?

Not applicable	Once a year	Twice a year	Three times a year

11) When the 6 week multidisciplinary rehabilitation treatment ended, did you and the person you care for continue to benefit from the treatment?

Not at all	Yes, a little	Yes, somewhat	Yes, a lot	Yes, to a great extent
If yes, please explain how you benefitted:				

12) Providing the 6 week multidisciplinary rehabilitation to people with Parkinson's is an expense to the National Health Service (NHS). If the cost is *£235* per patient, do you think that this is good value for money? *Circle if yes, and repeat question for next value until person responds no.*

£235	£435	£635	£835	Don't know
Please explain:				

13) Do you think it would be helpful to have some further assistance or support from care assistants, after the end of the 6 week multidisciplinary rehabilitation treatment?

Yes	No	Don't know

14) Providing continued care assistant support to people with Parkinson's is an expense to the National Health Service (NHS). If the cost is *£645* per patient for <u>one year</u> of support, do you think that this is good value for money? *Circle if yes, and repeat question for next value until person responds no.*

£645	£1245	£1845	£2445	Don't know
Please explain:				

15) Do you have any other comments about the treatment or study overall?

_____

_____

_____

_____

_____

_____

Appendix 16 Reflective feedback forms from the multidisciplinary team

Cohort 2

Specialist Parkinson's Integrated Rehabilitation Team Trial

As it is the end of the 2nd cohort, we would like you to reflect on your role in the MDT as well as how the team is working. Please consider the pros and cons and what may be done to improve the team working.

Cohort 6

Specialist Parkinson's Integrated Rehabilitation Team Trial

As it is the end of the 6th cohort, we would like you to reflect on your role in the MDT as well as how the team is working. Please consider the pros and cons, what has changed since the earlier cohorts, how things may have improved, how team working affects your input and because of the team configuration any differences made to key case studies.

Cohort 8

As it is the end of the 8th cohort, we would like you to reflect on your role in the MDT as well as how the team is working. Please consider the pros and cons, what has changed since the earlier cohorts, how things may have improved, how team working affects your input and because of the team configuration any differences made to key case studies.

Structured reflection

Specialist Parkinson's Integrated Rehabilitation Team Trial

MDT STRUCTURED REFLECTION

To help us in the writing up of the project, we would be grateful if you would reflect on your role within the MDT by briefly answering the following questions (with comments/examples, if any).

What is your background? _____

Please rate the following:

1. **Communication about patients within the MDT:**

☐ **Very good** ☐ **Good** ☐ **Satisfactory** ☐ **Poor** ☐ **Very Poor** ☐ **Don't Know**

Please explain:

_____
_____
_____

2. **Use of shared documents within the MDT:**

☐ **Very good** ☐ **Good** ☐ **Satisfactory** ☐ **Poor** ☐ **Very Poor** ☐ **Don't Know**

Please explain:

_____
_____
_____

3. **Joint care planning within the MDT:**

☐ **Very good** ☐ **Good** ☐ **Satisfactory** ☐ **Poor** ☐ **Very Poor** ☐ **Don't Know**

Please explain:

_____
_____
_____

4. **Involvement of patients and carers in care planning:**

☐ **Very good** ☐ **Good** ☐ **Satisfactory** ☐ **Poor** ☐ **Very Poor** ☐ **Don't Know**

Please explain:

_____
_____
_____

5. **Delegation of responsibilities within the MDT:**

☐ **Too much** ☐ **About right** ☐ **Too little** ☐ **Don't know**

Please explain:

_____
_____
_____

6. Support from other members of the MDT in your duties:

☐Very good ☐ Good ☐ Satisfactory ☐Poor ☐ Very Poor ☐ Don't Know

Please explain:

_____
_____
_____

7. Administrative support from project office:

☐Very good ☐ Good ☐ Satisfactory ☐Poor ☐ Very Poor ☐ Don't Know

Please explain:

_____
_____
_____

8. Can you see ways in which the MDT intervention has changed/evolved?

_____
_____
_____
_____
_____

9. Can you provide examples of good practice by the team where the team made a difference to a person with Parkinson's or carer?

_____
_____
_____
_____
_____
_____

10. Can you provide examples of difficult situations and how they were overcome?

_____
_____
_____
_____
_____
_____

11. Are there any key case studies of patients who had complicated issues/special needs, or where critical incidents occurred? Please reflect on how the MDT dealt with this (with or without Parkinson's Care Assistant involvement).

_____
_____
_____
_____

THANK YOU

Appendix 17 Exit interview topics for the multidisciplinary team

- Personal role and team leadership.
- Experience of the team: forming, evolving, working, ending.
- Team size and composition – missing professionals.
- Role and integration of the PCAs.
- Barriers and facilitators to effective team/interprofessional working.
- Differences from NHS working and implications for the NHS.
- View of programme and delivery, and lessons for the future.

Appendix 18 Analysis of missing items in multi-item outcome measures

Sample sizes of single-item outcome measures (people with Parkinson's only) in the PPA were as follows and are reduced (compared with the full sample of 227) for Timed Up and Go, posture and gait (because observations could not be done if the person with Parkinson's was experiencing an 'off' period), and for pain (due to participants finding difficulty understanding the concept of the VAS): EQ-5D Thermometer, $n = 226$; Timed Up and Go, $n = 210$; UPDRS posture, $n = 212$; UPDRS gait, $n = 212$; UPDRS speech, $n = 226$; pain VAS, $n = 164$; Emerson and Enderby voice, $n = 226$; Emerson and Enderby articulation, $n = 226$; Yale Depression Screen, $n = 225$; and falls, $n = 226$.

TABLE 39 Analysis of missing items

Participant	Outcome/instrument	Number of items	Sample size[a]	Total items for four assessments	Number of missing items at each assessment point				Total missing items (as % of all items)
					1: baseline	2: 6 weeks	3: 24 weeks	4: 36 weeks	
Person with Parkinson's	Self-Assessment Parkinson's Disability Scale (primary outcome)[69,70]	25	226	5650	16	3	6	2	27 (0.48)[b]
	Parkinson's Disease Questionnaire	8	227	1816	1	0	2	0	3 (0.17)
	Parkinson's Non-Motor Symptoms Questionnaire[74,75]	30	227	6810	19	10	23	5	57 (0.84)[c]
	Barthel ADL[76]	10	226	2260	3	0	2	0	5 (0.22)
	Frenchay Activities Index[77–79]	10	226	2260	2	1	2	2	7 (0.31)
	EQ-5D Index[80,81]	5	227	1135	0	0	0	0	0
	SF-36[82]	36	225	8100	1	0	10	10	21 (0.26)[d]
	HADS[83]	14	226	3264	1	0	0	1	2 (0.06)
	Self-Efficacy Scale[86]	6	226	1356	0	1	0	0	1 (0.07)
	Speech Self Report Questionnaire	26	227	5902	23	7	2	1	33 (0.56)[e]
	Total			**38,553**					**156 (0.40)**
Live-in carers	Modified Caregiver Strain Index (primary outcome)[71]	13	125	1625	2	1	2	1	6 (0.37)
	General Health Questionnaire-12[95]	12	125	1500	0	0	0	0	0
	Barthel ADL[76]	10	125	1250	0	0	0	0	0
	Frenchay Activities Index[77–79]	10	125	1250	1	0	0	0	1 (0.08)
	EQ-5D Index[80,81]	5	125	625	0	0	1	0	1 (0.16)
	SF-36[82]	36	125	4500	0	0	0	0	0
	HADS[83]	14	125	1750	0	0	0	0	0
	Total			**12,500**					**8 (0.06)**

a Number of participants included in analysis of each instrument. For inclusion, a participant had to have completed the instrument at all four assessment points. Instruments were disregarded if they contained more than two missing items.

Main missing items:

b Getting in/out of bath, use of public transport, opening tins.

c Sexual activity, incontinence.

d Coding errors.

e Speaking in shops, ordering in cafes, participating in meetings.

Appendix 19 Unit costs used in the calculation of intervention costs

TABLE 40 Unit costs used in the calculation of intervention costs

	Overall unit costs[a] (£/hour)	
Professional	**Patient-related work**	**In-home patient-facing care**
Nurse specialist	50	50
PT	34	34
OT	34	34
SLT	34	34
PCA	24	29
Fixed cost items		
Professional time spent to write notes, discuss patient at team meetings, etc.		30 minutes per home visit 15 minutes per telephone call
Median mileage per visit		23
Travel costs, £/mile[a]		0.45
Professional time in travelling		Based on 20 miles per hour
One hour of PNS time per patient to write letter (report) to GP		£50

a Costs are taken from Curtis.[99]
The hourly rates used are inclusive of all oncosts, and management office/administrative support and facilities overheads.

Appendix 20 Unit costs for analysis of service use

TABLE 41 Unit costs for analysis of service use

Service used	Unit cost (£)	Note; page (section number)[a]
A&E attendance, including emergency transport	223	91 (7.1): A&E services not admitted, weighted (national) average of all services (£106), plus mark-up for paramedic transfer of £117, calculated as 50% of average cost of all paramedic services (£234) (because 25% of people reporting use of A&E stated that they did not use hospital transport, and the rest stated they used it either all or some of the time)
Hospital day case	686	91 (7.1): weighted average of all stays
Hospital overnight ≤ 4 nights	549/night	91 (7.1): non-elective inpatient short-stay daily rate
Hospital overnight > 4 nights	2334	91 (7.1): non-elective inpatient long-stay rate (for whole stay)
Day care (per session)	36	28 (1.4): local authority day care for older people
Care home (per day)	71	26 (1.2): assumed private sector establishment cost per permanent resident week for older people £497
Nursing home (per day)	130	25 (1.1): private sector nursing homes establishment cost per permanent resident week for older people £719
Hospital neurologist	40	203 (15.5): consultant medical, £162 per hour, assume 15-minute consultation
Hospital geriatrician	40	203 (15.5): consultant medical, £162 per hour, assume 15-minute consultation
Psychiatrist	40	205 (15.7): consultant psychiatrist, £162 per hour, assume 15-minute consultation
GP surgery visit	36	149 (10.8): £3.10 per surgery/clinic minute, for consultation lasting 11.7 minutes
GP home visit	121	149 (10.8): 23.4 minutes including travel time
GP telephone call	22	149 (10.8): telephone consultation lasting 7.1 minutes
GP out of hours	121	149 (10.8): 23.4 minutes including travel time
PNS (per contact)	25	144 (10.4): nurse specialist hourly rate £50, assume 30-minute contact (same clinic and home visit)
District or practice nurse (per contact)	14	Practice nurse, 144 (10.6): £51 per hour face-to-face contact, allow 15 minutes = £13. District nurse, 141 (10.1): £73 per hour, £18.25 per home visit
PT (per contact)	17	133 (9.1): £34 per hour community PT, assume 30 minutes
OT (per contact)	17	134 (9.2): £34 per hour community OT, assume 30 minutes
SLT (per contact)	17	135 (9.3): £34 per hour community SLT, assume 30 minutes
Psychologist (per contact)	30	137 (9.5): £60 per hour clinical psychologist, assume 30 minutes
Social worker (per contact)	30	156 (11.2): approved social worker adult services, £59 per hour, assume 30 minutes
Alternative therapist (per contact)	30	Assumed as social worker
Health-care assistant (per contact)	10	145 (10.5): clinical support worker (community), £29 per hour, assumed 20 minutes

a All unit costs taken from Curtis (page and section numbers as shown).[99] Costs are fully loaded and include oncosts; non-patient-facing patient-related work; management, administrative and facilities overheads and qualifications.

Appendix 21 Baseline aids and adaptations

TABLE 42 Baseline aids and adaptations reported by 269 people with Parkinson's

Type of aid/equipment	Group A, *n* (%)	Group B, *n* (%)	Group C, *n* (%)	% self-paid
Electric wheelchair	1 (1.4)	3 (3.9)	2 (2.6)	100
Manual wheelchair	4 (20.8)	18 (23.7)	14 (18.2)	70
Walking trolley	9 (12.5)	10 (13.2)	7 (9.1)	54
Walking frame	16 (22.2)	32 (42.1)	21 (27.3)	43
Crutches	2 (2.8)	1 (1.3)	2 (2.2)	20
Electrically operated easy chair	15 (20.8)	15 (19.7)	9 (11.7)	98
Raised-height easy chair	3 (42.0)	2 (2.6)	4 (5.2)	67
Chair raise	6 (8.3)	4 (5.3)	7 (9.1)	12
Seat raiser	1 (1.4)	0 (0.0)	1 (1.3)	50
Table tray on wheels	3 (4.2)	1 (1.3)	1 (1.3)	100
Special cushions	4 (5.6)	5 (6.6)	8 (10.4)	94
Hospital bed	8 (11.1)	8 (10.5)	8 (10.4)	83
Leg raiser	0 (0.0)	0 (0.0)	0 (0.0)	0
Back rest	1 (1.4)	3 (3.9)	0 (0.0)	25
Bed table	1 (1.4)	1 (1.3)	1 (1.3)	100
Grab rails (bedroom)	16 (22.2)	25 (32.9)	19 (24.7)	15
Monkey pole	0 (0.0)	2 (2.6)	0 (0.0)	100
Commode	6 (8.3)	8 (10.5)	5 (6.5)	42
Raised toilet seat	7 (9.7)	17 (32.4)	15 (19.5)	15
Bed pan	7 (9.7)	17 (32.4)	15 (19.5)	84
Adapted shower unit	12 (16.7)	14 (18.4)	4 (5.2)	67
Bath seat	12 (16.7)	14 (18.4)	11 (14.3)	43
Grab rails (bathroom)	37 (51.4)	50 (65.8)	46 (59.7)	65
Incontinence aids	5 (6.9)	13 (17.1)	4 (5.2)	62
Kitchen gadgets	14 (19.4)	9 (11.8)	13 (16.9)	100
Special cutlery	2 (2.8)	3 (3.9)	7 (9.1)	100
Ramps inside and outside	2 (2.8)	7 (9.2)	2 (2.6)	82
Electric stair lifts	3 (4.2)	7 (9.2)	7 (9.1)	82
Adaptation conversion to car	1 (1.4)	1 (1.3)	2 (2.6)	100

Appendix 22 Analysis of prescribed medications

TABLE 43 Analysis of prescribed medications ($N = 269$ at baseline)

Group	Item 0 *n* (%)	1 *n* (%)	2 *n* (%)	3 *n* (%)	Total *n* (%)	*p*-value	Test
Parkinson's medications							
Levodopa preparations							
A	11 (12.5)	48 (54.5)	29 (33.0)	0 (0.0)	88 (100)	0.278	Chi-squared
B	6 (6.9)	51 (58.6)	29 (33.3)	1 (1.1)	87 (100)		
C	7 (7.5)	56 (60.2)	26 (28.0)	4 (4.3)	93 (100)		
Total	6 (5.7)	15 (14.3)	58 (55.2)	26 (24.8)	105 (100)		
Dopamine agonists							
A	34 (38.6)	50 (56.8)	4 (4.5)	N/A	88 (100)	0.978	Chi-squared
B	30 (34.5)	53 (60.9)	4 (4.6)	N/A	87 (100)		
C	36 (38.7)	53 (57.0)	4 (4.3)	N/A	93 (100)		
Total	100 (37.3)	156 (58.2)	12 (4.5)	N/A	268 (100)		
MAO-B inhibitors							
A	63 (71.6)	25 (28.4)	NA	N/A	88 (100)	0.387	Chi-squared
B	70 (80.5)	17 (19.5)	NA	N/A	87 (100)		
C	71 (76.3)	22 (23.7)	NA	N/A	93 (100)		
Total	204 (76.1)	64 (23.9)	NA	N/A	268 (100)		
COMT inhibitors							
A	79 (89.8)	9 (10.2)	N/A	N/A	0 (0.0)	0.263	Chi-squared
B	83 (95.4)	3 (3.4)	N/A	N/A	1 (1.1)		
C	87 (93.5)	6 (6.5)	N/A	N/A	0 (0.0)		
Total	249 (92.9)	18 (6.7)	N/A	N/A	1 (0.4)		
Glutamate antagonist							
A	83 (94.3)	5 (5.7)	N/A	N/A	88 (100)	0.021	Chi-squared
B	74 (85.1)	13 (14.9)	N/A	N/A	87 (100)		
C	89 (95.7)	4 (4.3)	N/A	N/A	93 (100)		
Total	246 (91.8)	22 (8.2)	N/A	N/A	268 (100)		
Anticholinergics							
A	87 (98.9)	1 (1.1)	N/A	N/A	88 (100)	0.585	Chi-squared
B	84 (96.6)	3 (3.4)	N/A	N/A	87 (100)		
C	91 (97.8)	2 (2.2)	N/A	N/A	93 (100)		
Total	262 (97.8)	6 (2.2)	N/A	N/A	268 (100)		

continued

TABLE 43 Analysis of prescribed medications ($N = 269$ at baseline) (*continued*)

Group	Item 0 *n* (%)	1 *n* (%)	2 *n* (%)	3 *n* (%)	Total *n* (%)	*p*-value	Test
Medications to manage non-motor symptoms and side effects							
Antidepressants							
A	81 (92.0)	7 (8.0)	N/A	N/A	88 (100)	0.608	Chi-squared
B	79 (90.8)	8 (9.2)	N/A	N/A	87 (100)		
C	88 (94.6)	5 (5.4)	N/A	N/A	93 (100)		
Total	248 (92.5)	20 (7.5)	N/A	N/A	268 (100)		
Dementia medications							
A	83 (94.3)	5 (5.7)	N/A	N/A	88 (100)	0.744	Chi-squared
B	81 (93.1)	6 (6.9)	N/A	N/A	87 (100)		
C	85 (91.4)	8 (8.6)	N/A	N/A	93 (100)		
Total	249 (92.9)	19 (7.1)	N/A	N/A	268 (100)		
Antipsychotics							
A	85 (96.6)	3 (3.4)	N/A	N/A	88 (100)	0.163	Chi-squared
B	87 (100)	0 (0.0)	N/A	N/A	87 (100)		
C	92 (98.9)	1 (1.1)	N/A	N/A	93 (100)		
Total	264 (98.5)	4 (1.5)	N/A	N/A	268 (100)		
Anxiolytics/muscle relaxants							
A	87 (98.9)	1 (1.1)	N/A	N/A	88 (100)	0.153	Chi-squared
B	84 (96.6)	3 (3.4)	N/A	N/A	87 (100)		
C	93 (100)	0 (0.0)	N/A	N/A	93 (100)		
Total	264 (98.5)	4 (1.5)	N/A	N/A	268 (100)		
Antiemetics							
A	87 (98.9)	1 (1.1)	N/A	N/A	88 (100)	0.999	Chi-squared
B	86 (98.9)	1 (1.1)	N/A	N/A	87 (100)		
C	92 (98.9)	1 (1.1)	N/A	N/A	93 (100)		
Total	265 (98.9)	3 (1.1)	N/A	N/A	268 (100)		
Osmotic laxatives							
A	87 (98.9)	1 (1.1)	N/A	N/A	88 (100)	0.358	Chi-squared
B	87 (100)	0 (0.0)	N/A	N/A	87 (100)		
C	93 (100)	0 (0.0)	N/A	N/A	93 (100)		
Total	267 (99.6)	1 (0.4)	N/A	N/A	268 (100)		
Antisecretory medications							
A	88 (100)	0 (0.0)	N/A	N/A	88 (100)	0.389	Chi-squared
B	87 (100)	0 (0.0)	N/A	N/A	87 (100)		
C	92 (98.9)	1 (1.1)	N/A	N/A	93 (100)		
Total	267 (99.6)	1 (0.4)	N/A	N/A	268 (100)		

N/A, not applicable.

TABLE 44 Total number of medications for Parkinson's, non-motor symptoms and side effects

	Item									
Group	0 *n* (%)	1 *n* (%)	2 *n* (%)	3 *n* (%)	4 *n* (%)	5 *n* (%)	6 *n* (%)	Total *N* (%)	*p*-value	Test
A	3 (3.4)	19 (21.6)	37 (42.0)	22 (25.0)	6 (6.8)	0 (0.0)	1 (1.1)	88 (100)	0.871	Chi-squared
B	1 (1.1)	18 (20.7)	42 (48.3)	16 (18.4)	8 (9.2)	1 (1.1)	1 (1.1)	87 (100)		
C	1 (1.1)	21 (22.6)	45 (48.4)	21 (22.6)	4 (4.3)	1 (1.1)	0 (0.0)	93 (100)		
Total	5 (1.9)	58 (21.6)	124 (46.3)	59 (22.0)	18 (6.7)	2 (0.7)	2 (0.7)	268 (100)		

Appendix 23 Per-protocol and intention-to-treat analysis of outcomes

Tables show the baseline means (SD) and changes in means between assessment points for the PPA (top table) and ITT (bottom table) analyses. Data from the PPA are graphically represented. For instruments where the outcome measures disability (such that an improvement is a reduction), the scales have been reversed to assist with visual interpretation, i.e. in all cases where the trend lines are upwards, this represents an improvement in the average condition of participants in the group. However, Parkinson's is a degenerative condition, and a reduction in the rate of deterioration (one group compared with another) may also be a positive outcome.

Sample sizes are shown in *Table 45*.

TABLE 45 Sample sizes

Analysis	*N*	Group A, *n*	Group B, *n*	Group C, *n*
ITT				
People with Parkinson's	269	88	88	90
Live-in carers	155	52	50	53
PPA				
People with Parkinson's	227	75	69	83
Live-in carers	125	45	37	43

People with Parkinson's

TABLE 46 People with Parkinson's: Self-Assessment Parkinson's Disability Scale[69,70]

				6 weeks		24 weeks				36 weeks			
	Baseline			Change 6–0		Change 24–6		Change 24–0		Change 36–24		Change 36–0	
Group (*n*)	Mean (SD)	Min.	Max.	Mean (SD)	*p*-value	Mean (SD)	*p*-value	Mean (SD)	*p*-value	Mean (SD)	*p*-value	Mean (SD)	*p*-value
A (75)	48.51 (17.15)	25	89	–3.47 (7.12)	**< 0.001**	3.28 (8.37)	**0.001**	–0.19 (9.5)	0.865	0.51 (6.76)	0.518	0.32 (8.72)	0.752
B (68)	50.66 (18.17)	25	112	–2.15 (10.56)	0.098	1.91 (8.26)	0.060	–0.24 (12.21)	0.874	2.46 (9.84)	0.043	2.22 (13.81)	0.189
C (83)	46.95 (16.3)	25	100	–0.72 (8.93)	0.463	1.73 (8.88)	0.079	1.01 (10.77)	0.394	–0.11 (8.73)	0.91	0.90 (10.99)	0.456
p-value													
A vs. B vs. C	0.418				0.157		0.475		0.716		0.167		0.590
A vs. B	0.467				0.379		0.328		0.979		0.166		0.333
A vs. C	0.560				0.036		0.264		0.461		0.624		0.711
B vs. C	0.188				0.371		0.9		0.506		0.092		0.515
A + B vs. C	0.277				0.087		NR		NR		NR		NR

Max., maximum; min., minimum; NR, not reported; SAPDS, Self-Assessment Parkinson's Disability Scale.
Bold indicates significant *p*-value.

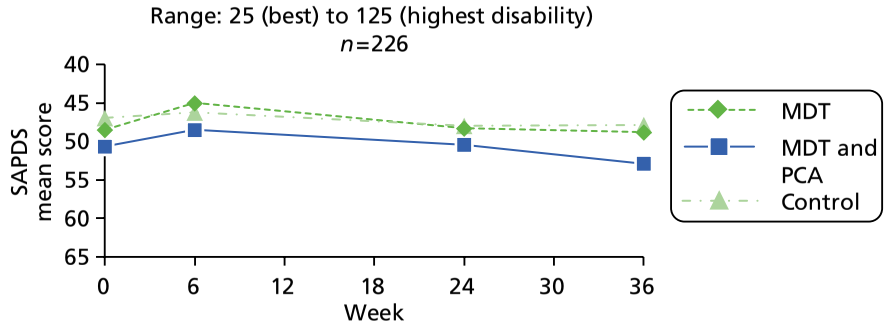

TABLE 47 Analysis of Self-Assessment Parkinson's Disease Disability Scale scores: $N = 269$ (ITT analysis)

	Baseline (0 weeks)				6 weeks						24 weeks										36 weeks									
PwP group	*n*	Mean (SD)	Median	Range	*n*	Mean (SD)	Median	Mean change 6–0	SD change 6–0	*p*-value 6–0	*n*	Mean (SD)	Median	Mean change 24–0	SD change 24–0	*p*-value 24–0	Mean change 24–6	SD change 24–6	*p*-value 24–6	*n*	Mean (SD)	Median	Mean change 36–0	SD change 36–0	*p*-value 36–0	Mean change 36–24	SD change 36–24	*p*-value 36–24		
MDT (A)	87	48.78 (17.05)	45.00	25–89	86	46.12 (16.83)	42.00	–2.68	8.11	**0.003**	76	48.30 (19.70)	44.00	–0.05	9.51	0.962	3.18	8.36	**0.001**	80	49.48 (19.15)	46.50	0.95	9.52	0.378	0.51	6.76	0.518		
MDT and PCA (B)	87	53.38 (19.91)	50.00	25–116	81	50.06 (19.69)	47.00	–2.49	10.52	**0.036**	73	52.74 (21.66)	49.00	0.34	12.45	0.815	2.63	8.84	**0.014**	71	53.01 (22.61)	48.00	2.11	13.71	0.198	2.77	10.10	0.026		
Control (C)	92	49.08 (17.76)	47.00	25–103	87	47.30 (18.55)	42.00	–0.21	9.42	0.838	85	48.48 (19.32)	48.00	1.15	10.68	0.323	1.85	8.96	0.061	85	48.08 (19.92)	45.00	0.89	10.93	0.456	–0.11	8.73	0.910		
Between Rx										***p*-value**						***p*-value**			***p*-value**						***p*-value**				***p*-value**	
A vs. B vs. C										0.178						0.159			0.774						0.621				0.764	0.106
A vs. B										0.104						0.897			0.828						0.693				0.552	0.114
A vs. C										0.910						0.067			0.453						0.331				0.972	0.624
B vs. C										0.128						0.139			0.660						0.586				0.539	0.062
A+B vs. C										0.397						0.056			N/A						N/A				N/A	N/A

N/A, not applicable; PwP, people with Parkinson's; Rx, treatment.
Bold indicates significant *p*-value.

TABLE 48 People with Parkinson's: Parkinson's Disease Questionnaire-8[72,73]

				6 weeks		24 weeks				36 weeks			
	Baseline			Change 6–0		Change 24–6		Change 24–0		Change 36–24		Change 36–0	
Group (*n*)	Mean (SD)	Min.	Max.	Mean (SD)	*p*-value	Mean (SD)	*p*-value	Mean (SD)	*p*-value	Mean (SD)	*p*-value	Mean (SD)	*p*-value
A (75)	23.04 (17.16)	0.00	75.00	–0.88 (9.24)	0.415	1.92 (12.70)	0.195	1.04 (11.51)	0.436	1.50 (9.02)	0.154	2.54 (12.97)	0.094
B (69)	24.50 (17.46)	0.00	75.00	0.18 (10.94)	0.891	1.27 (11.27)	0.353	1.45 (14.06)	0.395	–0.14 (8.89)	0.899	1.31 (13.34)	0.416
C (83)	23.64 (18.30)	0.00	81.25	0.98 (12.39)	0.474	2.71 (12.48)	0.051	3.69 (12.56)	**0.009**	–0.68 (11.31)	0.587	3.01 (12.21)	**0.027**
p-value													
A vs. B vs. C	0.884				0.571		0.766		0.370		0.364		0.709
A vs. B	0.614				0.531		0.747		0.849		0.276		0.576
A vs. C	0.832				0.285		0.693		0.171		0.186		0.815
B vs. C	0.770				0.678		0.460		0.301		0.747		0.414
A + B vs. C	0.968				0.374		NR		NR		NR		NR

Max., maximum; min., minimum; NR, not reported; PDQ-8, Parkinson's Disease Questionnaire-8.
Bold indicates significant *p*-value.

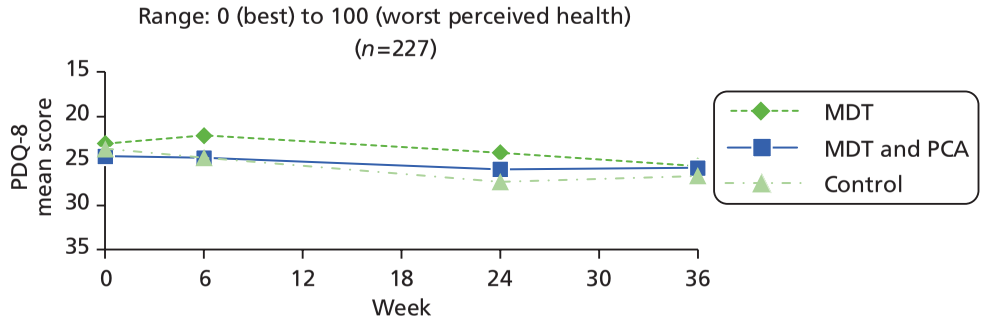

TABLE 49 Analysis of Parkinson's Disease Questionnaire-8 scores: $N = 267$ (ITT analysis)

	Baseline (0 weeks)				6 weeks						24 weeks										36 weeks								
PwP group	*n*	Mean (SD)	Median	Range	*n*	Mean (SD)	Median	Mean change 6–0	SD change 6–0	*p*-value 6–0	*n*	Mean (SD)	Median	Mean change 24–0	SD change 24–0	*p*-value 24–0	Mean change 3 24–6	SD change 24–6	*p*-value 24–6	*n*	Mean (SD)	Median	Mean 4 change 36–0	SD change 36–0	*p*-value 36–0	Mean change 36–24	SD change 36–24	*p*-value 36–24
MDT (A)	88	23.37 (17.95)	18.75	0–75	86	23.36 (17.01)	18.75	0.04	11.39	0.976	76	24.05 (16.21)	25.00	1.27	11.62	0.342	1.81	12.65	0.216	80	26.17 (18.65)	21.88	3.01	13.05	**0.042**	1.50	9.02	0.154
MDT and PCA (B)	87	25.65 (16.64)	21.88	0–75	82	25.30 (16.55)	25.00	–0.19	11.79	0.884	73	26.58 (16.82)	25.00	1.58	14.27	0.346	1.20	11.12	0.360	71	25.66 (18.14)	21.88	1.06	13.45	0.510	–0.14	8.89	0.899
Control (C)	92	25.34 (19.33)	21.88	0–81.25	87	25.47 (18.98)	25.00	0.86	12.39	0.518	85	27.39 (19.61)	28.13	3.49	12.66	0.013	2.46	12.44	0.071	85	27.39 (19.57)	25.00	2.86	12.21	**0.034**	–0.68	11.31	0.587
Between Rx										*p*-value						*p*-value			*p*-value						*p*-value			*p*-value
A vs. B vs. C										0.661						0.830			0.493						0.590			0.364
A vs. B										0.385						0.899			0.885						0.367			0.276
A vs. C										0.479						0.649			0.250						0.942			0.186
B vs. C										0.910						0.573			0.374						0.382			0.747
A + B vs. C										0.718						0.550			N/A						N/A			N/A

N/A, not applicable; PwP, people with Parkinson's; Rx, treatment.
Bold indicates significant *p*-value.

TABLE 50 People with Parkinson's: Non-Motor Symptoms Questionnaire[74,75]

				6 weeks		24 weeks				36 weeks			
	Baseline			Change 6–0		Change 24–6		Change 24–0		Change 36–24		Change 36–0	
Group (*n*)	Mean (SD)	Min.	Max.	Mean (SD)	*p*-value	Mean (SD)	*p*-value	Mean (SD)	*p*-value	Mean (SD)	*p*-value	Mean (SD)	*p*-value
A (75)	10.25 (5.03)	1.00	22.00	–1.17 (2.93)	**0.001**	1.00 (2.98)	**0.005**	–0.17 (3.17)	0.637	0.32 (2.70)	0.308	0.15 (3.39)	0.709
B (69)	10.62 (5.19)	1.00	23.00	–0.62 (3.42)	0.135	–0.01 (3.26)	0.971	–0.64 (3.66)	0.153	0.48 (3.06)	0.198	–0.16 (3.46)	0.703
C (83)	10.01 (5.32)	0.00	25.00	–0.08 (3.24)	0.813	0.54 (3.10)	0.115	0.46 (2.98)	0.166	–0.01 (3.12)	0.972	0.45 (3.48)	0.246
p-value													
A vs. B vs. C	0.769				0.104		0.150		0.117		0.579		0.559
A vs. B	0.665				0.301		0.053		0.416		0.742		0.593
A vs. C	0.770				**0.029**		0.346		0.200		0.478		0.585
B vs. C	0.477				0.321		0.283		**0.048**		0.332		0.286
A + B vs. C	0.558				0.062		NR		NR		NR		NR

Max., maximum; min., minimum; NMS, non-motor symptoms; NR, not reported.
Bold indicates significant *p*-value.

