

European Inventory

Appendices

March 2015

Produced on behalf of the EPDA by

Millbank Social Marketing Ltd

in collaboration with Dr Anette Schrag
International Parkinson and Movement Disorder Society
European Section (MDS-ES)



International Parkinson and
Movement Disorder Society

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Appendix I: Participant details

APPENDIX I : PARTICIPANT DETAILS

1.1. PwPs: DETAILS OF THE PARTICIPANTS

CURRENT AGE	GENDER	AGE AT DIAGNOSIS	LOCATION
62	Male	58	Denmark
77	Female	64	Denmark
Not known	Male	Not known	Denmark
62	Male	55	Denmark
72	Female	57	Denmark
67	Male	34	France
62	Female	54	France
76	Female	Not known	France
78	Female	73	France
65	Female	60	France
46	Female	40	Germany
72	Female	65	Germany
78	Female	65	Germany
59	Male	34	Germany
61	Male	38	Germany
60	Female	60	Hungary
68	Male	67	Hungary
67	Female	48	Hungary
65	Female	60	Hungary
62	Female	61	Hungary
57	Female	46	Hungary
67	Male	57	Ireland
49	Male	40	Ireland
49	Female	38	Ireland
57	Female	42	Ireland
60	Male	52	Ireland
66	Male	51	Ireland
79	Female	72	Italy
71	Male	65	Italy
60	Male	56	Italy
82	Female	70	Italy
64	Female	61	Italy
57	Female	53	Netherlands
54	Male	42	Netherlands
61	Male	54	Netherlands
45	Female	41	Netherlands
54	Male	46	Netherlands

CURRENT AGE	GENDER	AGE AT DIAGNOSIS	LOCATION
53	Male	49	Slovenia
64	Female	54	Slovenia
54	Male	48	Slovenia
58	Male	29	Slovenia
57	Female	43	Slovenia
48	Female	41	Spain
62	Female	40	Spain
64	Male	53	Spain
61	Male	40	Spain
60	Male	42	Spain
66	Male	59	Sweden
73	Male	68	Sweden
70	Male	59	Sweden
64	Female	58	Sweden
50	Female	Not known	Sweden
53	Male	45	UK
74	Male	73	UK
64	Female	61	UK
67	Male	63	UK
66	Male	57	UK
66	Female	57	UK
67	Male	64	UK
63	Male	57	UK

1.2. CARERS: DETAILS OF THE PARTICIPANTS

CURRENT AGE	GENDER	RELATIONSHIP TO PERSON WITH PARKINSON'S	NUMBER OF YEARS SINCE PERSON WITH PD WAS DIAGNOSED	LOCATION
70	Female	Wife	4	Denmark
Not known	Male	Husband	13	Denmark
Not known	Female	Wife	25	Denmark
59	Female	Wife	7	Denmark
74	Male	Husband	15	Denmark
56	Female	Wife	31	France
Not known	Female	Wife	Unclear	France
77	Male	Husband	10	France
77	Female	Wife	8	Germany
31	Female	Wife	4	Germany
29	Male	Son	2	Germany
48	Male	Husband	6	Germany
64	Female	Wife	2	Hungary
67	Male	Neighbour	6	Hungary
77	Male	Husband	10	Hungary
62	Female	Wife	10	Ireland
50	Male	Husband	11	Ireland
62	Female	Wife	15	Ireland
64	Female	Wife	10	Italy
48	Female	Wife	10	Italy
36	Female	Daughter	9	Italy
63	Female	Wife	15	Netherlands
56	Male	Son	5	Netherlands
57	Female	Wife	13	Netherlands
69	Male	Husband	10	Slovenia
69	Female	Wife	8	Slovenia
29	Female	Daughter	6	Slovenia
60	Female	Wife	26	Spain
50	Female	Wife	4	Spain
63	Female	Wife	27	Spain
72	Female	Wife	20	Sweden
70	Male	Husband	17	Sweden
82	Female	Wife	10	Sweden
76	Female	Wife	2	UK
70	Female	Wife	6	UK
67	Male	Husband	9	UK

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Appendix II: Findings from the survey by individual country

APPENDIX II-A: SURVEY FINDINGS FOR DENMARK

1.1. Sample profile

In total 146 respondents completed the survey from Denmark. 47% of respondents are male and the average age of respondents was 60 years when they were diagnosed with Parkinson's, with the youngest aged 38 and the oldest aged 79 years. Only 16% are currently employed. When asked to describe the area in which they live, 22% state rural, 63% town, with the remaining 15% living in cities.

1.2. Quality of life and disability scores

To explore quality of life, EuroQol's EQ-5D measure was utilised. This is a standardised instrument for the measuring of health status and requires respondents to answer five questions focusing on **mobility**, **self-care**, **usual activities**, **pain**, and **anxiety/depression**.

Regarding **mobility**, 50% report no problems walking, 47% report some problems while 3% of respondents indicate that they are confined to bed.¹

Moving on to **self-care**, 3% report they are unable to wash or dress themselves and 14% that they have some problems with washing or dressing. However, the majority of respondents - 83% - indicate no problems with self-care.

When asked about their current ability to perform **everyday activities** such as work and leisure, 48% of respondents experience some problems performing these activities, while 44% indicate no problems at all. Those who are unable to perform any everyday activities are the smallest group, accounting for 8% of the sample.

When discussing current levels of **pain and discomfort**, over half of the sample (56%) indicate that they suffer from moderate pain, while 41% indicate having no pain or discomfort. Again, those who suffer from extreme pain represent a relatively small proportion of the sample at 3%.

The final question assessing current quality of life focuses on levels of **anxiety and depression**. Over half of respondents indicate they are not anxious or depressed (53%), while 46% indicate moderate levels of anxiety or depression. Only 1% of the sample report feelings of extreme anxiety or depression.

Compared with their general health over the last 12 months, only 10% of respondents state that their health is *better*. The majority of respondents feel that their health is *much the same* (47%) while 43% of respondents feel that their health is *worse*.

When asked to rate which statement best describes how they feel about their independence, none of the respondents report to being bed bound. The most commonly recorded response is '*I am able to do all chores with some degree of slowness, difficulty and impairment, and am beginning to be aware of difficulty*' (59%) (Table 1).

¹ Results based on the number of respondents answering Question 7. This result may not tally with the number stating they are bedridden in Question 13, the results of which are shown in Table 1.

Table 1. Self-reported disability score (%)