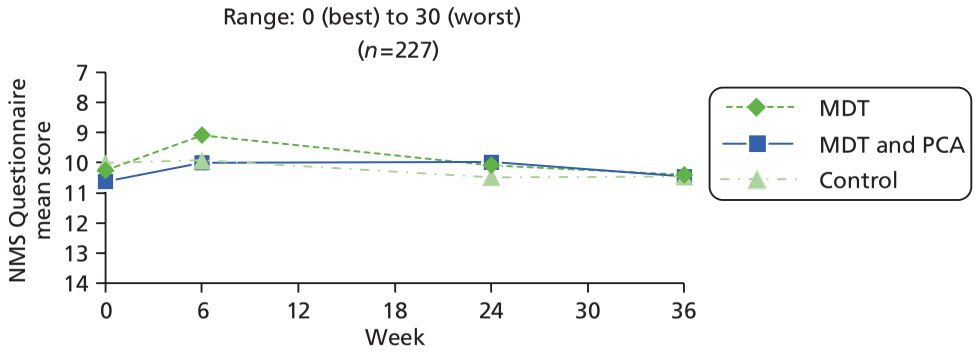

TABLE 51 Analysis of Non-Motor Symptoms Questionnaire scores: $N = 267$ (ITT analysis)

	Baseline (0 weeks)				6 weeks						24 weeks										36 weeks									
PwP group	*n*	Mean (SD)	Median	Range	*n*	Mean (SD)	Median	Mean change 6–0	SD change 6–0	*p*-value 6–0	*n*	Mean (SD)	Median	Mean change 24–0	SD change 24–0	*p*-value 24–0	Mean change 24–6	SD change 24–6	*p*-value 24–6		*n*	Mean (SD)	Median	Mean change 36–0	SD change 36–0	*p*-value 36–0	Mean change 36–24	SD change 36–24	*p*-value 36–24	
MDT (A)	88	10.67 (4.96)	11.00	1–22	86	9.57 (5.20)	10.00	–1.12	2.87	**0.001**	76	10.16 (5.07)	9.00	–0.12	3.19	0.747	1.01	2.96	**0.004**		80	10.59 (5.30)	9.50	0.10	3.31	0.788	0.32	2.70	0.308	
MDT and PCA (B)	87	10.80 (4.98)	10.00	1–23	82	10.11 (4.84)	10.00	–0.60	3.35	0.110	73	10.01 (5.00)	10.00	–0.68	3.73	0.121	–0.07	3.19	0.855		71	10.51 (5.51)	10.00	–0.13	3.43	0.757	0.48	3.06	0.198	
Control (C)	92	10.29 (5.44)	10.00	0–25	87	10.13 (5.63)	10.00	–0.06	3.19	0.867	85	10.72 (5.86)	11.00	0.61	3.21	0.082	0.68	3.22	0.054		85	10.59 (5.97)	10.00	0.48	3.47	0.211	–0.01	3.12	0.972	
Between Rx				*p*-value						*p*-value						*p*-value			*p*-value							*p*-value			*p*-value
A vs. B vs. C				0.787						0.088						0.055			0.099							0.536			0.579
A vs. B				0.858						0.282						0.320			**0.033**							0.681			0.742
A vs. C				0.628						**0.023**						0.150			0.500							0.479			0.478
B vs. C				0.513						0.285						**0.020**			0.144							0.280			0.332
A + B vs. C				0.502						0.053						N/A			N/A							N/A			N/A

N/A, not applicable; PwP, people with Parkinson's; Rx, treatment.
Bold indicates significant *p*-value.

TABLE 52 People with Parkinson's: Barthel ADL[76]

				6 weeks		24 weeks				36 weeks			
	Baseline			Change 6–0		Change 24–6		Change 24–0		Change 36–24		Change 36–0	
Group (*n*)	Mean (SD)	Min.	Max.	Mean (SD)	*p*-value	Mean (SD)	*p*-value	Mean (SD)	*p*-value	Mean (SD)	*p*-value	Mean (SD)	*p*-value
A (75)	18.48 (2.09)	12.00	20.00	–0.01 (1.47)	0.938	–0.33 (1.56)	0.069	–0.35 (1.93)	0.124	–0.24 (1.79)	0.250	–0.59 (2.13)	**0.019**
B (69)	17.78 (3.12)	6.00	20.00	–0.12 (1.96)	0.625	–0.30 (1.42)	0.079	–0.42 (1.79)	0.056	–0.38 (1.87)	0.099	–0.80 (2.42)	**0.008**
C (83)	18.53 (2.18)	10.00	20.00	–0.27 (1.53)	0.119	–0.17 (1.64)	0.353	–0.43 (1.93)	**0.043**	–0.07 (1.70)	0.700	–0.51 (1.78)	**0.011**
p-value													
A vs. B vs. C	0.131				0.630		0.775		0.954		0.575		0.687
A vs. B	0.115				0.722		0.908		0.813		0.655		0.579
A vs. C	0.883				0.295		0.521		0.777		0.547		0.795
B vs. C	0.096				0.599		0.591		0.965		0.296		0.394
A + B vs. C	0.264				0.375		NR		NR		NR		NR

Max., maximum; min., minimum; NR, not reported.
Bold indicates significant *p*-value.

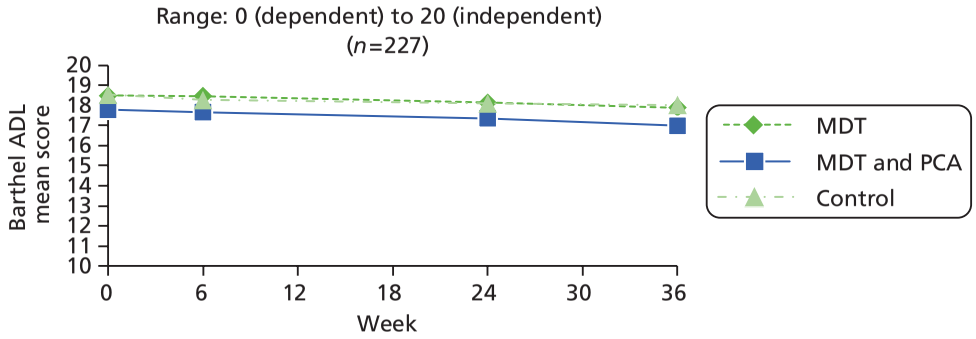

TABLE 53 Analysis of Barthel ADL scores: $N = 269$ (ITT analysis)

	Baseline (0 weeks)				6 weeks						24 weeks								36 weeks							
PwP group	*n*	Mean (SD)	Median	Range	*n*	Mean (SD)	Median	Mean change 6–0	SD change 6–0	*p*-value 6–0	*n*	Mean (SD)	Median	Mean change 24–0	SD change 24–0	*p*-value 24–0	Mean change 24–6	SD change 24–6	*p*-value 24–6	*n*	Mean (SD)	Median	Mean change 36–0	SD change 36–0	*p*-value 36–0	Mean change 36–24	SD change 36–24	*p*-value 36–24
MDT (A)	87	18.40 (2.13)	19.00	12–20	86	18.34 (2.17)	19.00	–0.01	1.47	0.941	76	18.16 (2.58)	19.00	–0.33	1.92	0.140	–0.30	1.57	0.098	80	17.89 (2.77)	19.00	–0.56	2.09	**0.020**	–0.24	1.79	0.250
MDT and PCA (B)	86	17.58 (3.43)	19.00	5–20	82	17.52 (3.60)	19.00	–0.09	1.91	0.687	73	17.07 (3.82)	18.00	–0.52	1.84	**0.018**	–0.42	1.53	**0.020**	71	17.07 (4.07)	18.00	–0.76	2.39	**0.009**	–0.38	1.87	0.099
Control (C)	93	18.37 (2.39)	19.00	10–20	87	18.25 (2.57)	19.00	–0.22	1.65	0.221	85	18.02 (3.07)	19.00	–0.45	1.91	0.034	–0.24	1.74	0.217	85	18.01 (2.60)	19.00	–0.53	1.78	**0.007**	–0.07	1.70	0.700

Between Rx	*p*-value	*p*-value	*p*-value	*p*-value	*p*-value	*p*-value
A vs. B vs. C	0.079	0.717	0.823	0.763	0.760	0.575
A vs. B	0.061	0.780	0.536	0.632	0.579	0.655
A vs. C	0.914	0.388	0.697	0.798	0.928	0.547
B vs. C	0.081	0.629	0.807	0.472	0.490	0.296
A+B vs. C	0.289	0.444	N/A	N/A	N/A	N/A

N/A, not applicable; PwP, people with Parkinson's; Rx, treatment.
Bold indicates significant *p*-value.

TABLE 54 People with Parkinson's: Frenchay Activities Index[77–79]

	Baseline			6 weeks		24 weeks				36 weeks			
				Change 6–0		Change 24–6		Change 24–0		Change 36–24		Change 36–0	
Group (*n*)	Mean (SD)	Min.	Max.	Mean (SD)	*p*-value	Mean (SD)	*p*-value	Mean (SD)	*p*-value	Mean (SD)	*p*-value	Mean (SD)	*p*-value
A (74)	19.01 (7.12)	20.00	3.00	–0.46 (3.75)	0.295	–0.88 (4.82)	0.121	–1.34 (4.35)	**0.010**	–0.22 (5.56)	0.739	–1.55 (5.97)	**0.028**
B (69)	18.13 (8.39)	18.00	2.00	–0.17 (4.25)	0.735	–0.49 (4.93)	0.409	–0.67 (4.64)	0.237	–1.07 (4.86)	0.071	–1.74 (4.54)	**0.002**
C (83)	21.31 (6.83)	22.00	5.00	–1.00 (4.15)	**0.031**	–0.95 (3.83)	0.026	–1.95 (4.90)	**<0.001**	–0.46 (3.95)	0.294	–2.41 (4.83)	**<0.001**
p-value													
A vs. B vs. C	**0.024**				0.440		0.805		0.239		0.549		0.547
A vs. B	0.498				0.670		0.637		0.374		0.330		0.836
A vs. C	**0.041**				0.395		0.916		0.410		0.752		0.323
B vs. C	**0.013**				0.228		0.519		0.101		0.391		0.383
A + B vs. C	**0.008**				0.225		NR		NR		NR		NR

FAI, Frequency Activities Index; max., maximum; min., minimum; NR, not reported.
Bold indicates significant *p*-value.

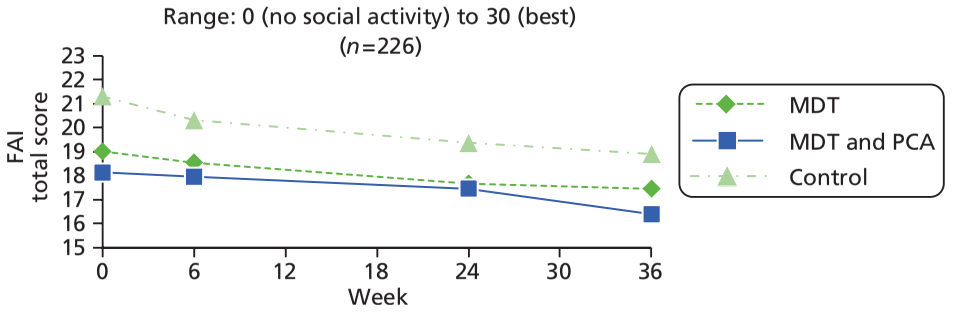

TABLE 55 Analysis of Frenchay Activities Index scores: $N = 267$ (ITT analysis)

	Baseline (0 weeks)				6 weeks						24 weeks									36 weeks							
PwP group	*n*	Mean (SD)	Median	Range	*n*	Mean (SD)	Median	Mean change 6–0	SD change 6–0	*p*-value 6–0	*n*	Mean (SD)	Median	Mean change 24–0	SD change 24–0	*p*-value 24–0	Mean change 24–6	SD change 24–6	*p*-value 24–6	*n*	Mean (SD)	Median	Mean change 36–0	SD change 36–0	*p*-value 36–0	Mean change 36–24	SD change 36–24	*p*-value 36–24
MDT (A)	87	18.86 (7.02)	20.00	3–30	86	18.35 (7.38)	19.00	–0.47	3.66	0.239	75	17.69 (7.61)	19.00	–1.35	4.32	**0.009**	–0.89	4.79	0.111	80	17.28 (8.03)	17.50	–1.72	5.84	**0.011**	–0.22	5.56	0.739
MDT and PCA (B)	87	17.51 (8.38)	18.00	0–30	82	17.59 (8.38)	18.00	–0.29	4.13	0.522	73	16.90 (8.98)	17.00	–0.92	5.05	0.125	–0.63	5.02	0.287	71	16.65 (9.01)	16.00	–1.65	4.52	**0.003**	–1.07	4.86	0.071
Control (C)	93	20.84 (7.01)	22.00	5–30	87	20.21 (7.38)	21.00	–1.14	4.16	**0.013**	85	19.27 (7.36)	20.00	–1.93	4.93	**0.001**	–0.87	3.99	**0.047**	85	18.87 (7.57)	20.00	–2.34	5.06	**<0.001**	–0.46	3.95	0.294

Between Rx	*p*-value	*p*-value	*p*-value	*p*-value	*p*-value	*p*-value
A vs. B vs. C	0.012	0.346	0.411	0.927	0.647	0.549
A vs. B	0.249	0.768	0.579	0.745	0.932	0.330
A vs. C	0.060	0.266	0.431	0.974	0.468	0.752
B vs. C	0.004	0.187	0.205	0.738	0.372	0.391
A + B vs. C	0.006	0.153	N/A	N/A	N/A	N/A

N/A, not applicable; PwP, people with Parkinson's; Rx, treatment.
Bold indicates significant *p*-value.

TABLE 56 People with Parkinson's: EQ-5D Thermometer[80,81]

				6 weeks		24 weeks				36 weeks			
	Baseline			Change 6–0		Change 24–6		Change 24–0		Change 36–24		Change 36–0	
Group (*n*)	Mean (SD)	Min.	Max.	Mean (SD)	*p*-value	Mean (SD)	*p*-value	Mean (SD)	*p*-value	Mean (SD)	*p*-value	Mean (SD)	*p*-value
A (75)	67.62 (18.49)	20.00	100.00	–0.01 (18.39)	0.998	–3.49 (15.09)	**0.049**	–3.49 (17.61)	0.090	2.26 (15.36)	0.207	–1.23 (16.69)	0.524
B (69)	65.78 (18.31)	20.00	97.00	–0.69 (18.72)	0.761	–2.47 (18.50)	0.271	–3.16 (21.40)	0.224	2.44 (15.84)	0.205	–0.72 (22.30)	0.790
C (82)	65.68 (20.62)	10.00	100.00	0.38 (21.36)	0.871	–2.65 (17.61)	0.177	–2.26 (22.10)	0.357	2.00 (17.21)	0.296	–0.26 (20.20)	0.907
p-value													
A vs. B vs. C	0.783				0.945		0.928		0.927		0.986		0.954
A vs. B	0.549				0.826		0.718		0.918		0.944		0.875
A vs. C	0.537				0.903		0.750		0.699		0.921		0.744
B vs. C	0.975				0.746		0.953		0.801		0.871		0.896
A + B vs. C	0.691				0.791		NR		NR		NR		NR

Max., maximum; min., minimum; NR, not reported.
Bold indicates significant *p*-value.

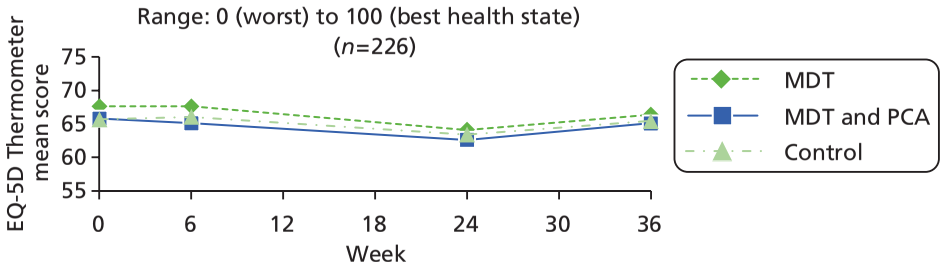

TABLE 57 Analysis of EQ-5D Thermometer scores: $N = 267$ (ITT analysis)

	Baseline (0 weeks)				6 weeks						24 weeks									36 weeks								
PwP group	*n*	Mean (SD)	Median	Range	*n*	Mean (SD)	Median	Mean change 6–0	SD change 6–0	*p*-value 6–0	*n*	Mean (SD)	Median	Mean change 24–0	SD change 24–0	*p*-value 24–0	Mean change 24–6	SD change 24–6	*p*-value 24–6	*n*	Mean (SD)	Median	Mean change 36–0	SD change 36–0	*p*-value 36–0	Mean change 36–24	SD change 36–24	*p*-value 36–24
MDT (A)	88	66.57 (18.39)	70.00	20–100	86	66.58 (18.56)	70.00	–0.15	18.07	0.941	76	64.07 (18.82)	65.00	–3.32	17.56	0.104	–3.44	14.99	**0.049**	80	66.36 (18.56)	70.00	–0.97	18.04	0.632	2.26	15.36	0.207
MDT and PCA (B)	87	64.19 (18.03)	70.00	20–97	82	62.98 (20.35)	66.00	–1.40	18.14	0.488	73	62.40 (21.31)	65.00	–2.77	21.14	0.267	–2.39	18.30	0.268	71	65.32 (20.46)	70.00	–0.36	22.11	0.892	2.44	15.84	0.205
Control (C)	92	64.70 (20.23)	65.00	10–100	87	65.53 (20.89)	70.00	0.51	21.42	0.826	85	63.80 (20.06)	70.00	–1.58	22.39	0.518	–2.09	17.91	0.284	84	65.05 (18.00)	70.00	–0.02	20.20	0.994	2.00	17.21	0.296
Between Rx						*p*-value						*p*-value																
A vs. B vs. C						0.679						0.810																
A vs. B						0.388						0.655																
A vs. C						0.516						0.829																
B vs. C						0.860						0.535																
A + B vs. C						0.776						0.620																

N/A, not applicable; PwP, people with Parkinson's; Rx, treatment.
Bold indicates significant *p*-value.

TABLE 58 People with Parkinson's: EQ-5D Index[80,81]

				6 weeks		24 weeks				36 weeks			
	Baseline			Change 6–0		Change 24–6		Change 24–0		Change 36–24		Change 36–0	
Group (*n*)	Mean (SD)	Min.	Max.	Mean (SD)	*p*-value	Mean (SD)	*p*-value	Mean (SD)	*p*-value	Mean (SD)	*p*-value	Mean (SD)	*p*-value
A (75)	0.61 (0.25)	–0.13	1.00	0.05 (0.18)	**0.012**	–0.06 (0.21)	**0.020**	–0.01 (0.23)	0.843	–0.01 (0.22)	0.610	–0.02 (0.18)	0.377
B (69)	0.53 (0.29)	–0.18	1.00	0.07 (0.22)	**0.009**	0.00 (0.17)	0.949	0.07 (0.21)	**0.006**	–0.04 (0.25)	0.150	0.03 (0.26)	0.392
C (83)	0.58 (0.26)	–0.18	1.00	0.01 (0.19)	0.561	–0.02 (0.19)	0.419	0.00 (0.23)	0.862	0.02 (0.20)	0.486	0.01 (0.24)	0.665
p-value													
A vs. B vs. C	0.208				0.173		0.163		0.067		0.264		0.473
A vs. B	0.083				0.586		0.067		**0.039**		0.428		0.230
A vs. C	0.385				0.179		0.201		0.981		0.396		0.380
B vs. C	0.329				0.085		0.538		**0.038**		0.108		0.690
A + B vs. C	0.951				0.073		NR		NR		NR		NR

Max., maximum; min., minimum; NR, not reported.
Bold indicates significant *p*-value.

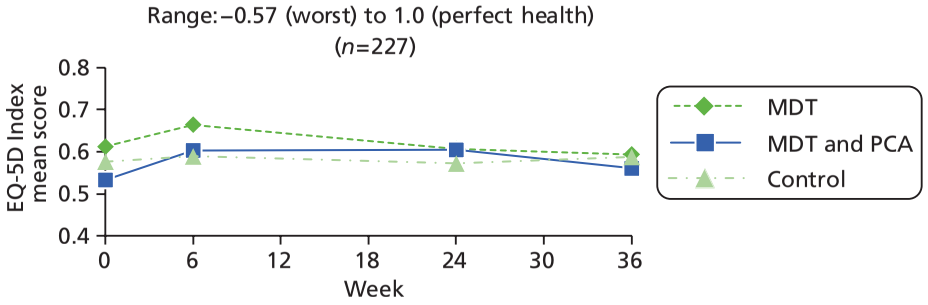

TABLE 59 Analysis of EQ-5D Index scores: $N = 267$ (ITT analysis)

	Baseline (0 weeks)				6 weeks						24 weeks									36 weeks							
PwP group	*n*	Mean (SD)	Median	Range	*n*	Mean (SD)	Median	Mean change 6–0	SD change 6–0	*p*-value 6–0	*n*	Mean (SD)	Median	Mean change 24–0	SD change 24–0	*p*-value 24–0	Mean change 24–6	SD change 24–6	*p*-value 24–6	*n*	Mean (SD)	Median	Mean change 36–0	SD change 36–0	*p*-value 36–0	Mean change 36–24	SD change 36–24	*p*-value 36–24
MDT (A)	88	0.59 (0.26)	0.62	–0.13–1	86	0.64 (0.26)	0.69	0.04	0.19	**0.038**	76	0.61 (0.27)	0.67	0.00	0.23	0.890	–0.05	0.21	**0.028**	80	0.59 (0.26)	0.63	–0.02	0.19	0.316	–0.01	0.22	0.610
MDT and PCA (B)	87	0.52 (0.28)	0.59	–0.18–1	82	0.59 (0.27)	0.62	0.07	0.20	**0.003**	73	0.59 (0.28)	0.64	0.06	0.21	**0.016**	–0.01	0.17	0.728	71	0.56 (0.34)	0.62	0.03	0.26	0.352	–0.04	0.25	0.150
Control (C)	92	0.54 (0.28)	0.63	–0.18–1	87	0.58 (0.27)	0.64	0.02	0.22	0.375	85	0.57 (0.28)	0.62	0.01	0.25	0.742	–0.02	0.19	0.375	85	0.58 (0.29)	0.69	0.01	0.24	0.783	0.02	0.20	0.486
Between Rx						*p*-value						*p*-value																
A vs. B vs. C						0.216						0.305																
A vs. B						0.083						0.408																
A vs. C						0.244						0.457																
B vs. C						0.566						0.135																
A+B vs. C						0.737						0.188																

N/A, not applicable; PwP, people with Parkinson's; Rx, treatment.
Bold indicates significant *p*-value.

TABLE 60 People with Parkinson's: SF-36 PCS[82]

				6 weeks		24 weeks				36 weeks			
	Baseline			Change 6–0		Change 24–6		Change 24–0		Change 36–24		Change 36–0	
Group (*n*)	Mean (SD)	Min.	Max.	Mean (SD)	*p*-value	Mean (SD)	*p*-value	Mean (SD)	*p*-value	Mean (SD)	*p*-value	Mean (SD)	*p*-value
A (75)	34.06 (10.07)	13.80	55.20	–0.74 (8.89)	0.471	0.68 (8.31)	0.482	–0.06 (8.23)	0.946	–1.14 (6.60)	0.138	–1.21 (8.62)	0.229
B (68)	33.81 (10.37)	13.10	55.60	–0.75 (7.34)	0.400	–0.45 (6.56)	0.570	–1.21 (8.95)	0.269	–1.10 (7.23)	0.213	–2.31 (7.93)	**0.019**
C (82)	35.23 (11.10)	13.80	59.40	–0.88 (8.80)	0.366	–1.32 (7.37)	0.109	–2.20 (8.82)	**0.027**	1.12 (7.08)	0.156	–1.08 (9.54)	0.308
p-value													
A vs. B vs. C	0.671				0.993		0.248		0.306		0.069		0.654
A vs. B	0.887				0.993		0.371		0.427		0.972		0.428
A vs. C	0.490				0.921		0.113		0.119		**0.040**		0.931
B vs. C	0.424				0.924		0.454		0.497		0.060		0.398
A + B vs. C	0.377				0.908		NR		NR		NR		NR

Max., maximum; min., minimum; NR, not reported.
Bold indicates significant *p*-value.

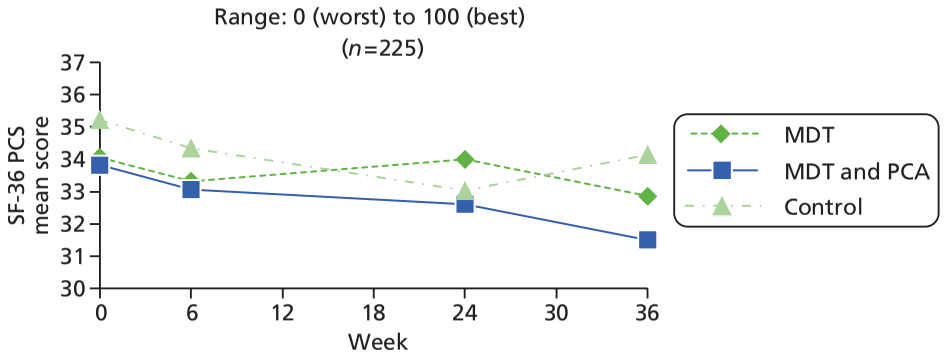

TABLE 61 Analysis of SF-36 PCS scores: $N = 265$ (ITT analysis)

	Baseline (0 weeks)				6 weeks						24 weeks									36 weeks							
PwP group	*n*	Mean (SD)	Median	Range	*n*	Mean (SD)	Median	Mean change 6–0	SD change 6–0	*p*-value 6–0	*n*	Mean (SD)	Median	Mean change 24–0	SD change 24–0	*p*-value 24–0	Mean change 24–6	SD change 24–6	*p*-value 24–6	*n*	Mean (SD)	Median	Mean change 36–0	SD change 36–0	*p*-value 36–0	Mean change 36–24	SD change 36–24	*p*-value 36–24
MDT (A)	87	33.59 (10.63)	34.00	13.7–55.6	86	33.16 (11.19)	33.05	–0.58	9.49	0.578	76	34.17 (10.66)	33.30	–0.17	8.23	0.857	0.87	8.42	0.372	79	33.04 (9.76)	32.70	–1.33	8.55	0.172	–1.14	6.60	0.138
MDT and PCA (B)	86	33.21 (9.87)	32.00	13.1–55.6	82	32.89 (9.70)	33.30	–0.55	7.11	0.489	73	32.38 (9.86)	33.40	–1.00	8.93	0.341	–0.38	6.52	0.622	70	31.65 (10.50)	30.20	–2.10	7.96	**0.031**	–1.10	7.23	0.213
Control (C)	92	34.98 (10.72)	35.05	13.8–59.4	87	33.90 (10.73)	31.00	–1.27	9.02	0.193	84	32.88 (10.35)	31.25	–2.33	8.85	**0.018**	–1.20	7.35	0.139	84	34.07 (11.59)	32.75	–1.16	9.51	0.271	1.12	7.08	0.156
Between Rx				*p*-value						*p*-value						*p*-value			*p*-value						*p*-value			*p*-value
A vs. B vs. C				0.489						0.824						0.283			0.218						0.786			0.069
A vs. B				0.808						0.982						0.556			0.316						0.577			0.972
A vs. C				0.385						0.624						0.113			0.099						0.901			**0.040**
B vs. C				0.254						0.565						0.351			0.463						0.514			0.060
A+B vs. C				0.241						0.534						N/A			N/A						N/A			N/A

N/A, not applicable; PwP, people with Parkinson's; Rx, treatment.
Bold indicates significant *p*-value.

TABLE 62 People with Parkinson's: SF-36 MCS[82]

				6 weeks		24 weeks				36 weeks			
	Baseline			Change 6–0		Change 24–6		Change 24–0		Change 36–24		Change 36–0	
Group (*n*)	Mean (SD)	Min.	Max.	Mean (SD)	*p*-value	Mean (SD)	*p*-value	Mean (SD)	*p*-value	Mean (SD)	*p*-value	Mean (SD)	*p*-value
A (75)	53.74 (9.48)	28.60	66.70	–0.35 (9.00)	0.739	–2.55 (7.62)	**0.005**	–2.90 (8.00)	**0.002**	–0.41 (7.19)	0.624	–3.30 (9.55)	**0.004**
B (69)	51.70 (9.78)	21.80	67.40	0.67 (8.76)	0.527	–0.68 (7.68)	0.463	–0.01 (8.63)	0.991	–0.29 (9.18)	0.793	–0.30 (8.28)	0.762
C (82)	53.02 (10.03)	30.20	70.30	–2.31 (7.90)	**0.010**	–0.31 (8.89)	0.753	–2.62 (8.17)	**0.005**	–0.41 (9.21)	0.689	–3.03 (8.78)	**0.002**
p-value													
A vs. B vs. C	0.451				0.092		0.192		0.072		0.996		0.085
A vs. B	0.206				0.493		0.146		**0.039**		0.932		**0.047**
A vs. C	0.646				0.147		0.094		0.832		1.000		0.852
B vs. C	0.417				**0.029**		0.785		0.059		0.938		0.053
A + B vs. C	0.849				**0.039**		NR		NR		NR		NR

Max., maximum; min., minimum; NR, not reported.
Bold indicates significant *p*-value.

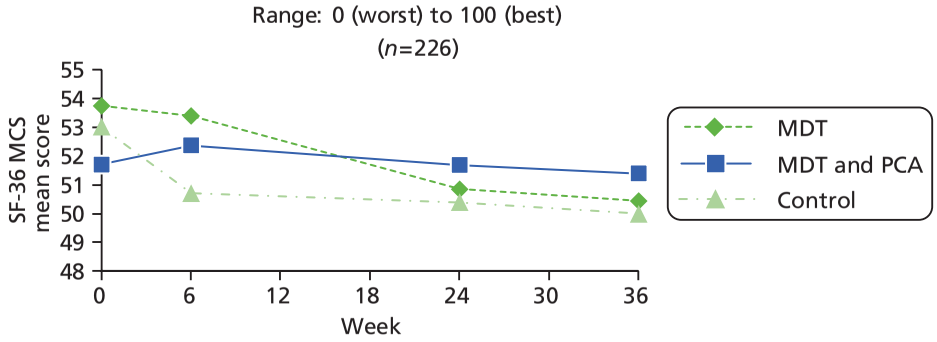

TABLE 63 Analysis of SF-36 MCS scores: $N = 265$ (ITT analysis)

	Baseline (0 weeks)				6 weeks						24 weeks										36 weeks								
PwP group	*n*	Mean (SD)	Median	Range	*n*	Mean (SD)	Median	Mean change 6–0	SD change 6–0	*p*-value 6–0	*n*	Mean (SD)	Median	Mean change 24–0	SD change 24–0	*p*-value 24–0	Mean change 24–6	SD change 24–6	*p*-value 24–6	*n*	Mean (SD)	Median	Mean change 36–0	SD change 36–0	*p*-value 36–0	Mean change 36–24	SD change 36–24	*p*-value 36–24
MDT (A)	87	52.80 (10.18)	55.60	25.6–66.7	86	52.50 (8.74)	54.20	–0.37	9.23	0.713	76	50.66 (10.14)	51.80	–2.74	8.07	**0.004**	–2.63	7.61	**0.004**	79	50.31 (10.23)	52.30	–3.34	9.44	**0.003**	–0.41	7.19	0.624
MDT and PCA (B)	86	51.26 (9.83)	52.95	21.8–67.4	82	51.99 (9.81)	52.65	0.49	8.85	0.616	73	51.65 (9.72)	53.80	–0.15	8.98	0.886	–0.52	7.53	0.554	71	51.29 (10.23)	54.00	–0.30	8.17	0.760	–0.29	9.18	0.793
Control (C)	92	52.21 (10.60)	54.85	29.5–70.3	87	50.25 (10.52)	52.60	–2.49	8.33	**0.007**	84	50.51 (11.06)	52.55	–2.73	8.26	**0.003**	–0.11	8.90	0.911	84	49.74 (10.67)	52.05	–2.87	8.84	**0.004**	–0.41	9.21	0.689
Between Rx						*p*-value						*p*-value																	
A vs. B vs. C						0.610						0.077																	
A vs. B						0.316						0.539																	
A vs. C						0.708						0.115																	
B vs. C						0.537						0.025																	
A+B vs. C						0.892						**0.030**																	

N/A, not applicable; PwP, people with Parkinson's; Rx, treatment.
Bold indicates significant *p*-value.

TABLE 64 People with Parkinson's: HADS – anxiety[83]

				6 weeks		24 weeks				36 weeks			
	Baseline			Change 6–0		Change 24–6		Change 24–0		Change 36–24		Change 36–0	
Group (*n*)	Mean (SD)	Min.	Max.	Mean (SD)	*p*-value	Mean (SD)	*p*-value	Mean (SD)	*p*-value	Mean (SD)	*p*-value	Mean (SD)	*p*-value
A (75)	5.76 (3.82)	0.00	19.00	–0.71 (2.59)	**0.021**	0.71 (2.62)	**0.022**	0.00 (3.01)	1.000	–0.31 (2.37)	0.266	–0.31 (2.81)	0.348
B (69)	5.87 (3.55)	0.00	15.00	–0.45 (2.39)	0.122	0.22 (2.59)	0.488	–0.23 (2.56)	0.454	0.20 (2.14)	0.433	–0.03 (2.33)	0.918
C (82)	6.10 (4.25)	0.00	18.00	0.23 (2.75)	0.448	0.28 (2.68)	0.346	0.51 (2.72)	0.092	–0.17 (2.44)	0.528	0.34 (2.93)	0.294
p-value													
A vs. B vs. C	0.858				0.066		0.469		0.238		0.401		0.326
A vs. B	0.859				0.537		0.262		0.620		0.179		0.521
A vs. C	0.603				**0.030**		0.316		0.265		0.724		0.160
B vs. C	0.724				0.110		0.884		0.087		0.323		0.397
A + B vs. C	0.597				**0.024**		NR		NR		NR		NR

Max., maximum; min., minimum; NR, not reported.
Bold indicates significant *p*-value.

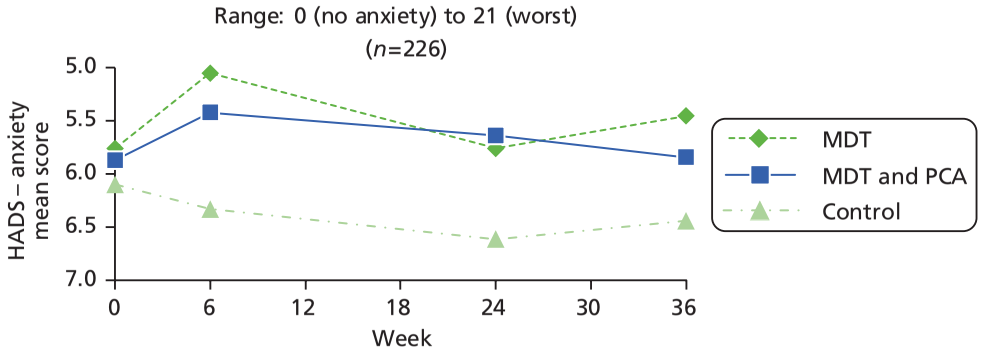

TABLE 65 Analysis of HADS anxiety scores: $N = 265$ (ITT analysis)

	Baseline (0 weeks)				6 weeks						24 weeks										36 weeks								
PwP group	*n*	Mean (SD)	Median	Range	*n*	Mean (SD)	Median	Mean change 6–0	SD change 6–0	*p*-value 6–0	*n*	Mean (SD)	Median	Mean change 24–0	SD change 24–0	*p*-value 24–0	Mean change 24–6	SD change 24–6	*p*-value 24–6		*n*	Mean (SD)	Median	Mean change 36–0	SD change 36–0	*p*-value 36–0	Mean change 36–24	SD change 36–24	*p*-value 36–24	
MDT (A)	87	5.86 (3.80)	5.00	0–19	86	5.17 (3.34)	4.00	–0.68	2.68	**0.021**	76	5.70 (4.04)	5.00	–0.09	3.09	0.796	0.59	2.79	0.068		80	5.51 (3.91)	5.00	–0.29	2.76	0.351	–0.31	2.37	0.266	
MDT and PCA (B)	86	6.06 (3.60)	6.00	0–15	82	5.41 (4.02)	5.00	–0.49	2.59	0.092	73	5.53 (3.75)	5.00	–0.19	2.52	0.518	0.14	2.67	0.663		71	5.83 (4.11)	5.00	–0.08	2.34	0.762	0.20	2.14	0.433	
Control (C)	93	6.47 (4.35)	6.00	0–18	87	6.52 (4.22)	6.00	0.30	2.71	0.306	85	6.64 (4.12)	7.00	0.54	2.72	0.071	0.24	2.70	0.424		84	6.52 (4.18)	6.00	0.27	2.93	0.395	–0.17	2.44	0.528	
Between Rx						*p*-value				*p*-value						*p*-value			*p*-value						*p*-value			*p*-value	
A vs. B vs. C						0.567				**0.039**						0.196			0.557						0.403			0.401	
A vs. B						0.728				0.634						0.830			0.311						0.623			0.179	
A vs. C						0.318				**0.018**						0.169			0.411						0.208			0.724	
B vs. C						0.489				0.055						0.083			0.819						0.408			0.323	
A+B vs. C						0.310				**0.012**						N/A			N/A						N/A			N/A	

N/A, not applicable; PwP, people with Parkinson's; Rx, treatment.
Bold indicates significant *p*-value.

TABLE 66 People with Parkinson's: HADS – depression[83]

				6 weeks		24 weeks				36 weeks			
	Baseline			Change 6–0		Change 24–6		Change 24–0		Change 36–24		Change 36–0	
Group (*n*)	Mean (SD)	Min.	Max.	Mean (SD)	*p*-value	Mean (SD)	*p*-value	Mean (SD)	*p*-value	Mean (SD)	*p*-value	Mean (SD)	*p*-value
A (75)	5.09 (3.43)	0.00	16.00	0.27 (2.54)	0.366	0.49 (2.52)	0.094	0.76 (2.61)	**0.014**	–0.31 (2.11)	0.211	0.45 (2.50)	0.121
B (69)	5.39 (3.20)	0.00	13.00	–0.38 (2.20)	0.159	0.17 (2.01)	0.474	–0.20 (2.43)	0.490	0.23 (1.93)	0.321	0.03 (2.59)	0.926
C (82)	5.20 (2.94)	1.00	12.00	0.61 (2.35)	**0.021**	–0.26 (2.74)	0.400	0.35 (2.58)	0.219	–0.10 (2.58)	0.733	0.26 (2.20)	0.296
p-value													
A vs. B vs. C	0.851				**0.039**		0.162		0.078		0.351		0.578
A vs. B	0.591				0.107		0.404		0.024		0.112		0.319
A vs. C	0.842				0.380		0.077		0.329		0.581		0.600
B vs. C	0.696				**0.009**		0.268		0.177		0.371		0.561
A + B vs. C	0.926				**0.049**		NR		NR		NR		NR

Max., maximum; min., minimum; NR, not reported.
Bold indicates significant *p*-value.

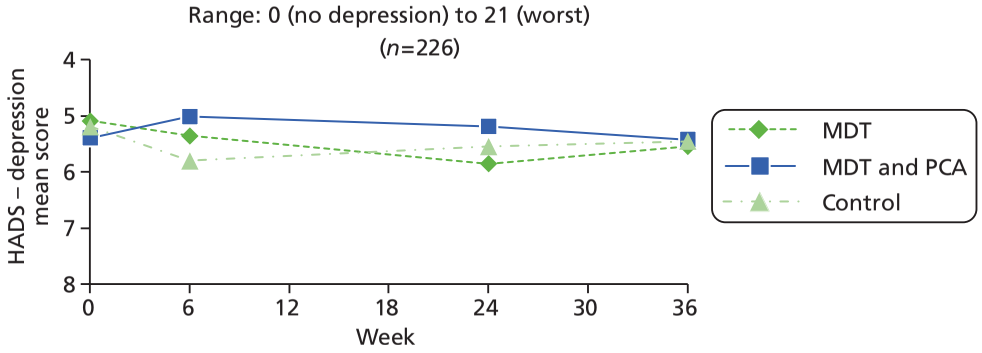

TABLE 67 Analysis of HADS – depression scores: $N = 265$ (ITT analysis)

	Baseline (0 weeks)				6 weeks						24 weeks									36 weeks							
PwP group	*n*	Mean (SD)	Median	Range	*n*	Mean (SD)	Median	Mean change 6–0	SD change 6–0	*p*-value 6–0	*n*	Mean (SD)	Median	Mean change 24–0	SD change 24–0	*p*-value 24–0	Mean change 24–6	SD change 24–6	*p*-value 24–6	*n*	Mean (SD)	Median	Mean change 36–0	SD change 36–0	*p*-value 36–0	Mean change 36–24	SD change 36–24	*p*-value 36–24
MDT (A)	87	5.24 (3.41)	5.00	0–16	86	5.64 (3.61)	5.00	0.40	2.61	0.162	76	5.91 (3.71)	5.00	0.80	2.62	**0.009**	0.54	2.53	0.067	80	5.76 (3.48)	5.50	0.59	2.59	**0.045**	–0.31	2.11	0.211
MDT and PCA (B)	86	5.55 (3.10)	5.50	0–13	82	5.18 (3.06)	5.00	–0.24	2.14	0.305	73	5.22 (3.14)	5.00	–0.19	2.44	0.503	0.11	2.04	0.647	71	5.44 (3.60)	5.00	0.04	2.55	0.890	0.23	1.93	0.321
Control (C)	93	5.49 (3.04)	5.00	1–13	87	6.00 (3.64)	6.00	0.70	2.32	**0.006**	85	5.60 (3.73)	5.00	0.36	2.58	0.196	–0.31	2.74	0.307	84	5.51 (3.36)	5.00	0.23	2.19	0.346	–0.10	2.58	0.733
Between Rx										*p*-value						*p*-value			*p*-value						*p*-value			*p*-value
A vs. B vs. C										0.795						0.032			0.060						0.366			0.351
A vs. B										0.539						0.084			0.018						0.192			0.112
A vs. C										0.599						0.425			0.287						0.327			0.581
B vs. C										0.910						**0.007**			0.168						0.630			0.371
A+B vs. C										0.804						0.051			N/A						N/A			N/A

N/A, not applicable; PwP, people with Parkinson's; Rx, treatment.
Bold indicates significant *p*-value.

TABLE 68 People with Parkinson's: Yale Depression Screen[84,85]

		6–0 weeks, *n* (%)				24–6 weeks, *n* (%)				24–0 weeks, *n* (%)				36–24 weeks, *n* (%)				36–0 weeks, *n* (%)			
Group (*n*)	Baseline, *n* (%)	Improved	Stayed same	Worsened	*p*-value	Improved	Stayed same	Worsened	*p*-value	Improved	Stayed same	Worsened	*p*-value	Improved	Stayed same	Worsened	*p*-value	Improved	Stayed same	Worsened	*p*-value
A (74)	13 (17.60)	6 (8.1)	61 (82.4)	7 (9.5)	0.782	6 (8.1)	64 (86.5)	4 (5.4)	0.527	6 (8.1)	63 (85.1)	5 (6.8)	0.76	5 (6.8)	60 (81.1)	9 (12.2)	0.285	6 (8.1)	59 (79.7)	9 (12.2)	0.439
B (69)	19 (27.50)	10 (14.5)	58 (84.1)	1 (1.4)	**0.007**	3 (4.3)	26 (85.5)	7 (10.1)	0.206	9 (13)	56 (81.2)	4 (5.8)	0.17	4 (5.8)	60 (87)	5 (7.2)	0.739	11 (15.9)	51 (73.9)	7 (10.1)	0.346
C (82)	28 (34.10)	14 (17.1)	66 (80.5)	2 (2.4)	**0.003**	5 (6.1)	72 (87.8)	5 (6.1)	1.000	16 (19.5)	62 (75.6)	4 (4.9)	**0.01**	6 (7.3)	65 (79.3)	11 (13.4)	0.225	14 (17.1)	61 (74.4)	7 (8.5)	0.127
p-value																					
A vs. B vs. C	0.064				**0.037**				0.367				0.153				0.759				0.244
A vs. B	0.153				**0.037**				0.176				0.384				0.221				0.546
A vs. C	**0.019**				**0.020**				0.638				0.055				0.917				0.101
B vs. C	0.382				0.787				0.328				0.312				0.479				0.744
A + B vs. C	0.055				0.117				NR				NR				NR				NR

NR, not reported.
Bold indicates significant *p*-value.

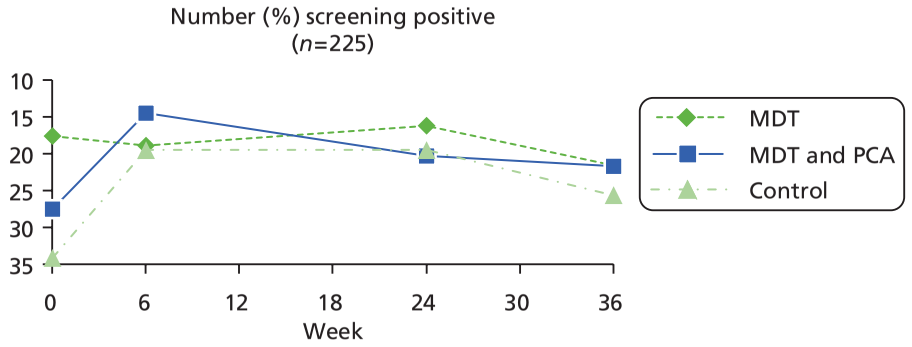

TABLE 69 Analysis of Yale Depression Screen scores: $N = 269$ (ITT analysis)

		6–0 weeks, *n* (%)				24–6 weeks, *n* (%)				24–0 weeks, *n* (%)				36–24 weeks, *n* (%)				36–0 weeks, *n* (%)			
Group (*n*)	Baseline, *n* (%)	Improved	Stayed same	Worsened	*p*-value	Improved	Stayed same	Worsened	*p*-value	Improved	Stayed same	Worsened	*p*-value	Improved	Stayed same	Worsened	*p*-value	Improved	Stayed same	Worsened	*p*-value
A (88)	17 (19.3)	6 (8.1)	61 (82.4)	7 (9.5)	0.782	6 (8.1)	64 (86.5)	4 (5.4)	0.527	6 (8.1)	63 (85.1)	5 (6.8)	0.763	5 (6.8)	60 (81.1)	9 (12.2)	0.285	6 (8.1)	59 (79.7)	9 (12.2)	0.439
B (88)	24 (27.3)	10 (14.5)	58 (84.1)	1 (1.4)	**0.007**	3 (4.3)	59 (85.5)	7 (10.1)	0.206	9 (13)	56 (81.2)	4 (5.8)	0.166	4 (5.8)	60 (87)	5 (7.2)	0.739	11 (15.9)	51 (73.9)	7 (10.1)	0.346
C (93)	37 (39.8)	14 (17.1)	66 (80.5)	2 (2.4)	**0.003**	5 (6.1)	72 (87.8)	5 (6.1)	1.000	16 (19.5)	52 (75.6)	4 (4.9)	**0.007**	6 (7.3)	65 (79.3)	11 (13.4)	**0.023**	14 (17.1)	61 (74.4)	7 (8.5)	0.127
p-value																					
A vs. B vs. C	**0.009**				**0.037**				0.367				0.153				0.759				0.244
A vs. B	0.212				**0.037**				0.176				0.384				0.566				0.221
A vs. C	**0.003**				**0.020**				0.638				0.055				0.917				0.101
B vs. C	0.075				0.787				0.328				0.312				0.479				0.744
A + B vs. C	**0.005**				0.117				NR				NR				NR				NR

NR, not reported.
Bold indicates significant *p*-value.

TABLE 70 People with Parkinson's: Self-Efficacy Scale[86]

				6 weeks		24 weeks				36 weeks			
	Baseline			Change 6–0		Change 24–6		Change 24–0		Change 36–24		Change 36–0	
Group (*n*)	Mean (SD)	Min.	Max.	Mean (SD)	*p*-value	Mean (SD)	*p*-value	Mean (SD)	*p*-value	Mean (SD)	*p*-value	Mean (SD)	*p*-value
A (75)	7.27 (1.87)	2.83	10.00	0.07 (1.50)	0.698	–0.67 (1.62)	**0.001**	–0.61 (1.68)	**0.003**	0.01 (1.68)	0.968	–0.60 (1.44)	**0.001**
B (69)	7.16 (1.76)	2.50	10.00	–0.16 (1.89)	0.479	–0.21 (1.64)	0.295	–0.37 (1.96)	0.121	–0.03 (1.54)	0.868	–0.40 (2.01)	0.102
C (82)	7.03 (2.13)	1.00	10.00	–0.16 (1.69)	0.395	–0.15 (1.44)	0.352	–0.31 (1.74)	0.113	–0.16 (1.78)	0.427	–0.47 (1.73)	**0.017**
p-value													
A vs. B vs. C	0.746				0.636		0.079		0.555		0.813		0.782
A vs. B	0.725				0.420		0.090		0.438		0.886		0.497
A vs. C	0.463				0.377		0.033		0.278		0.553		0.602
B vs. C	0.688				0.995		0.811		0.837		0.647		0.835
A + B vs. C	0.509				0.617		NR		NR		NR		NR

Max., maximum; min., minimum; NR, not reported.
Bold indicates significant *p*-value.

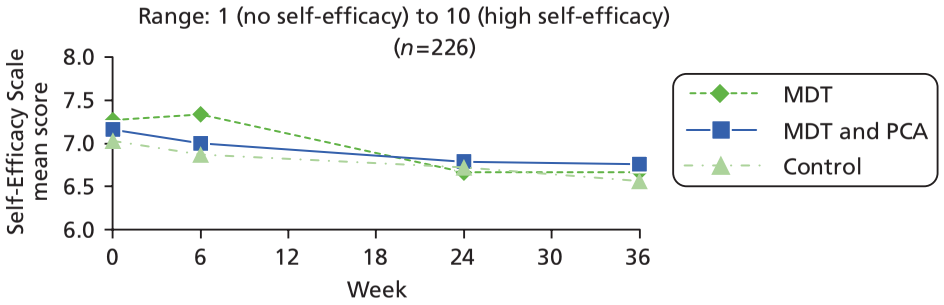

TABLE 71 Analysis of Self-Efficacy Scale scores: $N = 265$ (ITT analysis)

	Baseline (0 weeks)				6 weeks						24 weeks										36 weeks								
PwP group	*n*	Mean (SD)	Median	Range	*n*	Mean (SD)	Median	Mean change 6–0	SD change 6–0	*p*-value 6–0	*n*	Mean (SD)	Median	Mean change 24–0	SD change 24–0	*p*-value 24–0	Mean change 24–6	SD change 24–6	*p*-value 24–6		*n*	Mean (SD)	Median	Mean change 36–0	SD change 36–0	*p*-value 36–0	Mean change 36–24	SD change 36–24	*p*-value 36–24	
MDT (A)	87	6.98 (2.05)	7.17	1–10	86	7.13 (2.06)	7.50	0.11	1.61	0.530	76	6.68 (2.13)	6.92	–0.60	1.67	**0.002**	–0.65	1.62	**0.001**		79	6.65 (2.05)	7.00	–0.55	1.50	**0.002**	0.01	1.68	0.968	
MDT and PCA (B)	86	6.84 (1.89)	7.00	2–10	82	6.87 (2.15)	7.33	–0.04	2.12	0.877	73	6.76 (2.05)	6.83	–0.31	2.02	0.195	–0.15	1.68	0.440		71	6.75 (1.91)	7.17	–0.39	1.99	0.108	–0.03	1.54	0.868	
Control (C)	92	6.89 (2.10)	6.92	1–10	87	6.82 (2.27)	6.83	–0.13	1.70	0.468	85	6.68 (2.22)	7.00	–0.29	1.74	0.126	–0.16	1.45	0.307		84	6.55 (2.26)	6.25	–0.43	1.75	**0.026**	–0.16	1.78	0.427	
Between Rx						*p*-value				*p*-value						*p*-value			*p*-value							*p*-value			*p*-value
A vs. B vs. C						0.902				0.678						0.488			0.081							0.841			0.813
A vs. B						0.650				0.614						0.335			0.065							0.572			0.886
A vs. C						0.771				0.337						0.250			0.043							0.656			0.553
B vs. C						0.878				0.743						0.953			0.971							0.874			0.647
A + B vs. C						0.931				0.476						N/A			N/A							N/A			N/A

N/A, not applicable; PwP, people with Parkinson's; Rx, treatment.
Bold indicates significant *p*-value.

TABLE 72 People with Parkinson's: Timed Up and Go[87,88]

				6 weeks		24 weeks				36 weeks			
	Baseline			Change 6–0		Change 24–6		Change 24–0		Change 36–24		Change 36–0	
Group (*n*)	Mean (SD)	Min.	Max.	Mean (SD)	*p*-value	Mean (SD)	*p*-value	Mean (SD)	*p*-value	Mean (SD)	*p*-value	Mean (SD)	*p*-value
A (72)	18.48 (11.68)	8.49	80.00	1.68 (12.84)	0.271	2.80 (19.64)	0.230	4.48 (17.87)	**0.037**	–5.93 (17.72)	**0.006**	–1.45 (7.11)	0.088
B (60)	18.28 (13.29)	7.00	90.00	–1.45 (8.78)	0.207	1.95 (14.50)	0.302	0.50 (13.87)	0.779	–0.85 (21.69)	0.763	–0.35 (15.96)	0.867
C (78)	16.08 (12.68)	8.00	97.00	–1.35 (8.42)	0.161	2.42 (10.13)	**0.038**	1.07 (8.83)	0.287	0.17 (9.53)	0.878	1.24 (10.08)	0.282
p-value													
A vs. B vs. C	0.436				0.122		0.950		0.192		0.063		0.344
A vs. B	0.928				0.112		0.781		0.162		0.141		0.599
A vs. C	0.232				0.088		0.883		0.147		**0.011**		0.063
B vs. C	0.325				0.948		0.822		0.770		0.712		0.478
A + B vs. C	0.198				0.275		NR		NR		NR		NR

Max., maximum; min., minimum; NR, not reported.
Bold indicates significant *p*-value.

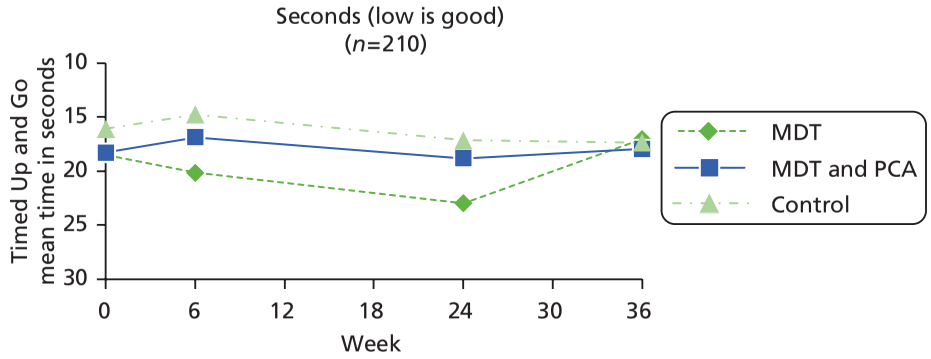

TABLE 73 Analysis of Timed Up and Go scores: $N = 265$ (ITT analysis)

	Baseline (0 weeks)				6 weeks						24 weeks										36 weeks								
PwP group	*n*	Mean (SD)	Median	Range	*n*	Mean (SD)	Median	Mean change 6–0	SD change 6–0	*p*-value 6–0	*n*	Mean (SD)	Median	Mean change 24–0	SD change 24–0	*p*-value 24–0	Mean change 24–6	SD change 24–6	*p*-value 24–6	*n*	Mean (SD)	Median	Mean change 36–0	SD change 36–0	*p*-value 36–0	Mean change 36–24	SD change 36–24	*p*-value 36–24
MDT (A)	85	18.70 (12.39)	14.00	8.49–80	84	21.49 (18.17)	15.00	1.95	12.77	0.171	76	23.39 (21.74)	16.00	4.17	17.62	**0.044**	2.67	19.38	0.239	76	16.96 (9.26)	14.00	–1.46	7.09	0.076	–5.81	17.63	**0.006**
MDT and PCA (B)	84	20.76 (16.45)	15.56	7–104	78	22.82 (35.87)	14.00	–1.90	12.24	0.183	68	26.03 (36.57)	15.00	2.43	22.10	0.378	2.81	22.65	0.310	66	18.44 (15.90)	14.00	0.14	15.88	0.944	–0.74	21.43	0.786
Control (C)	93	19.07 (18.90)	13.00	8–123	86	15.87 (10.65)	13.00	–1.26	8.19	0.159	82	19.09 (18.98)	13.00	1.09	9.76	0.315	2.70	10.31	**0.021**	81	17.11 (13.92)	13.00	1.21	9.91	0.274	0.17	9.53	0.878

Between Rx	*p*-value	*p*-value	*p*-value	*p*-value	*p*-value	*p*-value
A vs. B vs. C	0.677	0.067	0.519	0.999	0.328	0.065
A vs. B	0.358	0.056	0.607	0.970	0.430	0.134
A vs. C	0.878	0.054	0.184	0.991	0.055	**0.012**
B vs. C	0.528	0.692	0.649	0.972	0.620	0.738
A+B vs. C	0.755	0.367	N/A	N/A	N/A	N/A

N/A, not applicable; PwP, people with Parkinson's; Rx, treatment.
Bold indicates significant *p*-value.

TABLE 74 People with Parkinson's: falls

Group (*n*)	Baseline, *n* (%)	6–0 weeks, *n* (%)				24–6 weeks, *n* (%)				24–0 weeks, *n* (%)				36–24 weeks, *n* (%)				36–0 weeks, *n* (%)			
		Improved	Stayed same	Worsened	*p*-value	Improved	Stayed same	Worsened	*p*-value	Improved	Stayed same	Worsened	*p*-value	Improved	Stayed same	Worsened	*p*-value	Improved	Stayed same	Worsened	*p*-value
A (75)	31 (41.3)	16 (21.3)	52 (69.3)	7 (9.3)	0.061	5 (6.7)	51 (68)	19 (25.3)	**0.004**	12 (16.0)	46 (61.3)	17 (22.7)	0.35	16 (21.3)	54 (72.0)	5 (6.7)	**0.016**	16 (21.3)	49 (65.3)	10 (13.3)	0.239
B (70)	30 (42.9)	11 (15.7)	54 (77.1)	5 (7.1)	0.134	4 (5.8)	53 (76.8)	12 (17.4)	**0.046**	6 (8.7)	54 (78.3)	9 (13.0)	0.44	8 (11.6)	55 (79.7)	6 (8.7)	0.593	7 (10.0)	55 (78.6)	8 (11.4)	0.796
C (83)	31 (37.3)	13 (15.7)	61 (73.5)	9 (10.8)	0.394	8 (9.8)	59 (72.0)	15 (18.3)	0.144	11 (13.4)	57 (69.5)	14 (17.1)	0.55	18 (22.0)	56 (68.3)	8 (9.8)	**0.050**	16 (19.3)	59 (71.1)	8 (9.6)	0.102
p-value																					
A vs. B vs. C	0.064				0.067				0.445				0.926				0.327				0.378
A vs. B	0.153				0.652				0.371				0.756				0.140				0.274
A vs. C	**0.019**				0.386				0.232				0.729				0.803				0.882
B vs. C	0.382				0.656				0.738				0.954				0.244				0.170
A + B vs. C	0.055				0.437				NR				NR				NR				NR

NR, not reported.
Bold indicates significant *p*-value.

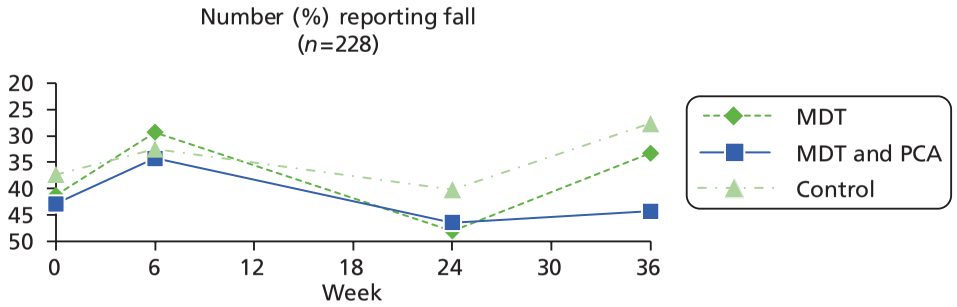

TABLE 75 Analysis of falls scores: $N = 265$ (ITT analysis)

		6–0 weeks, *n* (%)				24–6 weeks, *n* (%)				24–0 weeks, *n* (%)				36–24 weeks, *n* (%)				36–0 weeks, *n* (%)			
Group (*n*)	Baseline, *n* (%)	Improved	Stayed same	Worsened	*p*-value	Improved	Stayed same	Worsened	*p*-value	Improved	Stayed same	Worsened	*p*-value	Improved	Stayed same	Worsened	*p*-value	Improved	Stayed same	Worsened	*p*-value
A (88)	37 (42)	16 (21.3)	52 (69.3)	7 (9.3)	0.061	5 (6.7)	51 (68)	19 (25.3)	**0.004**	12 (16)	46 (61.3)	17 (22.7)	0.353	16 (21.3)	54 (72)	5 (6.7)	**0.016**	16 (21.3)	49 (65.3)	10 (13.3)	0.239
B (88)	37 (42)	11 (15.7)	54 (77.1)	5 (7.1)	0.134	4 (5.8)	53 (76.8)	12 (17.4)	0.046	6 (8.7)	54 (78.3)	9 (13)	0.439	8 (11.6)	55 (79.7)	6 (8.7)	0.593	7 (10)	55 (78.6)	8 (11.4)	0.796
C (93)	35 (37.6)	13 (15.7)	61 (73.5)	9 (10.8)	0.394	8 (9.8)	59 (72)	15 (18.3)	0.144	11 (13.4)	57 (69.5)	14 (17.1)	0.549	18 (22)	56 (68.3)	8 (9.8)	**0.050**	16 (19.3)	59 (71.1)	8 (9.6)	0.102
p-value																					
A vs. B vs. C	0.782				0.670				0.445				0.926				0.327				0.378
A vs. B	0.561				0.652				0.371				0.756				0.140				0.274
A vs. C	0.325				0.386				0.232				0.729				0.803				0.882
B vs. C	0.325				0.656				0.738				0.954				0.244				0.170
A + B vs. C	0.285				0.437				NR				NR				NR				NR

NR, not reported.
Bold indicates significant *p*-value.

TABLE 76 People with Parkinson's UPDRS – posture[89]

				6 weeks		24 weeks				36 weeks			
	Baseline			Change 6–0		Change 24–6		Change 24–0		Change 36–24		Change 36–0	
Group (*n*)	Mean (SD)	Min.	Max.	Mean (SD)	*p*-value	Mean (SD)	*p*-value	Mean (SD)	*p*-value	Mean (SD)	*p*-value	Mean (SD)	*p*-value
A (72)	0.94 (0.77)	0.00	4.00	–0.19 (0.66)	**0.015**	0.25 (0.67)	**0.002**	0.06 (0.75)	0.531	–0.32 (0.71)	**< 0.001**	–0.26 (0.75)	**0.004**
B (62)	0.94 (0.87)	0.00	3.00	–0.32 (0.65)	**< 0.001**	–0.03 (0.63)	0.687	–0.35 (0.63)	**< 0.001**	0.10 (0.47)	0.109	–0.26 (0.63)	**0.002**
C (78)	0.88 (0.72)	0.00	3.00	–0.15 (0.82)	0.103	0.13 (0.76)	0.141	–0.03 (0.72)	0.754	–0.23 (0.62)	**0.002**	–0.26 (0.76)	**0.004**
p-value													
A vs. B vs. C	0.880				0.371		0.065		**0.002**		**< 0.001**		0.998
A vs. B	0.949				0.262		**0.013**		**0.001**		**< 0.001**		0.962
A vs. C	0.623				0.741		0.301		0.500		0.416		0.952
B vs. C	0.705				0.188		0.174		**0.005**		**0.001**		0.989
A + B vs. C	0.616				0.333		NR		NR		NR		NR

Max., maximum; min., minimum; NR, not reported.
Bold indicates significant *p*-value.

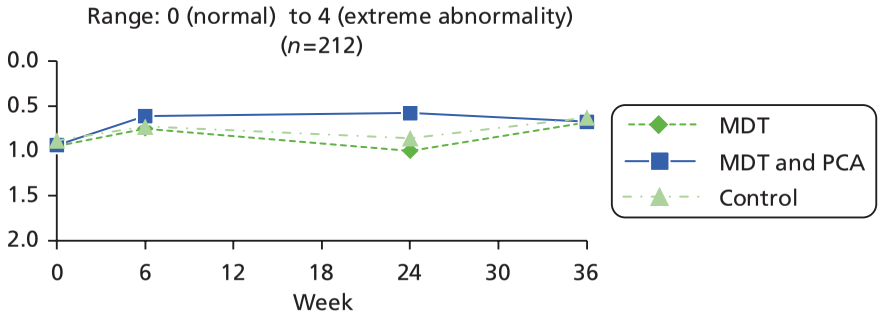

TABLE 77 Analysis of UPDRS – posture scores: $N = 265$ (ITT analysis)

	Baseline (0 weeks)				6 weeks						24 weeks									36 weeks							
PwP group	*n*	Mean (SD)	Median	Range	*n*	Mean (SD)	Median	Mean change 6–0	SD change 6–0	*p*-value 6–0	*n*	Mean (SD)	Median	Mean change 24–0	SD change 24–0	*p*-value 24–0	Mean change 24–6	SD change 24–6	*p*-value 24–6	*n*	Mean (SD)	Median	Mean change 36–0	SD change 36–0	*p*-value 36–0	Mean change 36–24	SD change 36–24	*p*-value 36–24
MDT (A)	87	1.03 (0.81)	1.00	0–4	85	0.85 (0.85)	1.00	–0.19	0.72	**0.017**	76	1.01 (0.82)	1.00	0.07	0.74	0.439	0.24	0.67	**0.003**	76	0.68 (0.68)	1.00	–0.32	0.79	**0.001**	–0.32	0.70	**<0.001**
MDT and PCA (B)	85	1.00 (0.87)	1.00	0–4	80	0.71 (0.68)	1.00	–0.30	0.63	**<0.001**	69	0.65 (0.66)	1.00	–0.30	0.65	**0.001**	–0.04	0.63	0.567	67	0.73 (0.66)	1.00	–0.23	0.63	**0.005**	0.10	0.47	0.109
Control (C)	93	0.98 (0.78)	1.00	0–4	86	0.77 (0.73)	1.00	–0.17	0.83	0.054	82	0.95 (0.83)	1.00	0.00	0.74	1.000	0.17	0.82	0.061	81	0.63 (0.68)	1.00	–0.25	0.77	**0.005**	–0.23	0.62	**0.002**

Between Rx	*p*-value	*p*-value	*p*-value	*p*-value	*p*-value	*p*-value
A vs. B vs. C	0.900	0.510	**0.006**	0.050	0.747	**<0.001**
A vs. B	0.789	0.313	**0.002**	**0.010**	0.464	**<0.001**
A vs. C	0.638	0.893	0.576	0.578	0.579	0.437
B vs. C	0.862	0.287	**0.011**	0.070	0.865	**0.001**
A + B vs. C	0.712	0.490	N/A	N/A	N/A	N/A

N/A, not applicable; PwP, people with Parkinson's; Rx, treatment.
Bold indicates significant *p*-value.

TABLE 78 People with Parkinson's UPDRS – gait[89]

				6 weeks		24 weeks				36 weeks			
	Baseline			Change 6–0		Change 24–6		Change 24–0		Change 36–24		Change 36–0	
Group (*n*)	Mean (SD)	Min.	Max.	Mean (SD)	*p*-value	Mean (SD)	*p*-value	Mean (SD)	*p*-value	Mean (SD)	*p*-value	Mean (SD)	*p*-value
A (72)	1.14 (0.77)	0.00	3.00	–0.32 (0.75)	**0.001**	0.17 (0.65)	**0.033**	–0.15 (0.76)	0.094	0.10 (0.75)	0.277	–0.06 (0.85)	0.583
B (62)	1.19 (0.85)	0.00	3.00	–0.24 (0.72)	**0.010**	0.05 (0.64)	0.553	–0.19 (0.79)	0.057	–0.10 (0.62)	0.223	–0.29 (0.71)	**0.002**
C (78)	1.00 (0.79)	0.00	3.00	–0.17 (0.71)	**0.042**	0.14 (0.68)	0.070	–0.03 (0.81)	0.779	–0.18 (0.60)	**0.010**	–0.21 (0.80)	**0.026**
p-value													
A vs. B vs. C	0.331				0.437		0.557		0.410		**0.035**		0.219
A vs. B	0.697				0.543		0.292		0.761		0.109		0.089
A vs. C	0.279				0.201		0.814		0.323		**0.013**		0.269
B vs. C	0.165				0.536		0.412		0.218		0.425		0.511
A + B vs. C	0.151				0.258		NR		NR		NR		NR

Max., maximum; min., minimum; NR, not reported.
Bold indicates significant *p*-value.

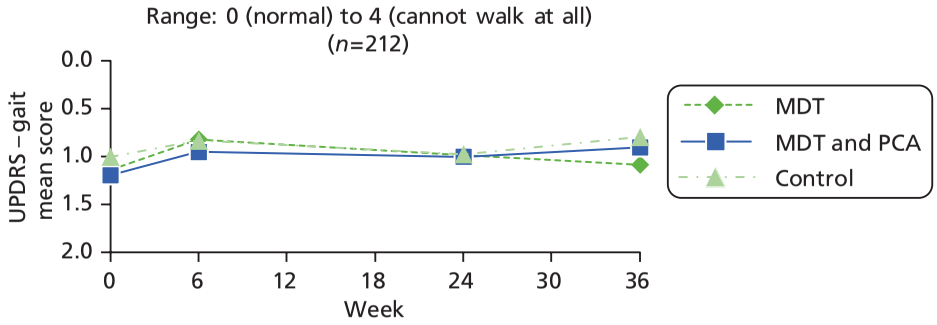

TABLE 79 Analysis of UPDRS – gait scores: $N = 265$ (ITT analysis)

	Baseline (0 weeks)				6 weeks						24 weeks										36 weeks									
PwP group	*n*	Mean (SD)	Median	Range	*n*	Mean (SD)	Median	Mean change 6–0	SD change 6–0	*p*-value 6–0	*n*	Mean (SD)	Median	Mean change 24–0	SD change 24–0	*p*-value 24–0	Mean change 24–6	SD change 24–6	*p*-value 24–6		*n*	Mean (SD)	Median	Mean change 36–0	SD change 36–0	*p*-value 36–0	Mean change 36–24	SD change 36–24	*p*-value 36–24	
MDT (A)	87	1.22 (0.83)	1.00	0–3	85	0.94 (0.76)	1.00	–0.29	0.72	**< 0.001**	76	1.00 (0.91)	1.00	–0.17	0.77	0.057	0.13	0.68	0.096		76	1.11 (0.79)	1.00	–0.04	0.89	0.699	0.11	0.76	0.219	
MDT and PCA (B)	85	1.26 (0.82)	1.00	0–3	79	1.04 (0.90)	1.00	–0.23	0.71	**0.005**	69	1.10 (0.79)	1.00	–0.13	0.80	0.172	0.04	0.67	0.594		67	0.94 (0.80)	1.00	–0.26	0.73	**0.006**	–0.10	0.61	0.223	
Control (C)	93	1.13 (0.85)	1.00	0–3	86	0.91 (0.79)	1.00	–0.15	0.71	0.052	82	1.02 (0.82)	1.00	–0.02	0.82	0.787	0.15	0.67	0.051		81	0.80 (0.80)	1.00	–0.21	0.80	**0.021**	–0.18	0.60	**0.010**	
Between Rx						*p*-value				*p*-value						*p*-value			*p*-value							*p*-value			*p*-value	
A vs. B vs. C						0.566				0.464						0.484			0.604							0.234			**0.025**	
A vs. B						0.748				0.645						0.780			0.429							0.115			0.088	
A vs. C						0.476				0.222						0.249			0.892							0.208			**0.010**	
B vs. C						0.302				0.459						0.409			0.344							0.709			0.413	
A+B vs. C						0.308				0.250						N/A			N/A							N/A			N/A	

N/A, not applicable; PwP, people with Parkinson's; Rx, treatment.
Bold indicates significant *p*-value.

TABLE 80 People with Parkinson's: pain 'on' state VAS[90–93]

				6 weeks		24 weeks				36 weeks			
	Baseline			Change 6–0		Change 24–6		Change 24–0		Change 36–24		Change 36–0	
Group (*n*)	Mean (SD)	Min.	Max.	Mean (SD)	*p*-value	Mean (SD)	*p*-value	Mean (SD)	*p*-value	Mean (SD)	*p*-value	Mean (SD)	*p*-value
A (48)	26.00 (27.34)	0.00	100.00	5.52 (26.71)	0.159	1.67 (27.49)	0.676	7.19 (23.97)	**0.043**	1.74 (19.30)	0.535	8.93 (26.44)	**0.024**
B (55)	27.32 (25.85)	0.00	82.00	5.54 (30.46)	0.183	–2.84 (27.42)	0.446	2.70 (32.91)	0.545	–1.35 (23.49)	0.673	1.35 (33.19)	0.763
C (61)	29.27 (25.10)	0.00	91.00	10.81 (27.56)	**0.003**	–8.48 (25.41)	**0.012**	2.34 (28.07)	0.518	2.95 (29.15)	0.432	5.29 (25.69)	0.113
p-value													
A vs. B vs. C	0.803				0.515		0.143		0.636		0.634		0.408
A vs. B	0.802				0.998		0.408		0.437		0.472		0.208
A vs. C	0.518				0.316		**0.049**		0.342		0.804		0.470
B vs. C	0.681				0.329		0.253		0.949		0.387		0.475
A + B vs. C	0.541				0.249		NR		NR		NR		NR

Max., maximum; min., minimum; NR, not reported.
Bold indicates significant *p*-value.

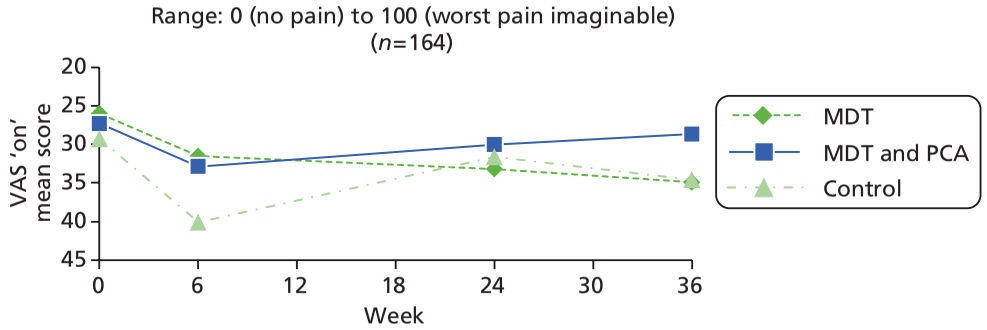

TABLE 81 Analysis of VAS 'on' scores: $N = 265$ (ITT analysis)

	Baseline (0 weeks)				6 weeks						24 weeks									36 weeks							
PwP group	*n*	Mean (SD)	Median	Range	*n*	Mean (SD)	Median	Mean change 6–0	SD change 6–0	*p*-value 6–0	*n*	Mean (SD)	Median	Mean change 24–0	SD change 24–0	*p*-value 24–0	Mean change 24–6	SD change 24–6	*p*-value 24–6	*n*	Mean (SD)	Median	Mean change 36–0	SD change 36–0	*p*-value 36–0	Mean change 36–24	SD change 36–24	*p*-value 36–24
MDT (A)	76	25.93 (27.05)	18.00	0–100	81	26.29 (25.93)	19.00	1.65	25.33	0.590	64	31.59 (27.02)	24.00	6.98	23.41	**0.031**	3.35	25.58	0.315	75	31.10 (26.20)	25.00	7.99	24.72	**0.011**	1.16	19.80	0.650
MDT and PCA (B)	80	25.48 (25.43)	20.50	0–82	78	29.22 (27.89)	21.00	3.85	31.67	0.302	69	28.46 (28.52)	20.00	1.08	32.04	0.789	–0.95	26.51	0.771	66	28.92 (27.95)	17.00	3.34	34.78	0.456	0.66	25.31	0.840
Control (C)	86	26.02 (24.70)	24.00	0–91	79	36.37 (28.65)	33.00	9.72	28.06	**0.003**	78	29.73 (27.32)	23.50	3.85	30.64	0.283	–7.09	26.10	**0.023**	72	32.75 (29.74)	26.50	5.66	26.47	0.085	2.52	28.21	0.471

Between Rx	*p*-value	*p*-value	*p*-value	*p*-value	*p*-value	*p*-value
A vs. B vs. C	0.989	0.208	0.549	0.069	0.665	0.908
A vs. B	0.913	0.650	0.260	0.356	0.392	0.903
A vs. C	0.983	0.071	0.528	**0.022**	0.603	0.756
B vs. C	0.888	0.231	0.604	0.170	0.670	0.697
A+B vs. C	0.925	0.086	N/A	N/A	N/A	N/A

N/A, not applicable; PwP, people with Parkinson's; Rx, treatment.
Bold indicates significant *p*-value.

TABLE 82 People with Parkinson's: pain 'off' state VAS[90–93]

				6 weeks		24 weeks				36 weeks			
	Baseline			Change 6–0		Change 24–6		Change 24–0		Change 36–24		Change 36–0	
Group (*n*)	Mean (SD)	Min.	Max.	Mean (SD)	*p*-value	Mean (SD)	*p*-value	Mean (SD)	*p*-value	Mean (SD)	*p*-value	Mean (SD)	*p*-value
A (41)	33.59 (28.29)	0.00	84.00	1.43 (36.17)	0.802	1.09 (32.05)	0.829	2.51 (32.98)	0.628	0.02 (30.32)	0.996	2.54 (32.24)	0.617
B (49)	37.34 (32.75)	0.00	100.00	–4.24 (29.95)	0.327	5.30 (31.26)	0.241	1.06 (39.96)	0.853	–3.33 (28.08)	0.410	–2.27 (33.96)	0.642
C (53)	40.02 (30.63)	0.00	100.00	–1.42 (29.00)	0.722	–2.27 (26.11)	0.529	–3.70 (32.83)	0.416	–0.10 (26.14)	0.978	–3.80 (30.33)	0.366
p-value													
A vs. B vs. C	0.604				0.697		0.438		0.666		0.802		0.625
A vs. B	0.566				0.419		0.531		0.853		0.588		0.496
A vs. C	0.299				0.672		0.577		0.366		0.983		0.331
B vs. C	0.670				0.631		0.186		0.511		0.549		0.810
A + B vs. C	0.410				0.966		NR		NR		NR		NR

Max., maximum; min., minimum; NR, not reported.

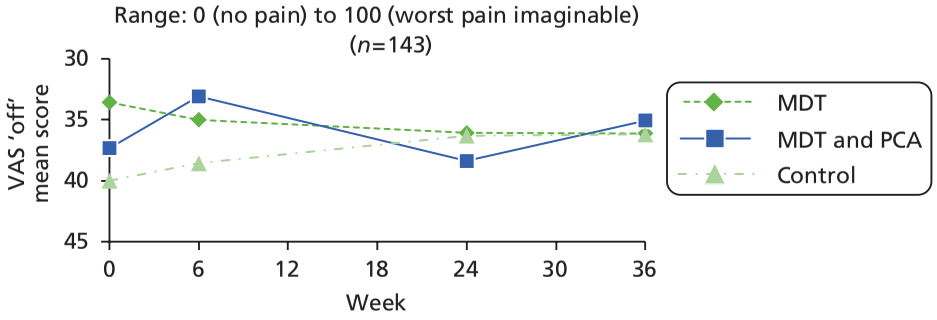

TABLE 83 Analysis of VAS 'off' scores: $N = 265$ (ITT analysis)

	Baseline (0 weeks)				6 weeks						24 weeks										36 weeks									
PwP group	*n*	Mean (SD)	Median	Range	*n*	Mean (SD)	Median	Mean change 6–0	SD change 6–0	*p*-value 6–0	*n*	Mean (SD)	Median	Mean change 24–0	SD change 24–0	*p*-value 24–0	Mean change 24–6	SD change 24–6	*p*-value 24–6	*n*	Mean (SD)	Median	Mean change 36–0	SD change 36–0	*p*-value 36–0	Mean change 36–24	SD change 36–24	*p*-value 36–24		
MDT (A)	66	33.31 (28.53)	31.75	0–100	77	27.29 (26.84)	19.00	–3.15	34.18	0.486	64	31.78 (28.05)	23.00	1.53	31.07	0.729	2.58	28.78	0.498	74	33.49 (27.04)	25.00	2.86	29.37	0.473	3.50	27.67	0.331		
MDT and PCA (B)	78	33.57 (32.27)	27.05	0–100	75	29.48 (27.88)	20.00	–3.28	32.01	0.401	68	33.35 (31.51)	21.60	–3.08	39.10	0.541	4.99	29.01	0.177	64	34.57 (28.67)	30.00	0.27	35.79	0.955	–0.27	28.28	0.941		
Control (C)	79	33.89 (31.17)	33.00	0–100	78	35.64 (30.14)	27.50	1.84	30.58	0.618	78	30.54 (27.37)	25.50	–1.92	32.88	0.631	–3.44	26.79	0.280	71	31.81 (29.86)	25.00	–3.33	29.46	0.389	1.04	25.22	0.740		
Between Rx				***p*-value**						***p*-value**						***p*-value**			***p*-value**						***p*-value**				***p*-value**
A vs. B vs. C				0.993						0.577						0.773			0.201						0.578				0.740
A vs. B				0.959						0.982						0.500			0.648						0.676				0.462
A vs. C				0.907						0.387						0.565			0.221						0.264				0.604
B vs. C				0.949						0.340						0.855			0.082						0.555				0.785
A+B vs. C				0.918						0.293						N/A			N/A						N/A				N/A

N/A, not applicable; PwP, people with Parkinson's; Rx, treatment.

TABLE 84 People with Parkinson's: Speech Self Report Questionnaire

				6 weeks		24 weeks				36 weeks			
	Baseline			Change 6–0		Change 24–6		Change 24–0		Change 36–24		Change 36–0	
Group (*n*)	Mean (SD)	Min.	Max.	Mean (SD)	*p*-value	Mean (SD)	*p*-value	Mean (SD)	*p*-value	Mean (SD)	*p*-value	Mean (SD)	*p*-value
A (75)	27.71 (22.96)	0.00	94.00	1.48 (13.83)	0.357	0.63 (14.48)	0.709	2.11 (15.88)	0.254	5.17 (20.17)	**0.029**	7.28 (19.65)	**0.002**
B (69)	27.09 (22.94)	0.00	115.00	–1.04 (12.96)	0.506	1.03 (13.51)	0.529	–0.01 (12.01)	0.992	0.77 (11.97)	0.596	0.75 (14.60)	0.669
C (83)	22.84 (22.49)	0.00	100.00	3.99 (15.22)	**0.019**	2.78 (15.54)	0.107	6.77 (18.00)	**0.001**	–0.87 (14.56)	0.589	5.90 (14.86)	**0.001**
p-value													
A vs. B vs. C	0.345				0.093		0.613		**0.024**		0.054		**0.047**
A vs. B	0.872				0.262		0.864		0.371		0.110		**0.025**
A vs. C	0.181				0.282		0.370		0.087		**0.034**		0.618
B vs. C	0.253				**0.032**		0.464		**0.006**		0.456		**0.034**
A + B vs. C	0.146				0.057		NR		NR		NR		NR

Max., maximum; min., minimum; NR, not reported.
Bold indicates significant *p*-value.

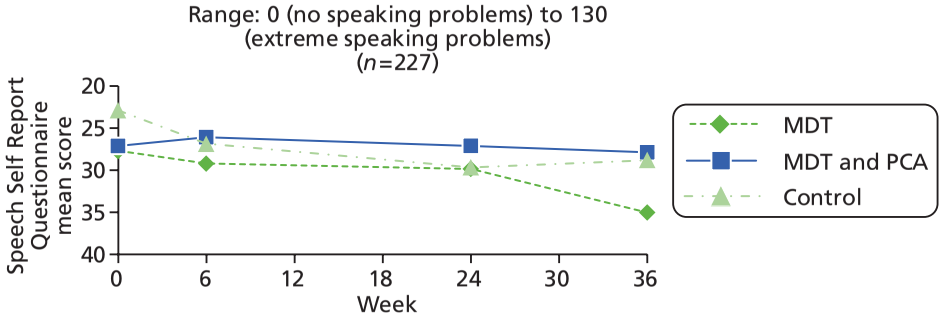

TABLE 85 Analysis of Speech Self Report Questionnaire scores: $N = 269$ (ITT analysis)

	Baseline (0 weeks)				6 weeks						24 weeks										36 weeks									
IPwP group	*n*	Mean (SD)	Median	Range	*n*	Mean (SD)	Median	Mean change 6–0	SD change 6–0	*p*-value 6–0	*n*	Mean (SD)	Median	Mean change 24–0	SD change 24–0	*p*-value 24–0	Mean change 24–6	SD change 24–6	*p*-value 24–6	*n*	Mean (SD)	Median	Mean change 36–0	SD change 36–0	*p*-value 36–0	Mean change 36–24	SD change 36–24	*p*-value 36–24		
MDT (A)	87	28.38 (22.30)	20.00	0–94	86	29.63 (23.96)	24.50	0.98	13.18	0.496	76	30.03 (23.35)	24.50	241	15.99	0.193	0.82	14.48	0.625	80	34.39 (26.12)	27.00	6.35	19.80	**0.006**	5.17	20.17	**0.029**		
MDT and PCA	87	28.60 (23.26)	24.00	0–115	82	26.94 (26.53)	20.50	–1.46	14.83	0.374	73	27.30 (24.11)	23.00	–1.19	12.92	0.433	0.73	13.37	0.644	71	28.01 (25.53)	18.00	0.99	14.55	0.570	0.77	11.97	0.596		
Control C	93	25.00 (23.78)	18.00	0–100	87	27.86 (27.52)	17.00	3.95	15.57	0.020	85	30.19 (27.34)	22.00	6.51	17.87	**0.001**	2.68	15.72	0.119	85	28.84 (27.12)	20.00	6.31	15.01	**<0.001**	–0.87	14.56	0.589		
Between Rx										***p*-value**						***p*-value**			***p*-value**					***p*-value**			***p*-value**		
A vs. B vs. C										0.502						0.055			**0.010**					0.630			0.080		0.054
A vs. B										0.950						0.262			0.134					0.969			0.063		0.110
A vs. C										0.328						0.178			0.129					0.436			0.986		**0.034**
B vs. C										0.307						**0.022**			**0.003**					0.405			**0.027**		0.456
A+vs. C										0.241						**0.031**			N/A					N/A			N/A		N/A

N/A, not applicable; PwP, people with Parkinson's; Rx, treatment.
Bold indicates significant *p*-value.

TABLE 86 People with Parkinson's: UPDRS – speech[89]

				6 weeks		24 weeks				36 weeks			
	Baseline			Change 6–0		Change 24–6		Change 24–0		Change 36–24		Change 36–0	
Group (*n*)	Mean (SD)	Min.	Max.	Mean (SD)	*p*-value	Mean (SD)	*p*-value	Mean (SD)	*p*-value	Mean (SD)	*p*-value	Mean (SD)	*p*-value
A (75)	0.80 (0.77)	0.00	3.00	–0.09 (0.60)	0.180	0.07 (0.62)	0.357	–0.03 (0.66)	0.726	–0.03 (0.59)	0.698	–0.05 (0.63)	0.469
B (69)	0.78 (0.86)	0.00	3.00	–0.20 (0.63)	**0.010**	0.09 (0.64)	0.260	–0.12 (0.70)	0.172	0.10 (0.55)	0.128	–0.01 (0.74)	0.871
C (82)	0.59 (0.78)	0.00	3.00	–0.07 (0.72)	0.358	0.15 (0.67)	0.051	0.07 (0.77)	0.390	–0.07 (0.62)	0.292	0.00 (0.72)	1.000
p-value													
A vs. B vs. C	0.179				0.438		0.722		0.265		0.182		0.887
A vs. B	0.898				0.286		0.847		0.430		0.180		0.735
A vs. C	0.086				0.849		0.442		0.384		0.633		0.624
B vs. C	0.142				0.244		0.579		0.118		0.072		0.903
A + B vs. C	0.064				0.422		NR		NR		NR		NR

Max., maximum; min., minimum; NR, not reported.
Bold indicates a significant *p*-value.

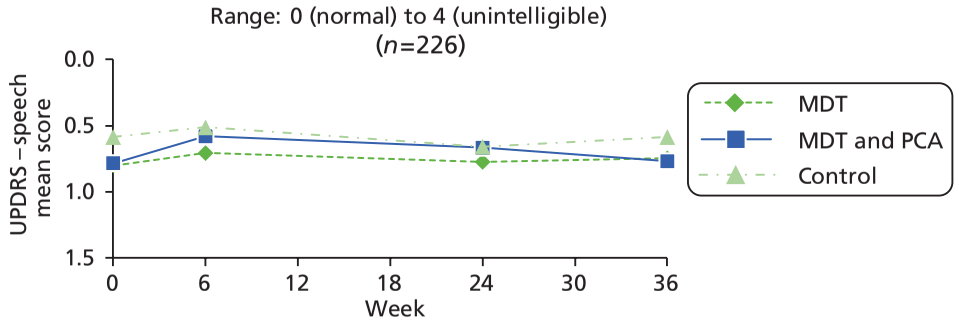

TABLE 87 Analysis of UPDRS – speech scores: $N = 269$ (ITT analysis)

	Baseline (0 weeks)				6 weeks						24 weeks									36 weeks							
PwP group	*n*	Mean (SD)	Median	Range	*n*	Mean (SD)	Median	Mean change 6–0	SD change 6–0	*p*-value 6–0	*n*	Mean (SD)	Median	Mean change 24–0	SD change 24–0	*p*-value 24–0	Mean change 24–6	SD change 24–6	*p*-value 24–6	*n*	Mean (SD)	Median	Mean change 36–0	SD change 36–0	*p*-value 36–0	Mean change 36–24	SD change 36–24	*p*-value 36–24
MDT (A)	88	0.84 (0.80)	1.00	0–3	86	0.76 (0.63)	1.00	–0.10	0.61	0.118	76	0.78 (0.74)	1.00	–0.03	0.65	0.726	0.07	0.62	0.357	79	0.77 (0.72)	1.00	–0.09	0.68	0.252	–0.03	0.59	0.698
MDT and PCA (B)	88	0.85 (0.88)	1.00	0–3	81	0.63 (0.64)	1.00	–0.21	0.63	**0.003**	72	0.69 (0.85)	0.50	–0.11	0.70	0.184	0.08	0.62	0.260	72	0.76 (0.72)	1.00	–0.03	0.73	0.748	0.10	0.55	0.128
Control (C)	93	0.62 (0.79)	0.00	0–3	87	0.53 (0.63)	0.00	–0.10	0.72	0.181	83	0.66 (0.80)	0.00	0.06	0.77	0.478	0.14	0.67	0.051	85	0.59 (0.64)	1.00	0.00	0.72	1.000	–0.07	0.62	0.292
Between Rx				*p*-value						*p*-value						*p*-value			*p*-value						*p*-value		*p*-value
A vs. B vs. C				0.110						0.487						0.329			0.714						0.721		0.182
A vs. B				0.929						0.275						0.448			0.864						0.598		0.180
A vs. C				0.068						0.991						0.448			0.441						0.422		0.633
B vs. C				0.067						0.308						0.153			0.557						0.812		0.072
A+B vs. C				**0.035**						0.547						N/A			N/A						N/A		N/A

N/A, not applicable; PwP, people with Parkinson's; Rx, treatment.
Bold indicates significant *p*-value.

TABLE 88 People with Parkinson's: Abridged Emerson and Enderby Screening Assessment Rating Scale – voice[94]

				6 weeks		24 weeks				36 weeks			
	Baseline			Change 6–0		Change 24–6		Change 24–0		Change 36–24		Change 36–0	
Group (*n*)	Mean (SD)	Min.	Max.	Mean (SD)	*p*-value	Mean (SD)	*p*-value	Mean (SD)	*p*-value	Mean (SD)	*p*-value	Mean (SD)	*p*-value
A (75)	2.23 (0.80)	1.00	4.00	0.01 (0.73)	0.874	–0.39 (0.79)	**< 0.001**	–0.37 (0.71)	**< 0.001**	0.48 (0.70)	**< 0.001**	0.11 (0.67)	0.172
B (69)	2.16 (0.90)	1.00	4.00	0.06 (0.68)	0.484	–0.01 (0.61)	0.843	0.04 (0.78)	0.643	0.10 (0.55)	0.128	0.14 (0.65)	0.068
C (82)	1.94 (0.85)	1.00	4.00	–0.02 (0.67)	0.741	–0.07 (0.78)	0.399	–0.10 (0.76)	0.251	0.21 (0.75)	**0.014**	0.11 (0.70)	0.161
p-value													
A vs. B vs. C	0.087				0.767		**0.005**		**0.003**		**0.003**		0.931
A vs. B	0.636				0.705		**0.002**		**0.001**		**< 0.001**		0.728
A vs. C	**0.031**				0.735		**0.013**		**0.021**		**0.020**		0.978
B vs. C	0.125				0.456		0.605		0.263		0.318		0.751
A + B vs. C	**0.031**				0.537		NR		NR		NR		NR

Max., maximum; min., minimum; NR, not reported.
Bold indicates significant *p*-value.

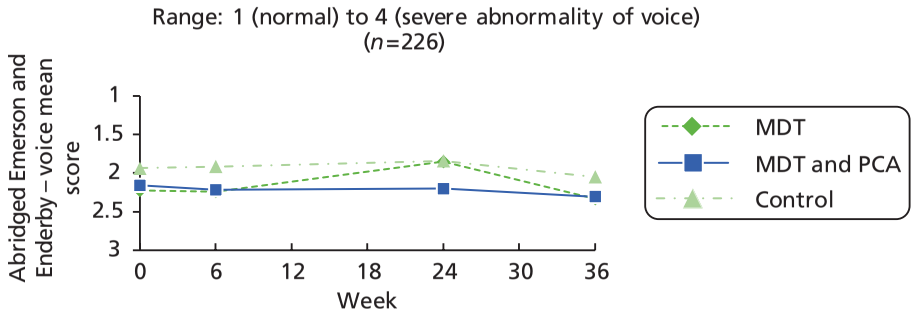

TABLE 89 Analysis of Abridged Emerson and Enderby Screening Assessment Rating Scale – voice scores: $N = 269$ (ITT analysis)

	Baseline (0 weeks)				6 weeks						24 weeks									36 weeks							
PwP group	*n*	Mean (SD)	Median	Range	*n*	Mean (SD)	Median	Mean change 6–0	SD change 6–0	*p*-value 6–0	*n*	Mean (SD)	Median	Mean change 24–0	SD change 24–0	*p*-value 24–0	Mean change 24–6	SD change 24–6	*p*-value 24–6	*n*	Mean (SD)	Median	Mean change 36–0	SD change 36–0	*p*-value 36–0	Mean change 36–24	SD change 36–24	*p*-value 36–24
MDT (A)	88	2.28 (0.83)	2.00	1–4	86	2.30 (0.72)	2.00	0.00	0.75	1.000	76	1.86 (0.83)	2.00	–0.38	0.71	**< 0.001**	–0.38	0.78	**< 0.001**	79	2.35 (0.77)	2.00	0.09	0.68	0.252	0.48	0.70	**< 0.001**
MDT and PCA (B)	88	2.23 (0.89)	2.00	1–4	81	2.25 (0.75)	2.00	0.04	0.70	0.634	72	2.22 (0.88)	2.00	0.03	0.77	0.760	0.00	0.61	1.000	72	2.29 (0.85)	2.00	0.13	0.65	0.106	0.10	0.55	0.128
Control (C)	93	1.96 (0.83)	2.00	1–4	87	1.92 (0.72)	2.00	–0.03	0.66	0.625	83	1.84 (0.86)	2.00	–0.11	0.77	0.200	–0.08	0.78	0.330	85	2.07 (0.72)	2.00	0.15	0.73	0.057	0.21	0.75	**0.014**

Between Rx	*p*-value	*p*-value	*p*-value	*p*-value	*p*-value	*p*-value
A vs. B vs. C	**0.023**	0.805	**0.004**	**0.004**	0.837	**0.003**
A vs. B	0.663	0.742	**0.001**	**0.001**	0.738	**< 0.001**
A vs. C	**0.009**	0.748	**0.021**	**0.018**	0.562	**0.020**
B vs. C	**0.037**	0.494	0.272	0.452	0.802	0.318
A+B vs. C	**0.007**	0.572	N/A	N/A	N/A	N/A

N/A, not applicable; PwP, people with Parkinson's; Rx, treatment.
Bold indicates significant *p*-value.

TABLE 90 People with Parkinson's: Abridged Emerson and Enderby Screening Assessment Rating Scale – articulation[94]

				6 weeks		24 weeks				36 weeks			
	Baseline			Change 6–0		Change 24–6		Change 24–0		Change 36–24		Change 36–0	
Group (*n*)	Mean (SD)	Min.	Max.	Mean (SD)	*p*-value	Mean (SD)	*p*-value	Mean (SD)	*p*-value	Mean (SD)	*p*-value	Mean (SD)	*p*-value
A (75)	1.75 (0.79)	1.00	4.00	–0.11 (0.65)	0.159	0.09 (0.70)	0.252	–0.01 (0.73)	0.874	–0.28 (0.58)	**< 0.001**	–0.29 (0.69)	**< 0.001**
B (69)	1.65 (0.80)	1.00	4.00	–0.17 (0.66)	**0.033**	0.03 (0.51)	0.641	–0.14 (0.67)	0.077	–0.06 (0.45)	0.288	–0.20 (0.58)	**0.005**
C (82)	1.46 (0.63)	1.00	3.00	–0.04 (0.66)	0.615	0.09 (0.61)	0.211	0.05 (0.56)	0.436	–0.27 (0.57)	**< 0.001**	–0.22 (0.52)	**< 0.001**
p-value													
A vs. B vs. C	0.052				0.440		0.793		0.188		**0.023**		0.624
A vs. B	0.478				0.540		0.529		0.262		**0.011**		0.401
A vs. C	**0.015**				0.503		0.940		0.549		0.899		0.455
B vs. C	0.115				0.204		0.546		0.060		**0.012**		0.854
A + B vs. C	**0.014**				0.260		NR		NR		NR		NR

Max., maximum; min., minimum; NR, not reported.
Bold indicates significant *p*-value.

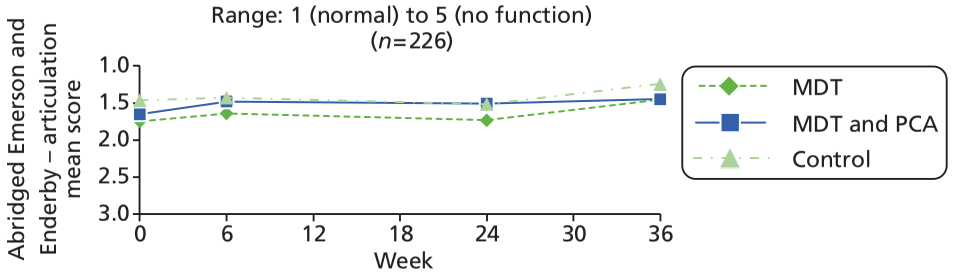

TABLE 91 Analysis of Abridged Emerson and Enderby Screening Assessment Rating Scale – articulation scores: $N = 269$ (ITT analysis)

	Baseline (0 weeks)				6 weeks					24 weeks								36 weeks							
PwP group	*n*	Mean (SD)	Median	Range	*n*	Mean (SD)	Median	Mean change 6–0	SD change 6–0	*p*-value 6–0	*n*	Mean (SD)	Median	Mean change 24–0	SD change 24–0	*p*-value 24–0	Mean change 24–6	SD change 24–6	*p*-value 24–6	*n*	Mean (SD)	Median	Mean change 36–0	SD change 36–0	*p*-value 36–0	Mean change 36–24	SD change 36–24	*p*-value 36–24
MDT (A)	88	1.78 (0.82)	2.00	1–4	86	1.69 (0.64)	2.00	–0.12	0.64	0.096	76	1.74 (0.79)	2.00	–0.01	0.72	0.874	0.09	0.70	0.252	79	1.49 (0.68)	1.00	–0.30	0.72	**< 0.001**	–0.28	0.58	**< 0.001**
MDT and PCA (B)	88	1.73 (0.84)	2.00	1–4	81	1.51 (0.67)	1.00	–0.19	0.65	**0.013**	72	1.51 (0.77)	1.00	–0.17	0.67	**0.039**	0.03	0.50	0.641	72	1.46 (0.69)	1.00	–0.18	0.59	**0.011**	–0.06	0.45	0.288
Control (C)	93	1.51 (0.65)	1.00	1–3	87	1.44 (0.64)	1.00	–0.05	0.65	0.508	83	1.51 (0.74)	1.00	0.04	0.57	0.567	0.07	0.62	0.292	85	1.26 (0.54)	1.00	–0.20	0.53	**0.001**	–0.27	0.57	**< 0.001**

Between Rx	*p*-value	*p*-value	*p*-value	*p*-value	*p*-value	*p*-value
A vs. B vs. C	**0.039**	0.379	0.142	0.809	0.411	**0.023**
A vs. B	0.651	0.492	0.183	0.519	0.251	**0.011**
A vs. C	**0.013**	0.473	0.632	0.850	0.299	0.899
B vs. C	**0.050**	0.167	**0.047**	0.628	0.828	**0.012**
A+B vs. C	**0.007**	0.226	N/A	N/A	N/A	N/A

N/A, not applicable; PwP, people with Parkinson's; Rx, treatment.
Bold indicates significant *p*-value.

Live-in carers

TABLE 92 Live-in carers: Modified Caregiver Strain Index[71]

				6 weeks		24 weeks				36 weeks			
	Baseline			Change 6–0		Change 24–6		Change 24–0		Change 36–24		Change 36–0	
Group (*n*)	Mean (SD)	Min.	Max.	Mean (SD)	*p*-value	Mean (SD)	*p*-value	Mean (SD)	*p*-value	Mean (SD)	*p*-value	Mean (SD)	*p*-value
A (45)	6.58 (4.58)	0.00	18.00	–0.96 (2.82)	**0.028**	0.56 (2.82)	0.194	–0.40 (2.93)	0.365	0.82 (2.44)	**0.029**	0.42 (2.86)	0.327
B (37)	8.11 (6.03)	0.00	23.00	–0.22 (2.87)	0.649	–0.57 (2.54)	0.183	–0.78 (2.85)	0.103	0.57 (4.20)	0.417	–0.22 (3.91)	0.739
C (43)	7.44 (6.92)	0.00	26.00	–0.67 (2.82)	0.124	0.98 (4.03)	0.120	0.30 (4.15)	0.635	0.33 (3.91)	0.588	0.63 (3.99)	0.308
p-value													
A vs. B vs. C	0.501				0.501		0.095		0.344		0.807		0.558
A vs. B	0.196				0.245		0.065		0.552		0.733		0.396
A vs. C	0.494				0.641		0.570		0.360		0.475		0.781
B vs. C	0.650				0.474		**0.041**		0.183		0.790		0.344
A + B vs. C	0.876				0.922		NR		NR		NR		NR

Max., maximum; MCSI, Modified Caregiver Strain Index; min., minimum; NR, not reported.
Bold indicates significant *p*-value.

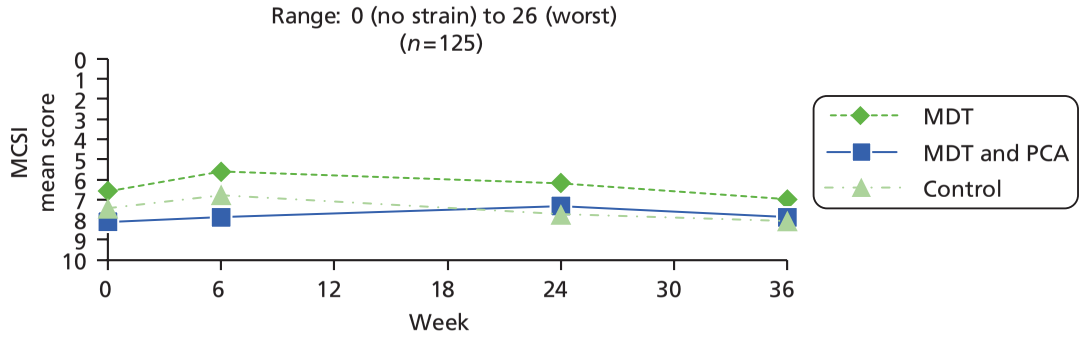

TABLE 93 Analysis of live-in carers Modified Caregiver Strain Index: $N = 155$ (ITT analysis)

	Baseline (0 weeks)				6 weeks						24 weeks									36 weeks							
PwP group	*n*	Mean (SD)	Median	Range	*n*	Mean (SD)	Median	Mean change 6–0	SD change 6–0	*p*-value 6–0	*n*	Mean (SD)	Median	Mean change 24–0	SD change 24–0	*p*-value 24–0	Mean change 24–6	SD change 24–6	*p*-value 24–6	*n*	Mean (SD)	Median	Mean change 36–0	SD change 36–0	*p*-value 36–0	Mean change 36–24	SD change 36–24	*p*-value 36–24
MDT (A)	52	6.79 (4.82)	6.00	0–19	51	6.10 (4.36)	5.00	–0.80	2.76	**0.042**	46	6.13 (4.34)	5.50	–0.35	2.92	0.424	0.57	2.79	0.177	48	7.04 (4.88)	6.00	0.35	2.79	0.383	0.82	2.44	**0.029**
MDT and PCA (B)	50	7.50 (6.11)	7.00	0–23	47	6.94 (6.53)	6.00	–0.53	3.15	0.254	40	7.23 (6.53)	6.50	–0.63	2.84	0.172	–0.43	2.62	0.311	40	7.53 (6.09)	6.00	–0.15	3.79	0.804	0.57	4.20	0.417
Control (C)	53	7.53 (6.63)	6.00	0–26	47	7.09 (7.13)	6.00	–0.49	3.09	0.284	46	7.85 (7.55)	5.00	0.39	4.04	0.514	0.80	4.03	0.183	44	8.05 (7.62)	6.00	0.48	4.07	0.440	0.33	3.91	0.588
Between Rx						*p*-value						*p*-value																
A vs. B vs. C						0.770						0.852																
A vs. B						0.514						0.650																
A vs. C						0.514						0.596																
B vs. C						0.982						0.947																
A+B vs. C						0.713						0.729																

N/A, not applicable; PwP, people with Parkinson's; Rx, treatment.
Bold indicates significant *p*-value.

TABLE 94 Live-in carers: General Health Questionnaire-12[95]

				6 weeks		24 weeks				36 weeks			
	Baseline			Change 6–0		Change 24–6		Change 24–0		Change 36–24		Change 36–0	
Group (*n*)	Mean (SD)	Min.	Max.	Mean (SD)	*p*-value	Mean (SD)	*p*-value	Mean (SD)	*p*-value	Mean (SD)	*p*-value	Mean (SD)	*p*-value
A (45)	10.38 (3.87)	6.00	22.00	–0.76 (3.24)	0.125	0.76 (3.68)	0.175	0.00 (4.56)	1.000	1.33 (4.43)	**0.050**	1.33 (4.61)	0.059
B (37)	11.38 (5.14)	6.00	24.00	–0.46 (2.74)	0.315	–0.43 (4.91)	0.595	–0.89 (4.70)	0.256	0.95 (5.12)	0.269	0.05 (4.74)	0.945
C (43)	10.53 (4.61)	4.00	30.00	0.02 (3.71)	0.967	0.95 (5.90)	0.295	0.98 (6.93)	0.361	–0.44 (6.78)	0.671	0.53 (6.06)	0.566
p-value													
A vs. B vs. C	0.576				0.535		0.403		0.322		0.296		0.528
A vs. B	0.332				0.661		0.228		0.387		0.714		0.221
A vs. C	0.863				0.296		0.851		0.435		0.152		0.487
B vs. C	0.441				0.516		0.261		0.169		0.311		0.697
A + B vs. C	0.731				0.296		NR		NR		NR		NR

GHQ-12, General Health Questionnaire-12; max., maximum; min., minimum; NR, not reported.
Bold indicates significant *p*-value.

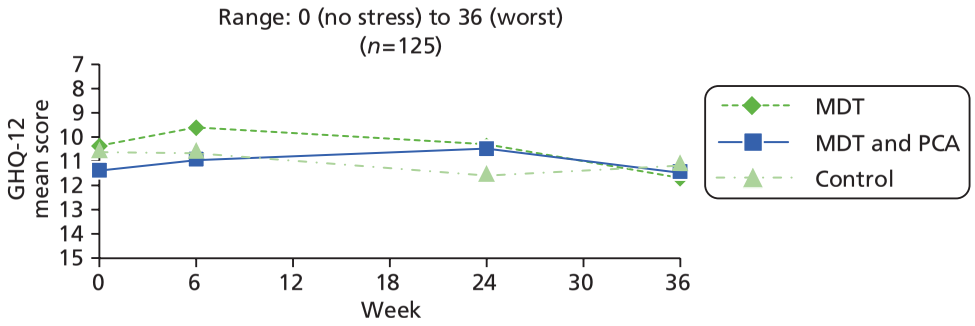

TABLE 95 Analysis of live-in carers General Health Questionnaire-12: $N = 155$ (ITT analysis)

	Baseline (0 weeks)				6 weeks						24 weeks										36 weeks								
PwP group	*n*	Mean (SD)	Median	Range	*n*	Mean (SD)	Median	Mean change 6–0	SD change 6–0	*p*-value 6–0	*n*	Mean (SD)	Median	Mean change 24–0	SD change 24–0	*p*-value 24–0	Mean change 24–6	SD change 24–6	*p*-value 24–6	*n*	Mean (SD)	Median	Mean change 36–0	SD change 36–0	*p*-value 36–0	Mean change 36–24	SD change 36–24	*p*-value 36–24
MDT (A)	51	10.65 (4.25)	9.00	6–22	51	10.41 (4.72)	9.00	–0.24	3.56	0.639	46	10.52 (4.35)	10.00	0.22	4.74	0.757	0.78	3.64	0.152	48	11.46 (5.05)	10.50	1.17	4.52	0.080	1.33	4.43	**0.050**
MDT and PCA (B)	50	11.04 (4.97)	10.00	4–24	47	10.55 (4.69)	9.00	–0.38	2.87	0.365	40	10.15 (5.74)	9.50	–1.05	4.60	0.157	–0.65	4.87	0.404	40	11.25 (5.26)	9.00	–0.20	4.69	0.789	0.95	5.12	0.269
Control (C)	53	10.75 (4.58)	10.00	4–30	47	10.94 (4.87)	10.00	0.13	3.87	0.822	47	11.62 (7.50)	11.00	0.91	6.72	0.356	0.87	5.87	0.321	44	11.02 (5.50)	10.50	0.48	6.00	0.601	–0.44	6.78	0.671

Between Rx	*p*-value	*p*-value	*p*-value	*p*-value	*p*-value	*p*-value
A vs. B vs. C	0.907	0.763	0.249	0.282	0.459	0.296
A vs. B	0.670	0.823	0.214	0.131	0.168	0.714
A vs. C	0.901	0.630	0.565	0.932	0.533	0.152
B vs. C	0.762	0.469	0.122	0.199	0.569	0.311
A+B vs. C	0.911	0.480	N/A	N/A	N/A	N/A

N/A, not applicable; PwP, people with Parkinson's; Rx, treatment.
Bold indicates significant *p*-value.

TABLE 96 Live-in carers: Barthel ADL[76]

				6 weeks		24 weeks				36 weeks			
	Baseline			Change 6–0		Change 24–6		Change 24–0		Change 36–24		Change 36–0	
Group (*n*)	Mean (SD)	Min.	Max.	Mean (SD)	*p*-value	Mean (SD)	*p*-value	Mean (SD)	*p*-value	Mean (SD)	*p*-value	Mean (SD)	*p*-value
A (45)	19.98 (0.15)	19.00	20.00	–0.04 (0.47)	0.533	–0.04 (0.77)	0.700	–0.09 (0.63)	0.352	0.09 (0.63)	0.352	0.00 (0.00)	N/A
B (37)	19.76 (0.76)	16.00	20.00	0.14 (0.79)	0.304	–0.05 (0.47)	0.487	0.08 (0.89)	0.584	0.03 (0.29)	0.571	0.11 (0.84)	0.440
C (43)	19.84 (0.61)	17.00	20.00	–0.05 (0.79)	0.700	0.14 (0.52)	0.083	0.09 (0.78)	0.439	–0.14 (0.68)	0.183	–0.05 (0.58)	0.599
p-value													
A vs. B vs. C	0.190				0.413		0.261		0.469		0.160		0.469
A vs. B	0.090				0.229		0.947		0.318		0.584		0.440
A vs. C	0.151				0.988		0.192		0.232		0.105		0.599
B vs. C	0.602				0.306		0.085		0.949		0.167		0.335
A + B vs. C	0.699				0.524		NR		NR		NR		NR

Max., maximum; min., minimum; N/A, not applicable; NR, not reported.

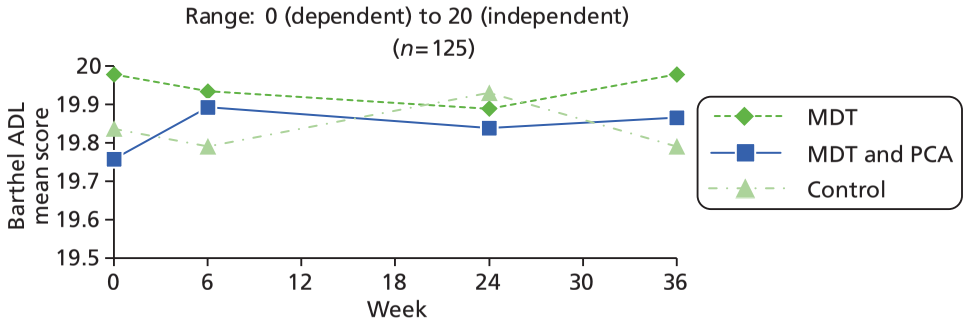

TABLE 97 Analysis of live-in carers Barthel ADL: $N = 155$ (ITT analysis)

	Baseline (0 weeks)				6 weeks						24 weeks								36 weeks							
PwP group	*n*	Mean (SD)	Median	Range	*n*	Mean (SD)	Median	Mean change 6–0	SD change 6–0	*p*-value 6–0	*n*	Mean (SD)	Median	Mean change 24–0	SD change 24–0	*p*-value 24–0	Mean change 24–6	SD change 24–6	*p*-value 24–6	*n*	Mean (SD)	Median	Mean change 36–0	SD change 36–0	*p*-value 36–0	Mean change 36–24	SD change 36–24	*p*-value 36–24
MDT (A)	51	19.96 (0.20)	20.00	19–20	51	19.92 (0.44)	20.00	–0.04	0.45	0.532	46	19.89 (0.60)	20.00	–0.09	0.63	0.351	–0.04	0.76	0.699	48	19.98 (0.14)	20.00	0.00	0.00	**<0.001**	0.09	0.63	0.352
MDT and PCA (B)	50	19.82 (0.66)	20.00	16–20	47	19.89 (0.31)	20.00	0.09	0.72	0.420	40	19.85 (0.43)	20.00	0.08	0.86	0.584	–0.05	0.45	0.486	40	19.88 (0.40)	20.00	0.10	0.81	0.440	0.03	0.29	0.571
Control (C)	53	19.75 (0.73)	20.00	17–20	47	19.77 (0.79)	20.00	–0.04	0.75	0.699	46	19.93 (0.44)	20.00	0.13	0.81	0.278	0.17	0.57	**0.044**	44	19.80 (0.79)	20.00	–0.05	0.57	0.599	–0.14	0.68	0.183

Between Rx	*p*-value	*p*-value	*p*-value	*p*-value	*p*-value	*p*-value
A vs. B vs. C	0.187	0.549	0.373	0.148	0.473	0.160
A vs. B	0.154	0.301	0.317	0.962	0.440	0.584
A vs. C	0.052	0.979	0.152	0.124	0.599	0.105
B vs. C	0.636	0.401	0.758	**0.049**	0.340	0.167
A+B vs. C	0.225	0.584	N/A	N/A	N/A	N/A

N/A, not applicable; PwP, people with Parkinson's; Rx, treatment.
Bold indicates significant *p*-value.

TABLE 98 Live-in carers: Frenchay Activities Index[77–79]

				6 weeks		24 weeks				36 weeks			
	Baseline			Change 6–0		Change 24–6		Change 24–0		Change 36–24		Change 36–0	
Group (*n*)	Mean (SD)	Min.	Max.	Mean (SD)	*p*-value	Mean (SD)	*p*-value	Mean (SD)	*p*-value	Mean (SD)	*p*-value	Mean (SD)	*p*-value
A (45)	28.20 (2.30)	21.00	30.00	0.24 (1.48)	0.274	0.11 (1.91)	0.698	0.36 (1.81)	0.195	–0.36 (2.79)	0.397	0.00 (2.28)	1.000
B (37)	27.11 (3.03)	20.00	30.00	–0.30 (2.20)	0.416	–0.24 (3.03)	0.628	–0.54 (3.59)	0.365	0.35 (1.99)	0.290	–0.19 (3.37)	0.734
C (43)	27.63 (4.05)	15.00	30.00	–0.19 (2.06)	0.557	0.12 (2.34)	0.746	–0.07 (2.12)	0.830	0.47 (2.18)	0.168	0.40 (2.80)	0.361
p-value													
A vs. B vs. C	0.308				0.392		0.756		0.290		0.219		0.634
A vs. B	0.067				0.205		0.521		0.173		0.199		0.763
A vs. C	0.421				0.262		0.991		0.314		0.129		0.469
B vs. C	0.523				0.816		0.552		0.487		0.809		0.399
A + B vs. C	0.896				0.608		NR		NR		NR		NR

Max., maximum; min., minimum; N/A, not applicable; NR, not reported.

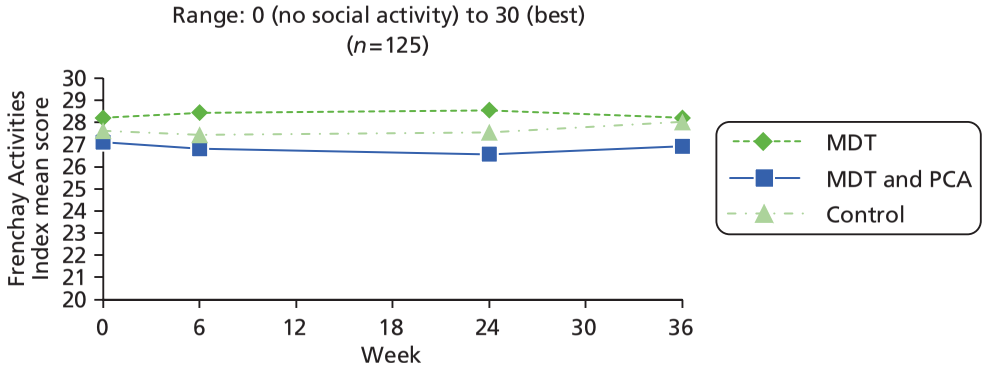

TABLE 99 Analysis of live-in carers Frenchay Activities Index: $N = 155$ (ITT analysis)

	Baseline (0 weeks)				6 weeks						24 weeks									36 weeks							
PwP group	*n*	Mean (SD)	Median	Range	*n*	Mean (SD)	Median	Mean change 6–0	SD change 6–0	*p*-value 6–0	*n*	Mean (SD)	Median	Mean change 24–0	SD change 24–0	*p*-value 24–0	Mean change 24–6	SD change 24–6	*p*-value 24–6	*n*	Mean (SD)	Median	Mean change 36–0	SD change 36–0	*p*-value 36–0	Mean change 36–24	SD change 36–24	*p*-value 36–24
MDT (A)	52	28.02 (2.55)	29.00	19–30	51	28.37 (2.55)	29.00	0.18	1.62	0.441	46	28.54 (2.09)	30.00	0.30	1.82	0.264	0.07	1.91	0.818	48	28.19 (2.87)	29.00	0.04	2.21	0.897	–0.36	2.79	0.397
MDT and PCA (B)	50	26.22 (4.33)	27.50	13–30	47	26.06 (4.10)	26.00	–0.26	2.52	0.491	40	26.40 (3.95)	27.50	–0.75	3.76	0.215	–0.38	3.01	0.436	40	26.73 (3.60)	27.00	–0.03	3.50	0.964	0.35	1.99	0.290
Control (C)	53	27.28 (4.18)	30.00	15–30	47	27.23 (4.10)	29.00	–0.28	2.05	0.360	47	26.79 (5.32)	28.00	–0.43	3.13	0.356	0.20	2.45	0.590	44	28.07 (2.77)	30.00	0.39	2.77	0.360	0.47	2.18	0.168
Between Rx										*p*-value						*p*-value			*p*-value						*p*-value			*p*-value
A vs. B vs. C										0.056						0.477			0.240						0.542			0.770													0.219
A vs. B										0.013						0.321			0.112						0.415			0.914													0.199
A vs. C										0.278						0.226			0.174						0.776			0.510													0.129
B vs. C										0.208						0.964			0.661						0.335			0.550													0.809
A+B vs. C										0.822						0.507			N/A						N/A			N/A													N/A

N/A, not applicable; PwP, people with Parkinson's; Rx, treatment.

TABLE 100 Live-in carers: EQ-5D Thermometer[80,81]

				6 weeks		24 weeks				36 weeks			
	Baseline			Change 6–0		Change 24–6		Change 24–0		Change 36–24		Change 36–0	
Group (*n*)	Mean (SD)	Min.	Max.	Mean (SD)	*p*-value	Mean (SD)	*p*-value	Mean (SD)	*p*-value	Mean (SD)	*p*-value	Mean (SD)	*p*-value
A (45)	80.57 (13.09)	50.00	99.00	–2.30 (10.62)	0.153	0.99 (13.80)	0.633	–1.31 (14.31)	0.542	–2.17 (9.62)	0.138	–3.48 (12.48)	0.068
B (37)	80.22 (17.75)	30.00	100.00	–1.39 (12.46)	0.501	–4.35 (18.02)	0.151	–5.74 (16.77)	**0.044**	2.47 (12.45)	0.235	–3.27 (11.58)	0.094
C (43)	78.26 (19.45)	10.00	100.00	–0.21 (18.70)	0.942	–2.06 (15.27)	0.382	–2.27 (22.38)	0.510	2.72 (13.35)	0.189	0.45 (18.08)	0.870
p-value													
A vs. B vs. C	0.792				0.792		0.303		0.523		0.101		0.371
A vs. B	0.918				0.723		0.133		0.200		0.061		0.939
A vs. C	0.513				0.518		0.328		0.811		0.051		0.237
B vs. C	0.641				0.744		0.540		0.440		0.932		0.285
A + B vs. C	0.498				0.534		NR		NR		NR		NR

Max., maximum; min., minimum; N/A, not applicable; NR, not reported.
Bold indicates significant *p*-value.

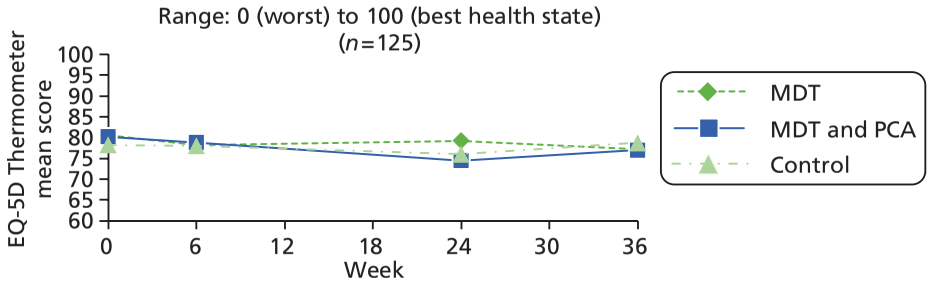

TABLE 101 Analysis of live-in carers EQ-5D Thermometer: $N = 155$ (ITT analysis)

	Baseline (0 weeks)				6 weeks						24 weeks										36 weeks									
PwP group	*n*	Mean (SD)	Median	Range	*n*	Mean (SD)	Median	Mean change 6–0	SD change 6–0	*p*-value 6–0	*n*	Mean (SD)	Median	Mean change 24–0	SD change 24–0	*p*-value 24–0	Mean change 24–6	SD change 24–6	*p*-value 24–6	*n*	Mean (SD)	Median	Mean change 36–0	SD change 36–0	*p*-value 36–0	Mean change 36–24	SD change 36–24	*p*-value 36–24		
MDT (A)	51	78.80 (15.88)	80.00	25–99	51	75.29 (19.57)	81.00	–3.51	15.60	0.114	46	78.97 (15.41)	83.50	–1.70	14.39	0.428	1.97	15.18	0.384	48	77.19 (15.64)	80.00	–2.60	12.83	0.166	–2.17	9.62	0.138		
MDT and PCA (B)	50	78.24 (17.32)	83.00	30–100	47	77.90 (19.23)	80.00	–0.65	12.51	0.724	40	74.90 (22.77)	80.00	–5.43	16.16	**0.040**	–4.46	17.35	0.112	40	76.70 (18.18)	79.50	–2.68	11.75	0.158	2.47	12.45	0.235		
Control (C)	53	78.30 (20.98)	85.00	10–100	47	78.19 (17.16)	80.00	–0.64	18.04	0.809	46	76.08 (17.09)	80.00	–2.51	21.74	0.438	–1.97	14.76	0.371	44	78.74 (13.33)	80.00	0.22	17.94	0.937	2.72	13.35	0.189		
Between Rx										*p*-value						*p*-value			*p*-value						*p*-value			*p*-value		
A vs. B vs. C										0.985						0.571			0.601						0.566			0.101		
A vs. B										0.865						0.322			0.261						0.979			0.061		
A vs. C										0.891						0.400			0.833						0.385			0.051		
B vs. C										0.987						0.997			0.488						0.390			0.932		
A+B vs. C										0.942						0.587			N/A						N/A			N/A		

N/A, not applicable; PwP, people with Parkinson's; Rx, treatment.
Bold indicates significant *p*-value.

TABLE 102 Live-in carers: EQ-5D Index[80,81]

	Baseline			6 weeks		24 weeks				36 weeks			
				Change 6–0		Change 24–6		Change 24–0		Change 36–24		Change 36–0	
Group (*n*)	Mean (SD)	Min.	Max.	Mean (SD)	*p*-value	Mean (SD)	*p*-value	Mean (SD)	*p*-value	Mean (SD)	*p*-value	Mean (SD)	*p*-value
A (45)	0.83 (0.20)	0.09	1.00	0.00 (0.09)	0.947	–0.01 (0.16)	0.590	–0.01 (0.18)	0.658	–0.01 (0.15)	0.711	–0.02 (0.10)	0.182
B (37)	0.80 (0.21)	0.09	1.00	–0.01 (0.17)	0.634	0.00 (0.21)	0.901	–0.02 (0.21)	0.605	0.02 (0.17)	0.478	0.00 (0.15)	0.940
C (43)	0.82 (0.23)	–0.07	1.00	0.00 (0.15)	0.830	–0.03 (0.14)	0.225	–0.02 (0.19)	0.450	0.02 (0.16)	0.452	0.00 (0.16)	0.897
p-value													
A vs. B vs. C	0.834				0.828		0.837		0.971		0.651		0.747
A vs. B	0.531				0.646		0.834		0.896		0.428		0.429
A vs. C	0.802				0.878		0.669		0.802		0.419		0.554
B vs. C	0.733				0.610		0.573		0.922		0.981		0.885
A + B vs. C	0.974				0.687		NR		NR		NR		NR

Max., maximum; min., minimum; NR, not reported.

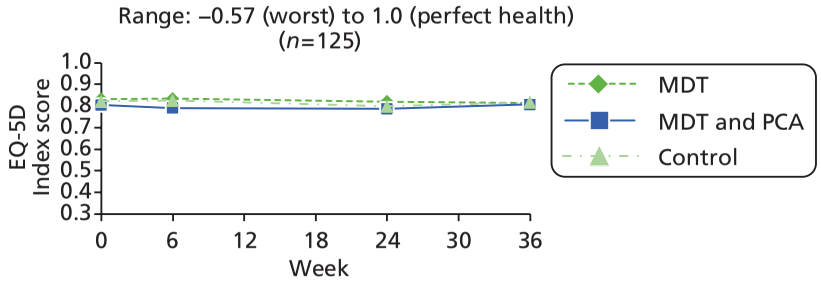

TABLE 103 Analysis of live-in carers EQ-5D Index: $N = 155$ (ITT analysis)

	Baseline (0 weeks)				6 weeks						24 weeks										36 weeks									
PwP group	*n*	Mean (SD)	Median	Range	*n*	Mean (SD)	Median	Mean change 6–0	SD change 6–0	*p*-value 6–0	*n*	Mean (SD)	Median	Mean change 24–0	SD change 24–0	*p*-value 24–0	Mean change 24–6	SD change 24–6	*p*-value 24–6	*n*	Mean (SD)	Median	Mean change 36–0	SD change 36–0	*p*-value 36–0	Mean change 36–24	SD change 36–24	*p*-value 36–24		
MDT (A)	51	0.81 (0.22)	0.85	0.03–1	51	0.83 (0.20)	0.85	0.01	0.12	0.426	46	0.82 (0.22)	0.85	–0.01	0.18	0.725	–0.01	0.16	0.664	48	0.82 (0.19)	0.81	–0.02	0.10	0.168	–0.01	0.15	0.711		
MDT and PCA (B)	50	0.78 (0.23)	0.80	0.09–1	47	0.78 (0.24)	0.80	0.00	0.17	0.870	40	0.79 (0.28)	0.88	–0.01	0.20	0.645	0.00	0.20	0.895	40	0.81 (0.22)	0.83	0.01	0.17	0.602	0.02	0.17	0.478		
Control (C)	53	0.80 (0.26)	0.85	–0.07–1	47	0.83 (0.19)	0.85	0.02	0.20	0.525	46	0.80 (0.21)	0.85	–0.02	0.19	0.450	–0.02	0.15	0.341	44	0.81 (0.16)	0.81	0.01	0.18	0.742	0.02	0.16	0.452		
Between Rx						*p*-value						*p*-value																		
A vs. B vs. C						0.758						0.908																		
A vs. B						0.439						0.748																		
A vs. C						0.773						0.872																		
B vs. C						0.659						0.699																		
A+B vs. C						0.929						0.735																		

N/A, not applicable; PwP, people with Parkinson's; Rx, treatment.

TABLE 104 Live-in carers: SF-36 PCS[82]

				6 weeks		24 weeks				36 weeks			
	Baseline			Change 6–0		Change 24–6		Change 24–0		Change 36–24		Change 36–0	
Group (*n*)	Mean (SD)	Min.	Max.	Mean (SD)	*p*-value	Mean (SD)	*p*-value	Mean (SD)	*p*-value	Mean (SD)	*p*-value	Mean (SD)	*p*-value
A (45)	44.59 (10.85)	20.00	58.60	0.94 (6.68)	0.349	0.22 (7.70)	0.850	1.16 (7.73)	0.320	0.39 (5.55)	0.639	1.55 (6.32)	0.107
B (37)	46.78 (9.48)	23.20	60.10	–3.43 (6.03)	**0.001**	–0.06 (9.61)	0.972	–3.49 (7.32)	**0.006**	1.98 (5.83)	**0.046**	–1.51 (8.23)	0.272
C (43)	47.19 (8.92)	27.00	62.20	1.01 (6.88)	0.340	–2.78 (7.66)	**0.022**	–1.77 (6.87)	0.099	–0.21 (8.34)	0.869	–1.98 (8.05)	0.114
p-value													
A vs. B vs. C	0.415				**0.004**		0.186		**0.016**		0.332		0.063
A vs. B	0.339				**0.003**		0.886		**0.007**		0.211		0.060
A vs. C	0.224				0.962		0.071		0.064		0.692		**0.024**
B vs. C	0.843				**0.003**		0.162		0.282		0.184		0.797
A + B vs. C	0.385				0.112		NR		NR		NR		NR

Max., maximum; min., minimum; NR, not reported.
Bold indicates significant *p*-value.

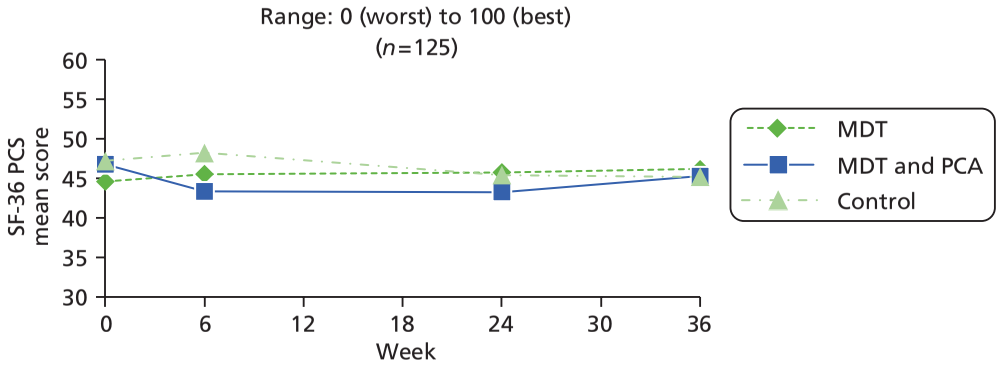

TABLE 105 Analysis of live-in carers SF-36 PCS: $N = 155$ (ITT analysis)

	Baseline (0 weeks)				6 weeks						24 weeks									36 weeks							
PwP group	*n*	Mean (SD)	Median	Range	*n*	Mean (SD)	Median	Mean change 6–0	SD change 6–0	*p*-value 6–0	*n*	Mean (SD)	Median	Mean change 24–0	SD change 24–0	*p*-value 24–0	Mean change 24–6	SD change 24–6	*p*-value 24–6	*n*	Mean (SD)	Median	Mean change 36–0	SD change 36–0	*p*-value 36–0	Mean change 36–24	SD change 36–24	*p*-value 36–24
MDT (A)	51	43.75 (11.89)	47.30	18.2–58.6	51	44.41 (11.51)	45.70	0.66	6.39	0.465	46	45.55 (11.13)	49.95	1.54	8.06	0.203	0.55	7.94	0.641	48	45.86 (11.03)	49.70	1.19	6.29	0.197	0.39	5.55	0.639
MDT and PCA (B)	50	45.11 (9.89)	46.05	23.2–60.1	47	42.59 (11.85)	44.30	–2.96	6.19	**0.002**	40	43.62 (10.69)	46.65	–3.09	7.19	**0.010**	0.16	9.39	0.916	40	44.94 (11.12)	49.50	–1.56	7.93	0.221	1.98	5.83	**0.046**
Control (C)	53	46.69 (9.23)	46.80	25.7–62.2	47	48.00 (9.21)	49.70	0.83	6.65	0.397	46	45.33 (9.91)	46.75	–1.88	6.89	0.071	–2.71	7.83	**0.024**	44	45.09 (10.03)	47.95	–2.05	7.97	0.095	–0.21	8.34	0.869
Between Rx										*p*-value						*p*-value			*p*-value						*p*-value			*p*-value
A vs. B vs. C										0.354						**0.006**			**0.012**						0.134			0.080			0.332
A vs. B										0.533						**0.006**			**0.006**						0.834			0.073			0.211
A vs. C										0.163						0.897			**0.032**						0.051			**0.032**			0.692
B vs. C										0.403						**0.005**			0.426						0.127			0.778			0.184
A + B vs. C										0.199						0.104			N/A						N/A			N/A			N/A

N/A, not applicable; PwP, people with Parkinson's; Rx, treatment.
Bold indicates significant *p*-value.

TABLE 106 Live-in carers: SF-36 MCS[82]

				6 weeks		24 weeks				36 weeks			
	Baseline			Change 6–0		Change 24–6		Change 24–0		Change 36–24		Change 36–0	
Group (*n*)	Mean (SD)	Min.	Max.	Mean (SD)	*p*-value	Mean (SD)	*p*-value	Mean (SD)	*p*-value	Mean (SD)	*p*-value	Mean (SD)	*p*-value
A (45)	53.69 (6.64)	40.20	66.40	0.74 (6.81)	0.467	–1.16 (6.06)	0.206	–0.42 (7.74)	0.720	–2.76 (7.41)	**0.016**	–3.18 (6.64)	**0.002**
B (37)	50.29 (10.58)	16.90	61.00	2.64 (7.53)	**0.040**	–1.72 (6.56)	0.119	0.92 (7.38)	0.453	–0.36 (8.31)	0.794	0.56 (9.47)	0.721
C (43)	51.66 (9.79)	18.80	65.70	–1.78 (7.81)	0.142	–0.81 (8.96)	0.557	–2.59 (8.35)	**0.048**	0.93 (9.57)	0.527	–1.66 (9.24)	0.245
p-value													
A vs. B vs. C	0.233				**0.029**		0.855		0.132		0.120		0.142
A vs. B	0.095				0.235		0.687		0.430		0.170		**0.039**
A vs. C	0.262				0.109		0.830		0.208		**0.046**		0.378
B vs. C	0.548				**0.012**		0.609		0.051		0.525		0.292
A + B vs. C	0.775				**0.016**		NR		NR		NR		NR

Max., maximum; min., minimum; NR, not reported.
Bold indicates significant *p*-value.

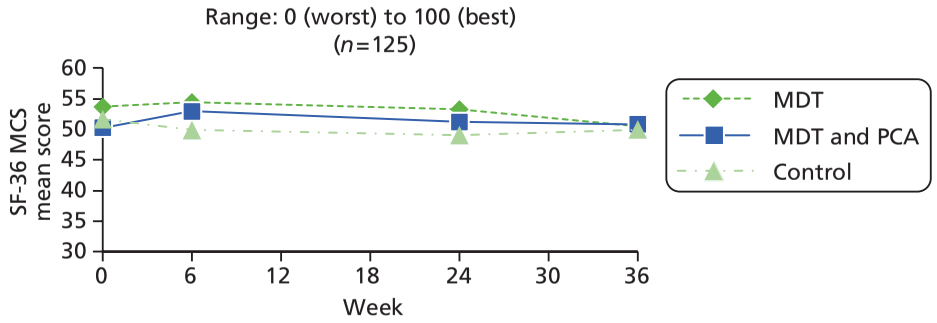

TABLE 107 Analysis of live-in carers SF-36 MCS: $N = 155$ (ITT analysis)

	Baseline (0 weeks)				6 weeks						24 weeks									36 weeks							
PwP group	*n*	Mean (SD)	Median	Range	*n*	Mean (SD)	Median	Mean change 6–0	SD change 6–0	*p*-value 6–0	*n*	Mean (SD)	Median	Mean change 24–0	SD change 24–0	*p*-value 24–0	Mean change 24–6	SD change 24–6	*p*-value 24–6	*n*	Mean (SD)	Median	Mean change 36–0	SD change 36–0	*p*-value 36–0	Mean change 36–24	SD change 36–24	*p*-value 36–24
MDT (A)	51	52.97 (8.30)	54.50	26–67.3	51	53.89 (8.67)	56.20	0.92	6.97	0.349	46	53.35 (7.48)	55.95	–0.64	7.80	0.582	–1.26	6.03	0.164	48	50.78 (9.25)	51.55	–2.93	6.52	**0.003**	–2.76	7.41	**0.016**
MDT and PCA (B)	50	50.34 (10.09)	53.95	16.9–61	47	52.96 (8.51)	55.90	2.43	6.85	**0.019**	40	51.55 (8.49)	53.95	1.06	7.19	0.359	–1.51	6.39	0.144	40	51.07 (9.70)	54.45	1.11	9.54	0.466	–0.36	8.31	0.794
Control (C)	53	51.70 (10.00)	55.90	18.8–65.7	47	49.47 (11.14)	54.30	–1.99	7.74	0.085	46	48.70 (11.82)	52.25	–2.62	8.17	**0.035**	–0.61	8.86	0.645	44	50.09 (12.36)	54.70	–1.71	9.14	0.220	0.93	9.57	0.527
Between Rx						*p*-value						*p*-value																
A vs. B vs. C						0.385						**0.012**																
A vs. B						0.157						0.285																
A vs. C						0.483						0.053																
B vs. C						0.496						**0.004**																
A+B vs. C						0.986						**0.005**																

N/A, not applicable; PwP, people with Parkinson's; Rx, treatment.
Bold indicates significant *p*-value.

TABLE 108 Live-in carers: HADS – anxiety[83]

				6 weeks		24 weeks				36 weeks			
	Baseline			Change 6–0		Change 24–6		Change 24–0		Change 36–24		Change 36–0	
Group (*n*)	Mean (SD)	Min.	Max.	Mean (SD)	*p*-value	Mean (SD)	*p*-value	Mean (SD)	*p*-value	Mean (SD)	*p*-value	Mean (SD)	*p*-value
A (45)	5.07 (3.28)	0.00	11.00	–0.47 (2.54)	0.224	0.31 (2.14)	0.335	–0.16 (2.24)	0.643	0.27 (2.23)	0.427	0.11 (2.77)	0.789
B (37)	5.81 (4.21)	0.00	15.00	–0.43 (2.30)	0.261	0.32 (2.38)	0.413	–0.11 (2.33)	0.779	–0.05 (2.80)	0.907	–0.16 (2.91)	0.737
C (43)	5.91 (3.95)	0.00	20.00	0.12 (2.80)	0.786	0.72 (2.70)	0.087	0.84 (3.23)	0.096	–0.33 (2.56)	0.409	0.51 (3.03)	0.274
p-value													
A vs. B vs. C	0.531				0.502		0.675		0.153		0.546		0.578
A vs. B	0.371				0.950		0.979		0.925		0.565		0.665
A vs. C	0.280				0.308		0.431		0.096		0.250		0.518
B vs. C	0.916				0.346		0.492		0.143		0.652		0.315
A + B vs. C	0.482				0.240		NR		NR		NR		NR

Max., maximum; min., minimum; NR, not reported.

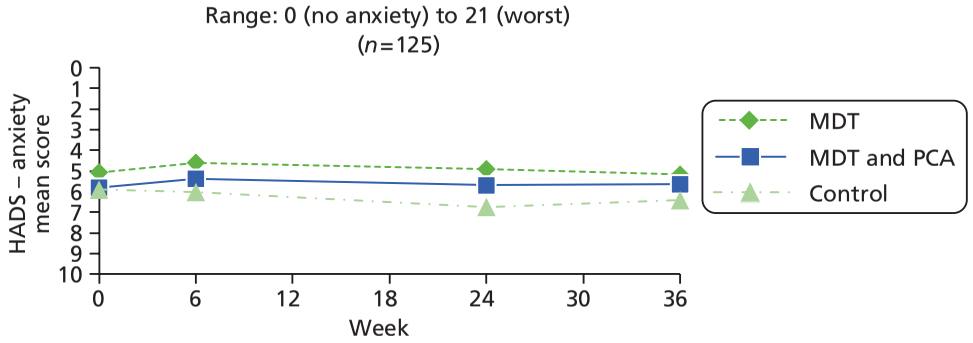

TABLE 109 Analysis of live-in carers HADS – anxiety: $N = 155$ (ITT analysis)

	Baseline (0 weeks)				6 weeks						24 weeks										36 weeks									
PwP group	*n*	Mean (SD)	Median	Range	*n*	Mean (SD)	Median	Mean change 6–0	SD change 6–0	*p*-value 6–0	*n*	Mean (SD)	Median	Mean change 24–0	SD change 24–0	*p*-value 24–0	Mean change 24–6	SD change 24–6	*p*-value 24–6	*n*	Mean (SD)	Median	Mean change 36–0	SD change 36–0	*p*-value 36–0	Mean change 36–24	SD change 36–24	*p*-value 36–24		
MDT (A)	51	5.31 (3.59)	5.00	0–14	51	4.96 (3.90)	4.00	–0.35	2.63	0.342	46	4.98 (3.42)	4.00	–0.09	2.26	0.795	0.30	2.12	0.335	48	5.06 (3.92)	4.00	0.08	2.70	0.831	0.27	2.23	0.427		
MDT and PCA (B)	50	5.54 (4.02)	5.00	0–15	47	5.36 (3.83)	5.00	–0.21	2.19	0.508	40	5.65 (4.19)	5.00	–0.08	2.25	0.834	0.23	2.33	0.544	40	5.63 (4.46)	4.00	–0.13	2.81	0.780	–0.05	2.80	0.907		
Control (C)	53	5.64 (3.86)	6.00	0–20	47	5.98 (4.33)	5.00	0.11	2.70	0.788	46	6.74 (4.14)	7.00	0.85	3.12	0.072	0.72	2.63	0.071	44	6.41 (4.44)	6.00	0.52	2.99	0.253	–0.33	2.56	0.409		
Between Rx										*p*-value						*p*-value			*p*-value						*p*-value			*p*-value		
A vs. B vs. C										0.905						0.656			0.149						0.577			0.561		0.546
A vs. B										0.766						0.776			0.980						0.869			0.724		0.565
A vs. C										0.655						0.396			0.103						0.409			0.461		0.250
B vs. C										0.896						0.530			0.124						0.364			0.311		0.652
A+B vs. C										0.739						0.380			N/A						N/A			N/A		N/A

N/A, not applicable; PwP, people with Parkinson's; Rx, treatment.

TABLE 110 Live-in carers: HADS – depression[83]

				6 weeks		24 weeks				36 weeks			
	Baseline			Change 6–0		Change 24–6		Change 24–0		Change 36–24		Change 36–0	
Group (*n*)	Mean (SD)	Min.	Max.	Mean (SD)	*p*-value	Mean (SD)	*p*-value	Mean (SD)	*p*-value	Mean (SD)	*p*-value	Mean (SD)	*p*-value
A (45)	3.44 (2.52)	0.00	9.00	–0.62 (1.75)	**0.021**	0.33 (1.58)	0.164	–0.29 (2.11)	0.363	0.73 (1.97)	**0.016**	0.44 (1.88)	0.119
B (37)	3.41 (2.90)	0.00	10.00	0.30 (1.93)	0.354	0.11 (1.85)	0.725	0.41 (2.27)	0.284	–0.16 (1.64)	0.552	0.24 (2.52)	0.561
C (43)	3.65 (3.68)	0.00	17.00	0.21 (2.46)	0.581	0.65 (2.23)	0.063	0.86 (2.93)	0.061	–0.40 (2.05)	0.213	0.47 (2.86)	0.293
p-value													
A vs. B vs. C	0.926				0.081		0.441		0.092		**0.016**		0.907
A vs. B	0.948				**0.026**		0.554		0.155		**0.030**		0.680
A vs. C	0.758				0.070		0.445		**0.037**		**0.010**		0.968
B vs. C	0.744				0.861		0.238		0.445		0.580		0.716
A + B vs. C	0.698				0.293		NR		NR		NR		NR

Max., maximum; min., minimum; NR, not reported.
Bold indicates significant *p*-value.

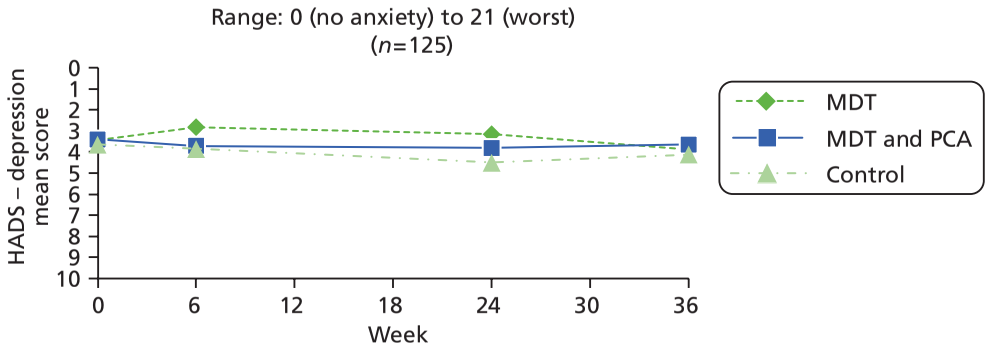

TABLE 111 Analysis of live-in carers HADS – depression: $N = 155$ (ITT analysis)

	Baseline (0 weeks)				6 weeks						24 weeks										36 weeks								
PwP group	*n*	Mean (SD)	Median	Range	*n*	Mean (SD)	Median	Mean change 6–0	SD change 6–0	*p*-value 6–0	*n*	Mean (SD)	Median	Mean change 24–0	SD change 24–0	*p*-value 24–0	Mean change 24–6	SD change 24–6	*p*-value 24–6		*n*	Mean (SD)	Median	Mean change 36–0	SD change 36–0	*p*-value 36–0	Mean change 36–24	SD change 36–24	*p*-value 36–24	
MDT (A)	51	3.59 (2.76)	3.00	0–12	51	3.24 (3.10)	2.00	–0.35	2.01	0.215	46	3.15 (2.79)	2.50	–0.26	2.09	0.402	0.30	1.58	0.197		48	3.85 (3.00)	3.00	0.44	1.82	0.103	0.73	1.97	**0.016**	
MDT and PCA (B)	50	3.56 (2.77)	3.00	0–10	47	3.47 (2.77)	3.00	0.00	2.03	1.000	40	3.68 (3.53)	2.00	0.23	2.44	0.564	–0.05	1.88	0.867		40	3.63 (3.39)	3.00	0.23	2.43	0.562	–0.16	1.64	0.552	
Control (C)	53	3.53 (3.54)	3.00	0–17	47	4.06 (3.40)	4.00	0.30	2.44	0.407	46	4.72 (3.32)	4.00	0.93	2.87	**0.032**	0.59	2.22	0.079		44	4.09 (3.40)	3.50	0.45	2.83	0.293	–0.40	2.05	0.213	
Between Rx						*p*-value						*p*-value																		
A vs. B vs. C						0.995						0.332					0.073										0.308				0.887		**0.016**
A vs. B						0.959						0.390					0.323										0.344				0.641		**0.030**
A vs. C						0.924						0.151					**0.025**										0.483				0.972		**0.010**
B vs. C						0.960						0.522					0.224										0.153				0.693		0.580
A+B vs. C						0.929						0.211					N/A										N/A				N/A		N/A

N/A, not applicable; PwP, people with Parkinson's; Rx, treatment.
Bold indicates significant *p*-value.

TABLE 112 Live-in carers: Yale Depression Screen[84,85]

		6–0 weeks, *n* (%)				24–6 weeks, *n* (%)				24–0 weeks, *n* (%)				36–24 weeks, *n* (%)				36–0 weeks, *n* (%)			
Group (*n*)	Baseline, *n* (%)	Improved	Stayed same	Worsened	*p*-value	Improved	Stayed same	Worsened	*p*-value	Improved	Stayed same	Worsened	*p*-value	Improved	Stayed same	Worsened	*p*-value	Improved	Stayed same	Worsened	*p*-value
A (45)	11 (24.4)	3 (6.7)	37 (82.2)	5 (11.1)	0.480	3 (6.7)	37 (82.2)	5 (11.1)	0.480	3 (6.7)	35 (77.8)	7 (15.6)	0.21	4 (8.9)	38 (84.4)	3 (6.7)	0.705	4 (8.9)	34 (75.6)	7 (15.6)	0.366
B (37)	11 (29.7)	2 (5.4)	32 (86.5)	3 (8.1)	0.655	3 (8.1)	30 (81.1)	4 (10.8)	0.705	4 (10.8)	27 (73.0)	6 (16.2)	0.53	4 (10.8)	33 (89.2)	0 (0.0)	**0.046**	5 (13.5)	29 (78.4)	3 (8.1)	0.480
C (43)	16 (37.2)	4 (9.3)	33 (76.7)	6 (14.0)	0.527	2 (4.7)	37 (86.0)	4 (9.3)	0.414	2 (4.7)	35 (81.4)	6 (14.0)	0.16	4 (9.3)	36 (83.7)	3 (7.0)	0.705	3 (7.0)	34 (79.1)	6 (14.0)	0.317
p-value																					
A vs. B vs. C	0.426				0.972				0.976				0.935				0.530				0.421
A vs. B	0.591				0.837				0.857				0.766				0.302				0.261
A vs. C	0.194				0.972				0.990				0.981				0.990				0.986
B vs. C	0.481				0.826				0.839				0.741				0.321				0.234
A+B vs. C	0.231				0.887				NR				NR				NR				NR

NR, not reported.
Bold indicates significant *p*-value.

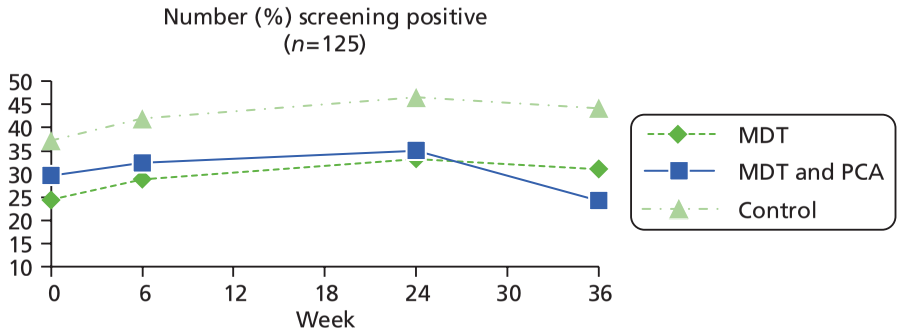

TABLE 113 Analysis of live-in carers Yale Depression Screen: $N = 155$ (ITT analysis)

		6–0, *n* (%)				24–6 weeks, *n* (%)				24–0 weeks, *n* (%)				36–24 weeks, *n* (%)				36–0 weeks, *n* (%)			
Group (*n*)	Baseline, *n* (%)	Improved	Stayed same	Worsened	*p*-value	Improved	Stayed same	Worsened	*p*-value	Improved	Stayed same	Worsened	*p*-value	Improved	Stayed same	Worsened	*p*-value	Improved	Stayed same	Worsened	*p*-value
A (52)	14 (26.9)	3 (5.9)	42 (82.4)	6 (11.8)	0.317	3 (6.5)	37 (80.4)	6 (13.0)	0.317	3 (6.5)	35 (76.1)	8 (17.4)	0.132	4 (8.9)	38 (84.4)	3 (6.7)	0.705	4 (8.3)	37 (77.1)	7 (14.6)	0.366
B (50)	16 (32.0)	2 (4.3)	42 (89.4)	3 (6.4)	0.655	3 (7.5)	33 (82.5)	4 (10.0)	0.705	4 (10.0)	30 (75.0)	6 (15.0)	0.527	4 (10.8)	33 (89.2)	0 (0.0)	**0.046**	5 (12.5)	32 (80.0)	3 (7.5)	**0.048**
C (53)	19 (35.8)	5 (10.6)	36 (76.6)	6 (12.8)	0.763	2 (4.3)	40 (87.0)	4 (8.7)	0.414	2 (4.3)	38 (82.6)	6 (13.0)	0.157	4 (9.3)	36 (83.7)	3 (7.0)	0.705	4 (9.1)	34 (77.3)	6 (13.6)	0.527
p-value																					
A vs. B vs. C	0.615				0.873				0.898				0.848				0.530				0.494
A vs. B	0.574				0.611				0.664				0.588				0.302				0.260
A vs. C	0.325				0.693				0.780				0.790				0.990				0.864
B vs. C	0.680				0.986				0.835				0.732				0.321				0.348
A+B vs. C	0.414				0.809				NR				NR				NR				NR

NR, not reported.
Bold indicates significant *p*-value.

Appendix 24 Comments from people with Parkinson's and live-in carers at 6 weeks regarding the multidisciplinary team intervention

People with Parkinson's

People with Parkinson's: text responses to acceptability questionnaire at assessment 2 (6 weeks), immediately post MDT treatment, groups A and B only, cohorts 4–10.

Question 1: how helpful did you find the treatment programme overall? Please explain.

Each of the interviewers brought up some helpful hints on dealing with the problems I face now and with some that are still in the future. Good, practical advice was given.

Extremely lovely people and explained everything in detail.

The advice I was given would show results much later e.g. arranging my bedside, exercises, writing practise.

More detail than previously received.

Some parts were more relevant than others.

I have found the treatment programme very helpful in answering my queries and in the suggestions given to help me in dealing with Parkinson's disease.

I was made very aware of a number of preventative strategies for all features of my condition: that is, what to look out for and how to prolong usage of voice and gestural flexibility. I found the insights and tips very helpful.

It was helpful to find out what were the Parkinson symptom's and what were caused by the drugs.

Very beneficial modification suggested re-medication by specialist nurse. Constipation successfully managed by suggested medication. Slippery bed sheet.

The programme was very informative and I have gained further knowledge about Parkinson's disease and how to cope better with various problem areas.

Meeting with various experts it was good to be able to ask questions as they arose. I found the visits interesting and things were noticed that were not 'visible' to me before this trial.

I was made aware of the various therapies and services available to Parkinson's sufferers in a useful 6 x 2hr session of presentations organised by the local PDS [Parkinson's disease specialist] nurse. However, it was invaluable to have dedicated individual sessions with each of the therapists and nurse specialists. The 2 sessions with the physiotherapist were particularly helpful and I regret not having had them soon after my diagnosis in Nov 06.

Each specialist gave another view of what was being done to improve day to day living – thinking of alternatives or reinforcing other ideas. Referred to speech therapist for swallowing problems and help with balance, walking and exercise.

It was great to learn ways of overcoming some of my difficulties which were easy to follow and with persistence would actually help to give results.

I have not been able to talk to people about PD [Parkinson's disease] beforehand.

I learnt quite a lot about how to take my tablets etc., also useful exercises.

Overall I found that the experience increased my natural pessimism since I am now aware of more things that might go wrong e.g. swallowing. However, I was encouraged by the professional team to see that being positive is part of the rehabilitation.

Being shown how to do things, i.e. using the bath. Being told about things on the market, i.e. carrying trays.

It helped me to focus on the issues that concern me most and offered me solutions to some of the problems.

I was able to discuss with them various points, also demonstrate where required.

Those that visited me were interested and they also knew their subject.

As I am in the early stages of Parkinson's I am still very independent but what I found helpful was being shown what was available to help in the future as my Parkinson's takes its course.

The treatment was individually tailored to my needs. Thoughtful questioning elicited several difficulties which I experience and can be helped to manage. Poor posture and its attendant problems of clavicular breathing, poor voice production and incorrect body alignment were all explained to me. I found the treatment programme incredibly helpful.

Very informative and made me feel more at ease.

After having Parkinson's for so long (4 years) I was grateful for any input which will help me manage myself. I would feel I had failed if I did not try my very best to cope. All suggestions were helpful and I have incorporated everything I could in my everyday life.

Many useful of information, discussed and noted.

Advice on treatment and other general aspects of the disease, given on a one-to-one basis was comprehensive. In addition, a dialogue was established quickly, allowing for an efficient use of time available. The competence and understanding of the team members was outstanding.

I now understand a great deal more about Parkinson's.

We had aspects of Parkinson's disease explained and how it affects the functions of the body. Also we were shown how it is possible to deal with some of the effects.

Any queries I had were answered for me by a very professional team of people.

It gave me a good insight into Parkinson's, I know a lot more now about the condition etc.

Gave a better understanding of Parkinson's.

I was most impressed with the quality of the experts that came to see me.

The care and understanding of my illness was exemplary in all cases. I really felt that at last, something is being done to help myself and others suffering from the awful aspects of Parkinson's. The information sheets that I received were all helpful.

I found the programme particularly helpful as it was carried out in the home in a relaxed manner, on a one to one basis. Experience of hospital visits to consultants (10 mins if you are lucky) and PDNS [Parkinson's disease nurse specialist] (20 mins) do not compare with the high quality of most of the assessments carried out on this programme. The professionals appeared to listen and were enthusiastic. However, it did seem rather intensive as it was effectively delivered over a 4 week period.

General explanations to problems.

The programme provided general information over a broad range of possible problems; provided advice tailored to my own problems; gave the opportunity to ask questions.

Parkinson's problems explained. Conditions that might arise in the future. Drug treatment mobility problems. Effects on myself. Modifications to home e.g. additional bannister rail.

Would have been much happier if this treatment and information had been given in the beginning when I was diagnosed.

I have learnt a lot about Parkinson's and what to expect in the future.

The fact that out of the blue I was being helped was in itself a great boost to my morale. I attend [local hospital] for physio and exercises but I found it difficult to be disciplined to carry through the exercise at home on a regular basis. Now I find that so many of the exercises can be done as I go about my daily chores.

Some of the researchers had more knowledge of PD [Parkinson's disease] than others.

The programme helped to reassure me that I could cope with my Parkinson's symptoms and thus improved my self-confidence. It also provided a lot of useful information and exercises to help maintain my physical abilities.

Although I had a lot of knowledge about Parkinson's I found that the treatment filled many gaps that I did not appreciate existed.

I learnt more about Parkinson's.

Treatment in the last 6 weeks has been very helpful where the SPIRiTT team has been great.

A very professional approach which has given me confidence in dealing with Parkinson's.

All members of the teams were prepared to listen and to explain queries and provide solutions to queries I might have enquired.

The team helped me to appreciate my problems with Parkinson's and all the team were very supportive and patient in explaining ways to help keep me mobile. The team have helped my wife and I to come to 'terms' with the problems posed by Parkinson's.

My writing is now so poor that I was quite unable to record all of the advice given to me by the various therapists, which I deeply regret, because it was given by each in a most friendly and professional manner. My memory is now not what it was and that was another disappointment for me that after each visit I just could not remember the amount of advice given. But to be given the basis of a one-to-one consultation was a special treat. They make a wonderful team. They were ALL extremely helpful.

Staff well trained and helpful. Paperwork very good. Well organized. Beneficial having the full team coming to the house to give advice and to talk things through. Good physio exercises.

I have been very lucky with my treatment mainly because I have a very good GP and [name] who works at [a local hospital]. The information passed on by your team mirrored everything I have learned over the past couple of years, which shows the right information is being passed on!

I am probably very lucky that the Parkinson's problem is low level and has not developed too quickly. The physiotherapist advice is probably the most important (person too!). Her exercise programme reaches the specific body areas that are relevant to my level of Parkinson's.

Very nice and knowledgeable people.

The survey will be very helpful in establish how the services available for the PD [Parkinson's disease] sufferer can be best used and what is best value for money. It will show I am sure, that the infinite variety of symptoms, are best treated one-on-one (or at least in small groups). I retain my starting unease that the answer to the question which your research project points can be made in one word, which is 'yes' – thus making money available for a much more important subject which is 'cause'.

When I first agreed to participate in the programme I was fairly fit apart from the Parkinson's, then my osteoporosis caused a fracture of the spine. I explained this when I was contacted for the second time. Therefore during the programme I couldn't always judge any improvement in my condition.

Helpful hints and tips for practical management of daily task. Helpful physio exercises encouraged.

Detailed and relevant questionnaires and a team of well-informed specialists enabled one to locate one's "position" on the "Parkinson's scale" and appreciate the importance of the therapy.

Helped with motivation but this faded as the visits decreased.

Although the services that came were indeed very helpful, the reason for the moderately tick was that in my opinion more could be done by having help with the emotional side of the illness. Also massage and relaxation – the massage to ease out tight muscles and retraction of sinews. The relaxation to help combat feeling tense.

I was made aware of aspects of Parkinson's disease e.g. symptoms, helpful problem solving. The opportunity to talk to professionals was particularly valuable as this is not always satisfactory with GP consultant as their time is short.

Filled a lot of gaps in my knowledge in the understanding of the disease and to have a dedicated hour with a top professional is almost unheard of in the public sector!

The entire programme gave me a better insight into the many varied problems that are manifested by Parkinson's.

The best part of the programme was the lady who helped with the various simple exercises. Although there are no results as yet I feel as if there will be – given time.

1. I learnt a lot about the condition and all questions were answered honestly. 2. I was reassured about the long term prospects, and types of medication. 3. I learnt the importance of exercises to keep supple. 4. I was given lots of hints and tips to help this.

It was helpful to have the help and views of the various experts each approaching the same problem (Parkinson's) but from a different angle.

It's given both an insight of how we can help with Parkinson, so that it does not take over.

All of the healthcare specialists gave me information, some of which I have acted on now and will remember for the future.

There was quite a lot of information that I did not know this applies to the rest of the questionnaire.

As yet am able to manage very well so did not need much advice.

By refreshing the knowledge that was given to me when first diagnosed I helped me to cope with the future – if only with communication skills with relatives/friends!

Everybody was very positive and I was sort of depressed at the time, and they were all so nice and kind and positive and that lifted me.

Overall I think it was a good programme with lots of advice documentation exercises etc. also time to discuss Parkinson's disease, all in the comfort of your own home. My thanks to all for their help and advice.

Six responses were removed as research related/not answering the question/illegible.

25 gave no response to the question.

Question 5: please explain, in your view, what were the most successful aspects of the programme.

All of it was useful and relevant.

Having more knowledge about Parkinson's and dealing with the medication.

Motivation to do certain tasks, morale boosting, consult my GP about medication (high blood pressure).

The nurse.

Suggestions for exercises and implements to help in day to day situations. Provision of literature to help deal with problems as they arise.

A chance to advice that is invaluable before it all gets worse. A chance to ask questions and get guidance from specialists in the field.

Discussion on on-going exercises.

Physiotherapy exercises.

Management advice most useful and agreed by consultant Neurologists support to carer.

I can't pick out anything as the whole programme was successful for me.

My symptoms are solely in my right arm and I learnt that when walking I didn't move the arm but did move the unaffected area. In need to physically move the right arm to 'swing' naturally.

First and foremost, the coordinated programme of sessions by the collective support team. I have been lucky with my own experiences but I know that for most of my local fellow sufferers, their exposure to and awareness of the support therapists and services has been very hit and miss.

Home visit which was relaxed and easier to discuss problem on ideas with, not as much time pressure.

Learning how to smile again (which I nearly missed, as I didn't ask the sp. [SLT] therapist because I didn't know she dealt with that) I was lucky that the nurse or physio (sorry I can't remember which) picked up on it and got me the facial exercise sheets. Having facial expressions has brought great relief and elation to my wife and daughters.

Finding out more on how to cope with PD [Parkinson's disease] Just being able to talk.

Parkinson's Nurse's for information on medication etc., also exercising and finding alternative ways to do movements that are not quite so easy now.

Provision of practical advice e.g. improve your handwriting by writing with a big, fat pen.

It made me feel I mattered to the NHS. It's very easy to feel insignificant especially with a confidence sapping illness like Parkinson's. I now feel there are people I can turn to for help.

To be able demonstrate and discuss various points with the people that came to see me.

The fact that these are people who care enough to help in the case of Parkinson's, especially I'm in the late stages.

Exercises and personal attention.

Being shown what is available in the future.

I very much appreciated that the treatment was 'home' based. I was also delighted to be questioned as an individual and given a programme to suit my individual needs. It is such a help to be given assistance in order to prevent problems with such things as poor posture before they become a real issue.

1. The physiotherapist exercises to improve my balance. 2. The occupational therapists suggestions to improving my writing.

Provided a better awareness of the progress of the disease. Very useful in pin-pointing weaknesses in my understanding of the topics that I can work on with the help of my wife. It is probable that I attempt to play down problems that I foresee in the future. When the progress is explained by the team members I see that I do accept the prognosis less pessimistically.

I knew more about Parkinson's after this programme than I have known in the last 8 years.

All the elements were good but the voice improvement and way 'freezing' when walking could be managed were the best.

Nothing could be improved from my perspective.

It made me realise that there are people to listen to me if needed.

Difficult to say. Speech and physio helpful.

I made me understand and feel a bit better.

I was impressed with how thorough they all were. The initial folder given by the occupational therapist was full of very useful information. One person gave me the information to get a new timer pill box.

The most successful aspect was the change of medication to mirtazapine which so lifted my mood of despair and anxiety. Two different neurologists had failed to help, but the PDNS [Parkinson's disease nurse specialist] who wrote to my GP concerning this did so much more.

Nurse/physio input and feedback to bring info up to date. The analysis of current state of deterioration was helpful.

Home visits, time allowed, individual input, explanations given to support advice.

The team were all specialists in their field so I was confident in their opinions. I didn't have to travel to the interviews.

Coming to terms with Parkinson's. All is not lost. Physiotherapy.

The exercises.

Physio made me realise the importance of keeping it up.

Speech and breathing exercises.

The physiotherapy – I would have liked to have further visits from [physiotherapist]. I feel that would have been more beneficial.

Mainly in giving me a broader perspective and understanding of Parkinson's and the action I can take to reduce the symptoms.

Mobility and balance although the programme was hindered because of my back problem.

Physiotherapy – advice on bing trolley to balance better – advice on turning over the bed useful.

Learning how to deal with Parkinson's.

The physiotherapist giving me exercises to maintain my posture and physical fitness.

Physio and speech.

Difficult to single out a specific area of work as the multidisciplinary approach deliver and used exercises.

The most successful aspects for me were the physio visits. The PDNS because she knew exactly the experiences of people with Parkinson's. The most successful aspects for me was being at ease in my own home environment.

Reassurance that my effort in getting on with life regardless of any problems is the right attitude.

It has helped my wife to understand my problems and the teams effort to keep me mobile including encouragement to persist with the exercises.

(a) The one to one basis of each consultation was very impressive and superbly conducted by each therapist (b) the easy manner of each – professional but friendly and unpretentious, (c) the enquiring mind applied by each to my particular requirements and needs which they all readily took on board, and (d) their anxiety to do what they could to make life easier for me.

Different therapist visiting. Different views.

The team's visits.

There are plenty of things for me to do to help myself and the team gave me the encouragement I needed.

Hard to say with preventive therapy.

All of it, do not change a thing. For people who are not coping too well it would be more relative for them and very helpful.

Exercise regime. Speech and language exercise.

There does not seen to be an even spread of problems from one Parkinson's affect person to another. My problems are minor when I view others with Parkinson's. It is all important but for me some of the practises may assume greater priority as the problem increases.

All aspects were enjoyable.

The practical exercises: e.g. how not to choke on ones food, how to keep constipation at bay, how to avoid the blues – in that how best to meet the inevitable challenges of this disease in old age.

Finding out aspects of the disease which helps you to understand the reasons for various aches and pains and posture.

Extra information on the disease.

Physio – exercises. Occ. Health – encouragement to purchase and use rollator and helpful hints for practical management of daily tasks.

The team generate confidence that aspects of the disease can be improved or circumvented provided the patient makes a continuing effort to exercise correctly.

Much of the information and advice given was already known as I have ha PD [Parkinson's disease] for many years, but revision of these appeared to help.

1. Being able to talk at length about how Parkinson's affects me, get it off my chest as it were. 2. Made me feel that I wasn't going to "be a victim" that I was the one responsible for myself – not to rely on others for help. Personally do what I can for myself – seek out what I need. In fact I had a big break through because of SPIRiTT in enabling me to find on old resource of mine for help (self-help books). Which got me out of my rut, and I am actually doing a small art exhibition at a local craft fair.

One to one for an hour. The OT procedures and practical guides.

The exercises are probably the most valuable aspect.

The fact that it is multidisciplinary.

Physiotherapy. [Parkinson's nurse] two interviews.

All those who visited me more helpful, but I have no one at home helping me.

One and one work and team.

I have learnt that different people have different symptoms and have been able to tell family and friends – all of whom help us and are supportive in many different ways.

Most of all I appreciated the explanations and suggestions – little beacons of hope lighting areas of despair.

His speech is greatly affected the speech therapist has helped a lot.

The fact that I don't drive and can't get out anymore, so the best thing was that the therapists came to me.

To enable them to understand about Parkinson's more.

Interesting to chat in a relaxed atmosphere.

That the professionals come to the patient's home and coordinated their input – it is very difficult for my GP to spare any time to do this.

I had lost confidence and got into a depressive state and seeing anybody in a short period of time lifted me and I picked up on their positivity. It was good that I did not have to wait long to see the next person.

The speech and physio therapy sessions.

1. I think I have become more stable. 2. Voice projection techniques were very helpful but I am finding it difficult to remember at times.

The detailed discussion with the PNS including work of the Parkinson's Disease Society also the speech therapist and physiotherapist exercise programmes.

Three responses were removed as research related/not answering the question/illegible.

19 gave no response to the question.

Question 6: please explain, in your view, what were the least successful aspects of the programme.

It seemed unnecessary to have the follow-up sessions with [care assistant].

I cannot identify a 'least successful aspect' other than that it should then be supported by an organised programme of coordinated follow-up sessions at least annually.

Seem to be answering the same questions several times. Basic background – list of medicines, length of suffering Parkinson's etc. could perhaps be compiled to supply each professional so that this was not necessary.

The Parkinson's nurse, as I already have one!

Learning that it finishes so soon!

Seeing too many different people over a short period of time. It was hard to digest and practise so much good advice. This is partly because we had so many other things happening at the same time and not necessarily a fault of the programme.

I'm not good at the exercises. I find them very tiring. I've tried but cannot do them every day as some days I cannot walk at all.

The Language Therapist has the least relevant to me.

The least successful aspect of the programme were their brief duration. I feel awe that many people would really benefit from some input by professional care assistants on an intermittent but regular basis after professionals have decided on a suitable programme for them.

The trial is carried out without involvement of my GP.

Hard to keep up the exercises after the programme has come to an end.

All aspects were successful but I learned less from the language and speech therapy as it is probably the least troublesome problem.

Follow up beyond the 6 week point.

Not really a rehabilitation programme as needed on going contact to assess effectiveness of advice given and adapt accordingly. Plus needed contact telephone numbers for advice. Mostly focussed on excellent assessments. Needs greater emphasis on keeping carer healthy, my husband felt quite neglected and some questionnaires inappropriate for carer.

I got least from the OT because I don't have any problems that needed her help.

No problems with speech.

The OT.

I had been well served by the occupational nurse previously therefore I didn't need another visit so soon after.

One-off visits seemed insufficient. I would have liked more return visits to assess my progress (if any) or otherwise.

Thankfully at present I do not need any aids so that the OT input was the least successful.

Now knowing the cause.

Handwriting not successful.

The least successful was the speech therapy.

It was generally very positive with good aspects it would be helpful if the programme continued for at least 6 months.

This is a difficult one to answer. Upon reflection though, whilst "posture" was covered, I was a bit disappointed I was not offered practical advice as to how to start correcting my developing Parkinsonian 'gait' by suggesting braces or suchlike undergarments. Also, with hindsight the seeming rapidity of consultations made it difficult to absorb the advice of one before the next turned up – the timetable seemed to me to be too concentrated (for me), but I have no alternative to suggest, I'm sorry the treatment programme would have to be extended.

Hard to say with preventive therapy but I was a bit disappointed in that it seem there is not a lot I can do to remedy my poor typing apart from using voice recognition techniques.

Too much filling in of forms. Better to spend the time on teaching the various exercises. Timetable of visits too sporadic.

Speech.

Speech therapists not needed.

The fact that the care and understanding does not carry on.

Need some feedback.

Parkinson's Nurse – as it seemed as if from the 2 visits that I had their role was mainly to take down facts and figures for the office side of things. But I understand that the SPIRiTT programme needs the facts and figures.

[Parkinson's nurse] was so busy that she changed the appointment – stayed long enough to complete her paperwork but did not stay to provide information/guidance on how to liaise with Parkinson's nurse [named].

The fact that it does rely on self to give the necessary help and I was greatly lucky in this!

I would like to have had more tact with [PD nurse named] since she is attached to the [local hospital] as a resident-member.

I found myself being part of a team which without basis. Take up at start of programme not clear.

I don't have a speech and language problem at the moment but I wouldn't hesitate to contact a therapist if I needed one.

Sessions were too long. I found it difficult and tiring to concentrate towards the end. One hour sessions would be better.

The OT advice and information was very good but in my present condition mainly not applicable. However there will most likely be a time when it will be.

Responses that did not identify a least successful aspect

Nine people said 'none' or 'nothing' was least successful.

I have only positive comments.

I would not criticize any of the advice and help that I was given. It would have been better though to have been given this advice earlier in my condition.

As previously mentioned I can't fault the attention and information given

Each aspect was covered satisfactorily.

All were equally successful.

I am unable to make any comments as I gained something from everyone.

Each section was valuable, and all sessions were helpful.

None, I was very interested in all aspects of the program.

In my view there were not any least successful aspects of the programme.

It is hard to say as all aspects helped.

I cannot think of any. It was extremely well thought out.

Sorry, I can't think of any drawbacks.

I thought it was all successful.

Found it all very helpful.

None, all aspects were successful.

I regard all aspects as successful.

They were all successful, but as I have said, it depends on ones stage of Parkinson's which aspect is most helpful.

None, all sessions were very useful.

I enjoyed them all.

None of it. It will be relative in different ways to different people so it is all theirs.

I can't really point to any one aspect as being unsuccessful.

No unsuccessful aspects – all were positive.

None. It met all expectations.

Nothing. I was pleased to see people do things and welcomed their input and they all had something offer.

For me I think speech/breathing exercises were the most helpful. However, also think that the whole management was very essential.

Nine responses were removed as research related/not answering the question/illegible.

24 gave no response.

Question 7: can you think of ways in which the programme can be improved?

I would find it helpful to have more visits from the Parkinson's nurse to discuss such subjects as diet and bladder and bowl problems.

Put more/most profile in Group A.

Would be nice if a nurse could make home visits on a regular basis rather than having to go to the hospital. It would also be nice to have someone to advise what benefits/help is available.

As I said above, to make the most of these sessions, they need to be supported by a coordinated programme of reinforcement visits.

Maybe meeting others.

If visits could be spread over a longer period it would be easier to focus on each suggestion and to make it part of our routine. Towards the end of the programme it would be useful to have a forum at which any participants of the programme who visited could share helpful advice and ask questions.

The programme could be extended since it is so valuable to patients.

Extend the programme to cover more deprived areas of the country.

Limited contact details of team members should be provided to the person with Parkinson's and the Carer, making it relatively easy to discuss problems that arise for specific conditions. Currently, it is difficult to identify the problem and the associated specialist.

Would appreciate a close relationship with a PNS. Her 'hands on' experience is invaluable.

The review of symptoms and (dis)abilities would provide monitory of progression of disease.

More one to one sessions.

I found it stressful and tiring to have 2 visits in a week, new exercises to do and still continue with daily necessities. Perhaps the programme could be extended to allow just one visit in a week.

Ways to improve ones well-being. Worry about the future.

More physio would be useful.

Maybe reviewed at certain time tables?

Apart from suggesting an adjustment to the programme to make it less intensive I'm sorry I can't be more helpful. At the end of the treatment I was left with the impression that my future is in my hands, and will depend on the amount of time I am prepared to devote to the copious exercise programme which was left with me.

Perhaps a few tips advice for the carer e.g. to intervene when the patient is having difficulty in doing up buttons, or not.

Make sure the people who are not coping get the support they need. Maybe introducing the people who are not coping to people who are relative to their age. I feel the boost some people could get and stop the 'wood through the trees' symptoms could refocus people again and move on!

Timetabling of visits could be improved – more evenly spaced if possible.

From initial visit determine the therapist needed.

Employing more staff to give more help and advice.

The literature hand out is very good. Improved by including a schematic diagram of how levodopa is converted to dopamine in the brain and the role of carbidopa and COMT. Could stimulate thoughts about the medication and its timing.

More one to one sessions with therapists.

1. Monthly assessment by a Parkinson's Nurse in collaboration with person who has Parkinson as to what the course for following month would be i.e.: exercise – speech etc. 2. Massage for easing out tightened muscles and sinews. 3. Complimentary therapies such as homeopathy – relaxation and holistic therapies – Bowens reflexology etc.

Who cares about the carers? There needs to be more emphasis on the support given to the carers and their interface with the patient.

More "leaders" coming in to see if you were doing the necessary things, like exercise.

To have it more individualised – did not feel occupational therapy/SALT [speech and language therapy] very relevant as not needed.

Do not think it necessary to have 2 visits from a physio and a PNS.

Not really. It is about right – the time in between was good. the only thing would be useful would be a card with health care professionals photographs to remember who each person was because of the short space of time in between visits.

Increase the physio and speech therapy sessions.

More time on physio thereby.

Needs to be done early on soon after diagnosis, as well as later, and focus on prevention. Advice line contact would be useful. Needs to reflect length of programme that professionals would need to assess, plan, implement, evaluate and amend.

Responses that did not identify an area for improvement

23 people said 'none' or 'no' area for improvement.

Three people said 'not at the moment'.

Two people said 'not really'.

It was well thought out just as it was.

All my questions were answered.

Not really all aspects seem to be covered.

No I cannot see how the programme can be improved but then I am not an expert!

Could not be improved as not much to work on.

You are doing a wonderful job and I hope the current programme will prove that further and deeper investigations are needed. Thank you all.

Not really. All aspects were covered.

I was satisfied with the programme; it went far beyond my expectations.

15 responses were removed as research related/not answering the question/illegible.

21 gave no response.

Question 14: other comments

I cannot fault the programme at all. Also found no one was in a hurry and that alone gives a person confidence.

Having had a telephone number makes me feel better. I enjoy the interaction and compassion.

I have been appreciative of the help given through the study and hope that my contribution has been of some help.

A very positive experience – pleased to have taken part in it!

I was in hospital for 4 weeks with pulmonary fibrosis right in the middle of my 6 weeks. As a result I was not able to follow up on the planned exercises and activities.

Perhaps the emergence of spring weather has helped! Overall the timing has been brilliant.

If this was an annual event it would be good to review progress from one year to the next.

I welcome the study and am delighted that in such difficult times it has been possible to put such a well-mannered, talented team together with such a strong support base. I look forward to the results of the study and hope that it provides the basis for a co-ordinated programme of support for ALL Parkinson's sufferers.

The entire team were friendly, helpful and non-intimidating (with their advice and suggestions). They put me at my ease, yet were truly professional.

Thank you to everyone for being so nice to me.

The specialists who called on me were very caring and friendly, which made the questions and answers very easy to answer, in all a very worthwhile program.

I have enjoyed meeting the helpers and have found it a great help.

It's been a very positive experience.

In my opinion all aspects of this programme was extremely helpful, including the pamphlets.

My wife has filled in this form. I have written answers on a piece of paper for her to copy but my writing would not be understood. Many thanks. I think we have both gained from the study and will miss the visitors!

A very good idea and very well organised.

Thank you for allowing me to participate in this. I am very grateful.

The value of the treatment was limited since Parkinson's affects me to a very limited extent. However, I hope that my inclusion were worthwhile as an outlier.

It's unusual to find a study that will certainty have an effect on the well-being of the interviewee. This is one such study and could form a bench mark to others.

I found the whole study very interesting. I learnt a lot and I found everyone in the team very friendly and helpful. It was so personal and not just a number.

We were glad to have been involved in this study, and hope it will continue to offer help.

Got what I wanted out of it. Seeing the Parkinson's nurse specialist, physiotherapist etc. The team is doing a brilliant job.

I was very apprehensive about the programme at first and then found it very useful and informative.

The difficulty with two types of analysis is the wide range of ability depending on whether one is "switched off" or "switched on".

I would like to see it further developed with on-going support which could be delivered at centres for the mobile. Definitely keep the initial home assessments. Needs to have greater support and contact with consultant neurologists as the consultant I see was disappointingly dismissive of the suggestion made by the PDSN regarding medication. Also dietary input would be very relevant.

I wish that the programme had been available as an assessment when I was diagnosed so that I could have begun remedial exercises straight away. Doing the voice exercises occasionally would have given me warning that my breathing was deteriorating and that my voice was losing its flexibility.

Appears to be a carefully thought out programme. An initial assessment might be helpful to tailor make a list of treatment for an individual. It could for example be split into four parts representing different stages of the disease.

Thank you to all the professionals in this time.

I would like the assessments to continue on a regular basis. It is reassuring to have someone I know that I could contact if I wanted help.

I thought it was very good and helpful. In question 9 and 10 I indicated that I would not want to have the rehabilitation programme repeated with the frequency suggested but would be interested in a repeat at 2 or 3 year intervals. Overall very worthwhile.

I would just like to say that overall performance of the entire programme was very professional and kindly carried out.

Very positive with all the team members welcome in our home.

Only to express my thanks to all the team for the great support given and also the enthusiasm they generated for the SPIRiTT project.

I was given no prior warning to the detailed nature of this questionnaire and I would like to think it could have been sent to me at the beginning of the treatment so that greater care with each therapist could have been taken in some way to record my responses before memory-rot set in. The latter and wretched writing skills have made completion of the questionnaire all the more time consuming I feel my responses to be inadequate, but I have done my best. I'm so sorry – you do deserve better.

Very good would recommend to other Parkinson people.

We find it very interesting. Would like to know any outcomes.

Before any of this treatment begins, it is so important to get their minds focused first. If they cannot be bother to get out of bed none of it will work. They must except and move on and that help should come first.

Not sure of distinction between physiotherapy and occupational therapy.

All of you are doing a fantastic and very important task – I hope the results will eventually be able to share your views.

All 'visitors' were very helpful put me at ones ease and were sympathetic. They appeared to be reasonably clear as to what they were trying to get out of the study, but I hope that this study in itself will sharpen the individual effort made by the NHS as a whole. e.g. I don't need (much) help on exercises; I do need help on more aspects of mind over matter. The recognition of the individuality of symptoms is most important if more research into the causes of this foul disease [writing ineligible].

I hope this isn't the end of interest in letting people know about Parkinson's.

(a) Nurse helped with drugs – information. (b) OT advised me on items to purchase which will help me. (c) Physio took great time finding exercises that would help me.

Very helpful and informative.

The 'Just Met My Expectations' was/is not a really fair way of marking what I thought as an excellent programme put together by the SPIRiTT Team. It is because in my opinion the National Health Service is not able to treat people in a holistic way as well as what its good at already.

Many thanks to be included in this particular scheme. It produced more confidence in myself and my wife.

Since being diagnosed in 2000 I have always felt I was affected to a relatively low level of Parkinson's. This study has reinforced that view and has given me some appropriate actions to take.

Overall useful to have taken part.

Everyone I've met has been so friendly, helpful and knowledgeable – thank you all so much.

I was very pleased that i was given the chance to take part in the survey.

Was impressed by the extreme pleasantness and approachability of the team, who obviously enjoyed their work.

Excellent programme put together and idea. Very much appreciated and it helped me very much. Overall, very very good and should be available to people as soon as someone is diagnosed. I was left out in the cold and had no idea what to expect and what would happen. It was only a few years later, that I was sort of brought into it and told about things, so I think initially someone should visit and say "This is Parkinson's and what it is about" and then followed up with the 6 week multidisciplinary team programme.

When my health centre sent me the letter rejoining this programme I didn't know what to expect. However I have been very grateful for everyone's care and attention.

12 people said 'no' or 'no other comment'.

12 responses were removed as research related/not answering the question/illegible.

30 gave no response.

Live-in carers

Live-in carer's text responses to acceptability questionnaire at assessment 2 (6 weeks), immediately post MDT treatment, groups A and B only, cohorts 4–10.

Question 1: how helpful did you find the treatment programme overall? Please explain.

Information was good and explanations clear and thorough, and all was done with kindness and great respect to my husband.

Physio exercises for balance and strength very useful. Also info from Parkinson's specialists. Others not so directly relevant.

My husband was given exercises to help prolong flexibility etc. and we learned a lot about non-motor symptoms and were given suggestions to help deal with problems. It was very informative and we learned a lot.

The breadth of the programme and the multi discipline input gave me a full picture of Parkinson's disease in all its aspects. Especially, it made both my husband and me think more clearly about the best way to look after him and his individual needs.

Cheerful and helpful.

A better understanding of Parkinson's that I already had gained over the past 10/12 years with [name].

The physio was the most helpful in emphasizing the need to keep mobility by various forms of exercise – good for motivation.

The visits and interest of taking part and being involved made [NAME] more alert and made more effort in exercising and getting around on his own.

We gained a comprehensive range of extra knowledge and lots of strategies and physical exercises to counteract problems encountered in daily life, and exercise routines to help with mobility, balance, flexibility and forward thinking (i.e. anticipation and management of everyday difficult situations). Above all, it was highly motivational and changed my husband's attitude to one of willingness to co-operate because he understood reasons behind strategies and exercises.

Lots of information – advice – practical help meeting people from different disciplines.

Made both of us more focused.

As a result of consolidation of advice and strategies, he has gained confidence, some independence and a more positive attitude.

Physiotherapy.

He is in the early stages of Parkinson's so is still very independent. It was very useful to know that these treatments are available and some were also helpful now in showing how he could maintain his independence.

This is the first time (in 9 years) that we have both been involved in such a programme, as carer and as PD [Parkinson's disease] sufferer. The discussions we have had, both during the visits of the healthcare professionals – and afterwards – have been extremely beneficial and have created an improved understanding for me in the reasons for treatments, for exercises, for facilities (to improve manoeuvrability) which I have subsequently been able to discuss and develop with my spouse.

Gave us the opportunity to talk about Parkinson's disease and the effect on both our lives. The explanations, all very clear, on how the effects of the illness can be modified or delayed, with drugs, exercises and keeping fit.

Gave us information and helpful suggestion of dealing with some of the problems.

Very nice people, who explained everything so well and professional.

Programme of exercises covering posture, walking and balance very helpful in preventing fall. Voice and breathing exercise assist voice/speech.

I know what to expect in the future and what to do to help the condition e.g. Exercises 1. Movement 2. Speech.

Some helpful exercises and information.

Gave a better understanding.

The change of medication has made my life so much happier.

Really good to have different perspectives and overall update. Definitely positive and motivating for my husband while in progress.

Insufficient time – Assessment (only in the main). For a programme to succeed the needs to be feedback and incrementing advancement accordingly. Too short. Felt like a research project not a programme.

I found the fact the patient (PwP) was seen for so much longer, and in check our home, so I felt a true understanding of how his life was affected (as people are so different) could be been [incomplete sentence].

We now understand more aspect of Parkinson's. We are encouraged that our own exercise routine included most of the suggested exercises. The programme uncovered some new problems that we are now tackling with new exercises. We are both very encouraged to continue resisting Parkinson's and have been able to adjust our daily routines to include more exercise.

The information given enabling a greater understanding was extremely helpful. The exercises were also helpful.

[Name] has gained more insight into his condition and it is encouraging to see him more determined to overcome his condition as best he can.

It helped us understand Parkinson's a little more.

It helped understanding of the condition.

Everyone who has visited my husband has been really positive with practical encouragement.

Made [name] more aware that exercise can help him and also the importance of taking medication regularly.

It was helpful as my wife found it pleasant to converse with people who are aware of how a person with Parkinson's feels.

Positive encouragement that fits our philosophy for just getting on with life.

I found the support given by the team extremely helpful. It has helped us to cope with the Parkinson's.

This helped both of us in helping and coping with the disease and its effects. Also felt somebody was listening to how we felt about it.

I felt that my wife had been given encouragement and the means to help herself in her daily struggle with PD [Parkinson's disease] talking to knowledgeable and supportive people about the disease was extremely valuable in my view.

The specialists' input/suggestions have been very helpful with respect to coping with tasks/actions which are proving difficult.

Helpful hints and tips for practical management of daily tasks. Helpful physio exercises set and encouraged.

Motivated my husband to do more exercise.

Helpful at point of combat but seemingly very little lasting effect. Pack of booklets/leaflets very useful.

My wife is now calmer about her problem and her day to day coping.

This reinforces most of what I know because I am a nurse. Great to have my husband to have one to one with a professional therapist.

Has given [name] lots of tips and also increased his positive outlook on his condition.

My understanding of Parkinson's is greatly improved thanks to all of our visitors.

For me as his carer it has helped a lot with his speech.

The programme inspired my husband to exercise and follow the speech therapy programme.

Impressed by all members of staff who visited. Advice given very helpful but would like assurance that in the future a programme would be available or contact base that a carer would ask for advice re progression of Parkinson's.

Three responses removed as research related/not answering the question/illegible.

Six gave no response to question.

Question 5: please explain, in your view, what were the most successful aspects of the programme.

Personal care and attention – friendliness of therapists and their methods of teaching. Leaflets and reading material the help.

Having a chance to talk to specialists and learn about the disease in your own home. Having specialists see patient moving and using things in own home.

The information provided about way Parkinson's affects the body was helpful and reassuring. It reduced stress and resulted in an earlier visit to the GP to deal with frequency of urination.

1. Although I've read much about PD the clarity of each participant gave me answers to the disease. 2. We could not have asked for more helpful, interested and likeable team – such a pleasure to meet each one of you. 3. The programme helped to confirm that as things are at the moment, I'm helping understand in the right way to see him and his need for independence.

By being present with [name] so we both know what has to be done – i.e. exercises etc.

Important with someone who has Parkinson's to feel he is not forgotten. One often loses friends when speech is difficult and involvement in interests has disappeared. These visits gave him something to have in the future to feel he has to 'improve' so it doesn't seem so hopeless but is manageable and that there is help there.

For me, learning how the brain affects not only physical movements, reflexes and repercussions of lack of balance and perception of space but also learning how it releases chemicals, hormones etc. differently, thus affecting mood, memory, senses etc. My husband's behaviour suddenly began to make sense!

Knowing what was going on and why, made a big difference to my own emotional acceptance of the condition, and to my attitude as carer (i.e. informed instead of bewildered). Secondly, learning that there were lots of things that we could actually do (to make life easier and to commit to an exercise programme) helped enormously with morale and motivation.

Information gained.

Re-assuring my wife, helping her see how well she is coping.

Being able to discuss Parkinson's with qualified persons and have some of our questions answered.

The most important aspect of the programme was the high lighting and consolidating of strategies both new and previously learned but forgotten. The final fortnightly visits of the carer re-enforced these and were very useful in keeping up the momentum, making exercises part of a daily routine.

Good ideas from all on how to manage Parkinson's. Exercise regime suited to the person's individual needs. The care and concern shown. Someone to talk to and able to express a carer's concern for not only the person with Parkinson's but also for the carer.

Exercises

Allowed him to continue with advice.

Just knowing that this help is available. Also for the reinforcement to the importance of keeping active.

There is no doubt that the success of this programme can be attributed to the individual interests paid to the person with PD [Parkinson's disease] by the health-care specialists. These are one-to-one discussion, with a shared interest and professional concern have been both supportive and stimulating, and have allowed an up to date programme to be developed on an individual basis. As a carer, I can see how encouraging this has been as my wife grasps on to the new ideas.

My husband does not yet require active help, with most tasks of daily living he remains independent if slower than pre-diagnosis. It gave him hope that there were things he could do rather than increasing drug dosage. Time to talk re illness.

They were all successful but speech and physio had the most impact for us.

My wife was anti this programme at first, she handles things in her own way, as nobody seemed to care. Have changed her mind we find the programme really really helpful.

Speech, posture, swallowing were excellent.

It was good to know that exercise in all forms can only be helpful. It was good to learn how to deal with various problems and particularly what to do to slow the progress of Parkinson's.

It gave my husband a programme to follow.

One to one treatment.

The approach and kindness of all concerned.

Helping understand what processes were operating and how to make a difference all professionals working together made of joined up and you felt things progressed overall no matter who the professional was.

The fact of home visits meant that there was no rush and we had their individual attention in our own environment.

The professionals had time to explain and to listen to our problems, time is always at premium when dealing with the medical profession.

The questionnaires and interviews provided the first full assessment of [name] problems. The interviews were tailored to tackle problems [name] has and provide enough information to access help with future problems. Meetings in our home meant that [name] was more relaxed than after travelling to another venue. [Name] is v. hard of hearing. We were impressed with the way the therapists spoke clearly and not too quickly and consistently faced him so he could lip read.

The information imparted.

The programme gave [name] more insight into his illness and the physio made him realise he needs to keep up the exercises. I still need to 'encourage' him though!

During the sixteen years since my husband's diagnosis of PD [Parkinson's disease]. I had never had the opportunity to discuss his illness with anyone. The G.P. did not seem very interested, or to know a great deal about the disease. This programme has given me contact with the experts with whom I was able to discuss PD and ask questions.

The help the physio gave my husband with his balance and walking.

Helping me to understand and therefore act.

My husband is keen to get on with exercises each morning – that needs motivation!

The physiotherapy and the speech/language therapy.

The physio visits seemed to be the most beneficial to my wife for the future.

Promoting of physical exercise.

Helping my husband with his mobility and general encouragement.

Although it still tries my patient's. As i find him very demanding and not much time for myself.

Already answered previously the nurse and the physio were of particular benefit. We had already had a OT from our surgery (at my request) visited before the research OT otherwise the OT would have been much more useful. If we had this help on a regular basis it would have saved me a lot of time and stress, trying to find out what help I could get for my husband.

Probably mobility and speech considerations. Problems associated with both on going a great deal on our everyday life.

My appreciation of what Parkinson's effects are has been heightened and hence I tend to watch more carefully when problem activities are undertaken by my wife. The 'one-to-one' aspects of the programme are without doubt successful.

Physio – exercises. Occ. Health – encouragement of purchase and use Rollator and helpful hints for practical management of daily tasks.

Suggested we got in touch with our local occupational therapist and social services which have proved very helpful. The in depth questionnaires obviously understand some of the problems involved.

I was a pleasure to see and chat with all the visitors who did their best to inform and help but then was very little we weren't aware of already about the condition. It was encouraging for the patient and instigated motivation for a while.

Not worrying about sharing. Not so self-conscious. She enjoys physio exercising.

Having contact with up to date practitioners, lengthy periods of time, who were able to demonstrate very clearly and succinctly their view and helpful ideas.

Although I was not present at the sessions, [name] has reported back useful tips and info. I also feel it has helped him with a more positive attitude.

Knowing that there is help out there if [name] problem gets worse, and knowing what to look for with books and all the information that was left with us.

Showing me how to get my husband with his speech and walking.

Helping my wife to understand and live with her symptoms and helping me to do the same.

The programme has helped with my wife's stability and voice projection. It has also increased her confidence.

Three responses removed as research related/not answering the question/illegible.

Three gave no response to question.

Question 6: please explain, in your view, what were the least successful aspects of the programme.

Speech – patient not always compliant to practise.

OT is not relevant yet.

Naturally too short. Not dealing with any psychological problems that could have been labelled talked through with disabled and carer but perhaps this is not part of the program but is a part of the whole.

The short period spent with the Parkinson's person was not able to assess the whole day care. I quite understand this is not probable.

Speech and language because didn't take part.

The OT but only because it isn't needed at the moment. But it was useful to know about for the future.

Obviously the programme appeared to be too brief, and the allocation of time and resources needs to be discussed, but information here would have more value from the experience of the healthcare specialists (particularly in a world where we are resource-limited!).

Could be frustrating to listen whilst my husband, was too positive re his abilities and how he felt. We did resolve this. It is difficult to give a different point of view that doesn't destroy their confidence.

The only downside was that the visits could not continue.

Really would be better to have some follow-ups to keep on track, so will be interested on feedback from the group that has this.

This was not in all reality a 'rehabilitation' programme.

The frequency of the visits made it a rather stressful experience at times because we already have rather busy days. [Name] tires easily so his 'day' can be quite short. These follow-up questionnaires ask us to remember who told us what in order to comment on the value of the topic. It is almost impossible because of the overlap between one discipline and another and because of the speed with which one visit followed on from another.

Given [name] condition i.e. not having much of a problem with speech, speech therapy was not too helpful, but others may need this. The patient's condition at any given time should dictate the support given.

We had an OT visit early on in [name] diagnosis who helped with a few aids and changes so there was not much required at this visit.

The Parkinson's Nurse visited two weeks in succession and asked the same questions. I would have thought that an interval of several weeks or even months may have been more beneficial. I did not see the point of the second visit.

I felt my husband's needs did not require the OT or SLT.

I believe the least successful aspects from the speech therapist.

Thought I would find more about medication.

None, really. All aspects covered proved useful. But OT was perhaps least successful but not sure how much else could be done.

Rather a lot of information in a short time.

The caring role seemed to be more secondary as a retired RGN I do not know a good deal about the care. I was however not asked about how I felt or what problems I had or my expectations for myself or my husband.

Responses that did not identify a least successful aspect

Eight people said 'nothing' or 'none' was least successful.

All team members had a wide knowledge of Parkinson's Disease. Their advice on managing the everyday problems, were very much valued.

Found it all very helpful.

I have no complaints at all.

I cannot think of any. It was very informative and helpful.

To be honest, nothing obvious comes to mind.

None, it was all well planned.

None really.

It was generally positive and with good results.

Programme was successful.

All were successful.

10 responses were removed as research related/not answering the question/illegible.

Seven gave no response to question.

Question 7: can you think of ways in which the programme can be improved?

Additional visits from any particular specialist as required by individual.

A one stop clinic where you would be able to see all members of the team and specialist Parkinson's disease consultant with an appointment system, but also an ability to telephone and speak to an appropriate member of the team if a problem arose.

By being on-going.

Very difficult. Managing the person/disease as it advances is very difficult on the carer. On more than one occasion 'breaking point' was reached. I think 'caring' could be looked at, i.e. on the best way to relaxation, physically and mentally.

Maybe more visits from an experienced Parkinson's Nurse. A close association with the patient's GP would be an advantage.

More integration with local Parkinson's services (and inspiring them to work together more!).

More input for carers and how carers can help – No support offered for carers – Focus totally on PD [Parkinson's disease] patients.

The programme would have been better for us with more time between visits. The time spent at each visit was about right. We believe the most benefit to us would have come from this at the time [NAME} was diagnosed because we would have been more knowledgeable about how far Parkinson's was already affecting [NAME] and about the help available.

The patient should be assessed then the treatment schedule set up.

More physiotherapy input.

I would have liked to have had an interview on my own on one occasion. There were things I would like to have said, out of my husband's presence – not wanting him to think that he was in any way a burden to me.

Maybe reviewed at certain timetables.

It would be helpful if the programme could continue for 6 months.

Not really. Everyone's different carers meeting perhaps.

Recommendation to local groups for speech therapy and physiotherapy.

Increasing speech therapy and physiotherapy input. Easier more frequent access to a Parkinson's nurse. Massage could well be therapeutic and helps to relieve stiffness and pain.

More physio.

Some therapeutic input for the carer. I was interested in being present in the meeting but could have easily not taken part at all. I feel that the carer needs to be more involved in the therapists' mind.

Including more physio and speech therapy treatments e.g. 4 of each.

The sessions were too long. I really think they should be about a hour. Concentration is difficult after them.

Programme can only be improved if the services can be continued. Having learned that every Parkinson's patients care needs progress at different times it would be helpful if their needs could be monitored at regular intervals. Elderly carers need assurance when symptoms change and advice.

Responses that did not identify an area for improvement

Eight people said 'no' or 'not really' area for improvement.

Only more of the same.

Nothing springs to mind.

Not really – carrying out a survey/team trial couldn't really be carried out without forms! Possibly the form filling could be 'fine tuned' but I fully understand the need for forms!

No! It was very comprehensive and covered just about everything.

Not yet.

No – everything worked well.

Sorry, nothing obvious comes to minds.

No, brilliant!

No, very good as it is!

Seven responses were removed as research related/not answering the question/illegible.

11 gave no response to question.

Question 14: other comments

To want to commend and thank all the therapists for their approach both of carer and patient. Without exception they treated us with kindness and respect and imparted their expertise in very understandable ways. We were very impressed with them all. Thank you.

Thank you for the opportunity of taking part.

It was a very positive experience and I am pleased to have taken part in it. It was very informative and helpful.

I'd like to re-iterate how much we appreciated the kindness and patience shown to us by each of the professionals involved in SPIRiTT. We were privileged to be part of the cohort and we very much enjoyed meeting each of the sessions.

Patient has now enrolled for group speech therapy. This is an achievement.

Nice to know there are others out there working at Parkinson's problems and its effect on patient and carer – (usually unpaid spouse). During the early stages of confirmation of 'Parkinson's' we were left to our own devises somewhat with the expectation of GP trying to settle out the main course of medication for [name].

I am not really involved at this stage as a carer but will be interested to read the final report to see if this has kick-started any exercise programme for those further down the line.

It is very difficult to assess improvement or input over this short time, if I have not found it exceeded my expectations it is because I don't know what my expectations should be and each member of the group were very good. A direction or understanding of the study would have helped. It has been very difficult to assess the particular import of the study as we have not long ago been helped by the local specialists above, who helped enormously and left little for these dedicated people to add. If we had not been involved with local specialists, the difference would have been easier to assess.

It was very intensive, but the information was all put over in a very friendly, motivational and "patient-aware" manner. All the health care professionals were pleasant, friendly and easy to talk to, non-intimidating, and we felt each visit was time well spent. I strongly hope the study achieves all its objectives, as it has been so worthwhile for myself as a carer, and my husband as a patient, to take part in!!!

It was very helpful and I gained further knowledge of Parkinson's.

Very professional. Ticked all the boxes. Well worth the cost to the NHS.

Would be nice to have a "2 monthly" follow up, the support given was appreciated.

We feel we definitely benefited from the programme. Rather than repeat the whole programme, it would be very helpful to have regular visits, say twice a year, from the physiotherapist and speech and language therapist.

Just to say thank you. I don't feel so isolated now knowing there are people outside our home with helpful and caring ideas most of which I shall endeavour to take on board.

I think it has been beneficial.

The follow-up – twice a year – would be most helpful.

This is an amazing programme for both PD [Parkinson's disease] patients and their carers. Not only does it generate interest in the difficulties encountered and brings tailor-made advice on the manner in which these may be overcome, but it also demonstrates how latest ideas on treatments may be used to advantage, thus enhancing a patient's quality of life for the future. The more widespread adoption of such a programme is to be thoroughly recommended.

Absolutely brilliant cost effective way of incorporating the well-being of Parkinson's sufferers and their families therefore making people feel cherished and important within the vast NHS system.

No – but we were very happy to take part and there were many benefits.

All members of the team were very helpful. In managing Parkinson's. A cure is the ultimate wish, however, every assistance is valuable.

The study should be continued with the present understanding of the carers needs.

In the past we have had quite good input from other Parkinson's nurses and OTs. What was particularly effective here is that they worked as part of a team and it all felt co-ordinated. Also, the whole team were so positive and inspiring and left you feeling that there is always some small thing that can make things more positive.

Focus was more towards "treatment" or rather "assessment". It cannot be called rehabilitation. Six weeks was not long enough to establish a treatment regime. Only 2 visits from each of the physio and PNS and one from OT.

I thought all the professionals were very punctual, easy to talk to, and listened to us and very helpful – and also had time.

We would have benefited from this type of assessment soon after [name] diagnosis for 2 reasons: 1) It would have given a base for measuring future effects and tailored exercises could have begun earlier. 2) The questionnaire promoted discussion between us of topics we had not previously considered together and this discussion has been illuminating and re-enforced us as a team fighting problems. All exercises were intended to mitigate what were seen as Parkinson's problems. Our experience is that [NAME] was gradually losing fitness prior to diagnosis. The medication allowed him to begin a home exercise programme which has improved his general fitness and confidence. This type of exercise should probably be advised for all Parkinson's sufferers. It is difficult for anyone to keep up exercises alone particularly if Parkinson's is causing memory problems. We think the spouse/carer should be helped to exercise with the P[arkinson's] sufferer to improve the likelihood of the exercises continuing, to check that the exercises are being carried out properly and to keep their own fitness. I think the term carer should be discarded in favour of 'enabler' because it emphasises the team aspect of living with PD [Parkinson's disease] and because becoming a spouse's carer is the most important aspect of the relationship rather than wife/husband as previously.

This type of support should be provided to each patient when first diagnosed by the NHS.

Well organised and beneficial.

[Physiotherapist] seemed the most well informed with regard to PD [Parkinson's disease]. She was a great inspiration to us. I am not convinced that the single visits were of any great value. I would like to see assessments repeated two or three times a year from all the specialists. I look forward to seeing the final report on this survey.

The above is only on the reports I have back from my husband. Thank you for visiting him it would be very good to have the team back in the future.

The overall performance of the entire programme was very professional and kindly carried out.

It should be obvious but congratulations should be given to personnel for choosing first rate people.

I wish to express my thanks for the support given by everyone concerned with the project.

All visitors very helpful especially the man answering phone very helpful. Good work.

I do hope that the NHS will fund this on a regular basis for Parkinson's sufferers and their carers. Please do let us know the results of the survey.

I found the various leaflets very useful, information in a straightforward manner.

Very pleased that we participated.

Very helpful and informative.

It is good to involve the carer as the disease affects both our lives.

I felt the title was a little misleading. To me multi-rehabilitational programme suggested a more intensive course of therapies – not a couple of visits over the six weeks from a speech and a physiotherapist. I don't think my husband benefitted much from these, maybe this is because he has had PD [Parkinson's disease] for over 12 years and is in the more advanced stages of the illness.

A very useful insight into the latest thinking and technique. Very good for the patient to have the time of so many disciplines, especially so if they are not so confident in their own PD [Parkinson's disease] nurse which my husband is not. All of the practitioners were very professional and pleasant and thank you very much for being included in this survey.

Many thanks to all involved for your care and support towards [NAME] – he has found it an uplifting experience in a difficult year.

The study was well worth giving the time spent on it. Your team of ladies were wonderful.

As explained above, most of the visits involved my wife not myself, although she did tell me all about them. Her symptoms are still relatively mild, and my involvement in day to day routines has not needed to change much so far. I did not really know about, or have expectations with regard to the visits, and I do not feel able to comment meaningfully on them, apart from feedback information from my wife. The overall effect was obviously beneficial and confidence building, and should symptoms worsen, the need for and effect of advice/help would increase proportionally for both of us.

The treatment visits encourage the client its keep up the regular exercise routine.

There is need for follow up in say a years time.

OT not really applicable at the moment – gave advice for future use of equipment at a later date.

One response was removed as research related/not answering the question/illegible.

Eight gave no response to the question.

Appendix 25 Responses from people with Parkinson's and live-in carers at 24 weeks regarding the multidisciplinary team intervention

People with Parkinson's

People with Parkinson's: text responses to acceptability questionnaire at assessment 3 (24 weeks), immediately post PCA treatment, groups A and B only.

People with Parkinson's: group A

Question 11: when the 6-week multidisciplinary rehabilitation treatment ended, did you continue to benefit? If yes, please explain how you benefited.

Since the programme started my condition has deteriorated. Some of the benefits then, will not be the same in the future so who knows?

By the various suggestions into practice – especially physio.

Unable to remember.

Made me try harder with all my activities.

Learnt things about Parkinson's disease.

Do exercises every evening.

Incorporated facial exercises and walking exercises into gym routine.

Voice improved, techniques learned for eating, getting out of chair and bed.

By being aware of what is available to Parkinson's sufferers.

I am more aware of how I can help myself and I know what is available as and when needed.

I tried harder to slow down on my speech. I also do exercises every morning to keep things working correctly.

Continue to practice speech therapist suggestions and physio.

Made me find exercise and hydrotherapy.

I continued to do the exercises.

Continued with the exercises but unfortunately Parkinson's has now become worse.

I am sure I will benefit but I have had a urine infection.

Have been shown how to cope with various aspects of Parkinson's and given a better understanding of what can be done.

Some benefit from speech therapy and exercises but not ready sure that if was totally beneficial.

As [name] goes to a gym three times a week he continued with this and not the exercise, as this would have recount exercising all the time. However it would be a benefit for most people.

It gave me the opportunity to put into practice the suggestions, ideas and routines that they had and to see the results and benefits.

Useful exercises – information.

I tried to continue with exercises. The speech therapist explained about the weakness in my voice and how it was caused by PD [Parkinson's disease].

Only a little because I was hospitalised with IPF [idiopathic pulmonary fibrosis] shortly afterwards.

Access to physio was of great benefit. Also felt our own experiences had been put to good use which would improve funding and treatment of newly diagnosed sufferers.

With my speech.

Doing exercises.

Remembering to speak loudly and clearly.

Comprehensive exercise.

Not sure.

1. My handwriting has improved. 2. General reassurance.

I continue to do the exercises.

The treatment and specialists optimism was infectious.

There was so much literature to read and answer problems as the exercises were very helpful.

Retained the knowledge – but self-motivation reduced after it ended. Would like it to be on-going.

By learning more about actual disease.

Snippets of information were useful for later.

Greater understanding of condition and ideas for managing it.

Personal Trainer has now been engaged to keep carry on with programme.

I feel I benefited from the advice given by the professionals and feel more motivated to exercise. Balance has improved.

From the various exercises shown to keep mobile, and other advice given.

Exercises.

Exercise seems to be the most important.

Speech therapy and exercises have been good.

By continuing with the advice and exercises.

I retain the improved confidence that resulted from the rehabilitation treatment and continue to benefit from the exercises and information.

Following advice from physio.

General improvement in mobility.

There was no continuing treatment to benefit from!!

Kept up with exercising tried to remember what they said.

Can still use the knowledge gained.

Much better informed about aspects of the disease.

By applying the lessons learned from home visits.

Nothing other than explained before. Also, understanding of why the speech and swallowing is affected, means able to understand what is happening.

I benefited from observing the changes in performance of the various exercises.

SALT [speech and language therapy] input.

The positive recalculation of my waning remaining gifts and talent, providing a full life. Positive attitude.

Focused my mind more on controlling my movements affected by the Parkinson's.

Some of the knowledge e.g. times of taking pills have been altered which has proved to be beneficial.

The equipment recommended has really helped, especially the back roll.

Helped with balance.

Gained one or two ideas for coping with minor problems.

Got me rethinking about my health.

Assessment 3: people with Parkinson's, group B

Question 11: when the 6-week multidisciplinary rehabilitation treatment ended, did you continue to benefit? If yes, please explain how you benefited.

It helped with my confidence and ability.

From exercises.

Exercise.

I have become more aware of problems with balance and also of my quiet speech and the need to talk much more loudly and distinctively.

Teaching us the way to keep on moving, not to sit around doing nothing.

Learnt new things about PD [Parkinson's disease].

The information and knowledge from the healthcare professionals was utilised after the 6 weeks in daily life, with benefit.

[Care assistant] input kept it going.

Greater all round awareness.

Encouraged to think about how to improve on wellbeing.

Continued with suggestions made by team.

Following instruction sheets on both exercises and face movements.

From the regular programme of exercises.

By keeping up with the exercises.

Continue with posture exercises. Consult paperwork for useful reference.

Having someone come in and suggest and follow-up at next visit was a motivator. Knowing there are things to do to alleviate symptoms.

We have confidence to have learned more about Parkinson's disease.

A reminder to maintain the regime.

Yes because I continued with the recommendation – I contacted social services which resulted in hand rails being installed bed rails and pillow lifter. Without the information I would have still been struggling out of bed.

In the short term the CA [care assistant] carried on with the work set out by the physiotherapist. The main on-going benefit to me, is the recognition that in order to keep my symptoms under control and potentially reduce the speed of deterioration I must help myself. In my case dedicate time to practice movement and flexibility but also to take regular aerobic exercise.

Tried to do more exercise.

Learnt new things about PD [Parkinson's disease] that can be applied to day to day life.

Able to use mobility suggestions on a regular basis.

Continued exercises both physical and speech therapy with carers encouragement.

More aware of movements.

I am more aware of the support available.

This answer is predicted, because we only finish the programme this week. However we are sure the benefit will continue.

I continue to exercise as instructed and try to maintain a positive attitude.

I am still keeping up with the exercises to keep me mobile for longer, also received information from Parkinson's nurse.

With [care assistant] coming in, enabled support needed to continue benefiting.

I am more confident in knowing what exercises will improve/maintain what mobility I have and my speech.

I carried on using the information I was given and found it very helpful (i.e.) exercises and speech therapy

More knowledge on how to manage Parkinson's.

I have become reconciled with Parkinson's and am clearer about what I should do.

I have learnt more about PD [Parkinson's disease] which is very helpful to me in dealing with my general slowness, my tendency to tire quickly and with speech difficulties and balance.

Exercising, etc.

My speech, balance, swallowing improved enabling me to enjoy life more. Unfortunately curtailed by my stroke.

Were given some good tips for doing things.

A better understanding of the need for exercise and the need to keep trying and not to indulge in self-pity.

Exercises – continued doing exercises, and has prompted me to join a local exercise group.

Kept me focused.

I have been stimulated to keep going particularly with daily exercises.

I know now how to keep up my mobility.

Period of time insufficient to assess the benefits.

Provided necessary discipline for the exercises.

Regular exercises. I mean to do well with working on exercises and breathing to improve my speech.

I learnt the exercises to help my posture etc. and I was motivated to keep doing them. It also helped get over the early part of my PD when I was slightly down.

Speech better. Walking a little better.

Increased confidence in handling Parkinson's.

Continued with exercises.

It has confirmed my thoughts about physical fitness. Both patient and carer need to be able to work together to make sure that any exercises are done, and to encourage each other.

Felt the exercises were valuable and effective, even though physical condition deteriorated.

Continuation of exercises has been helpful.

I met experts in the problems of creeping problems. The team of this survey gives confidence that Parkinson's is not a killer but can be controlled and most of the control comes from a team of experts and it is up to the individual to motivate and apply the advice given. The rehab is up to you.

Continued our exercises. Encouraged me to attend local exercise class.

The six weeks on its own would not have had much of a result but the extra input received certainly bettered the outcome.

I felt that my stress levels were a lot lower. And that when I did the exercises and the breathing and voice exercises that my capabilities improved breathing more easily. Also I would like to have the opportunity to meet/contact other people who have Parkinson's – maybe we could set up a web group? This would be very useful.

I was able to continue the advice given as to mobility etc. and motivate myself to keep pushing the boundaries of what I can presently do in all aspects of my day to day living.

I felt more confident having survived it.

Doing the exercises from the physio with [care assistant] was beneficial.

By using the 'hints and tips' given to me and continuing the exercises.

Continued with the exercises with [care assistant].

By having the follow-up appointments with CA [care assistant].

Follow-up visits from [care assistant]. Also the positive attitude of the healthcare professionals encouraged me to be positive and act on the information they gave me.

Live-in carers

Live-in carers' text responses to acceptability questionnaire at assessment 3 (24 weeks), immediately post PCA treatment, groups A and B only.

Live-in carers: group A

Question 11: when the 6-week multidisciplinary rehabilitation treatment ended, did you and the person you care for continue to benefit from the treatment? If yes, please explain how you benefited:

We recognised the need to buy wheelchairs, etc.

More aware of resources available.

It was good to think back to what the person has told you.

It was good to see that John included the suggestions into this exercise regime.

Forgotten some of the things we learned so not as effective as it would be.

Understanding the illness was of great value.

Better attitude in general.

Continuation of exercises maintains mobility and flexibility.

Unfortunately the person I care for got a urine infection after the rehabilitation treatment ended – which has been a setback. Therefore, at the moment, I cannot answer this question but feel that we certainly will benefit.

Made carer and patient feel more positive about the future and ability to cope.

Continued with the exercises and speech therapy for a period of time.

It got him enthused to attend a weekly exercise class. Understanding the importance of letting him be as independent as possible for a long as possible.

He confirmed to try and do the things he was shown to keep the illness steady.

Awareness of moving and speaking in the patient reinforced what I was saying.

Kept more focused on exercises etc.

Probably greater awareness of the whole problem

Yes with physiotherapy – but not so much occupational – or speech and language – and [PDNS] is invaluable – but she is our PDNS [Parkinson's disease nurse spcialist] and easily contactable.

Using some of the tips provided, but difficult to maintain the programme.

More positive on being able to slow down the progression and the disease with self-help, e.g. exercises, voice control.

We benefited by the information and greater understanding of what is possible with a bit more effort.

To have someone to talk to, to explain things to you.

Gave a real boost to sheet with re-mobility but this has diminished. Someone comes in to the home was much more helpful than just seeing professionals in a clinic environment.

It gave the patient a focus with specific exercises which gave benefits as well as 'feel good' and 'can do' mentality.

Still doing the exercises. [Name] has increased motivation to do them.

We both understand the condition better.

It keeps us going on.

If only one aspect was beneficial it was the advice of getting in and out of bed and moving about in the bed.

New attitude point of view exercise and talking without about things generally.

It gave my husband things to work at and gave him a purpose to exercise.

We reminded ourselves about what we had been told and applied the knowledge to the current situations as they happened.

Live-in carers: group B

Question 11: when the 6-week multidisciplinary rehabilitation treatment ended, did you and the person you care for continue to benefit from the treatment? If yes, please explain how you benefited.

Learning more about Parkinson's and ways of helping my husband.

The discipline of exercise has kept the muscles toned so when he is able to walk, he can do so very well.

The treatment offered a sufferer and bench mark for the patient and carer and reinforced by visits with practical application.

Advice given and exercise programme helped in continuing care. Provided helpful ways of managing things like 'freezing', getting in and out of bed etc.

Learnt knew things about PD [Parkinson's disease].

Continued with exercises.

We were encouraged to carry on with the suggestions received.

The exercises were very helpful.

With the help of the Parkinson's Nurse from [local hospital] we continued with private physiotherapy at [local day centre]. This is aiming to improve posture and mobility beyond our expectations.

It was good to learn more about Parkinson's Disease.

A fuller knowledge of what was involved.

My husband continues with recommended exercises, from physio and speech and language which should help slow the diseases progress. Our knowledge base is much greater.

It drew our attention to all the disciplinary we were shown are most important and we hope to be able to keep it up for the benefit of my husband.

My wife has learnt she has to be more disciplined in carrying out 'in house' treatment/exercises etc.

It is too soon to answer this accurately, as the programme only finishes this week. Predicted response – benefits in balance and mobility should continue, as we will certainly keep up all the things we have learned.

I was able to answer questions from my wife. Refer to literature.

When speech or mobility problems are at their worst we have strategies to try to overcome them.

He tries whatever possible to exercise but speech now is very difficult.

Improved knowledge of the problems and how they are relevant and relate to the patient. New ways of caring for/attending to PD [Parkinson's disease], e.g. exercise regimes for balance improvement, importance of stature maintenance. Improved knowledge of therapies, e.g. impact of drugs used etc.

Made you feel more confident.

Exercise advice continuing.

By remembering what we were advised to do to keep Parkinson's at bay, my husband's Parkinson's is slow in changing, thankfully.

It gave my wife confidence and determination.

Time will tell – as it has only just finished!

My husband concentrated on the physio exercises.

I was assured by my husband that he had learnt many exercises and had a greater knowledge of the condition.

When [NAME] remembers to do the exercises he moves much better and speaks more clearly.

Physio exercise and positive attitude to the future.

By being in the way of doing some of the exercises on a regular basis.

Continuation of speech and physical exercises has helped my wife over the last weeks. We feel less isolated than before.

Explanations of what to expect of the Parkinson's sufferer and hence a deeper understanding of their situation.

The programme helped to encourage the patient in exercising with both voice and body.

My wife is now more relaxed and happier.

EME
HS&DR
HTA
PGfAR
PHR

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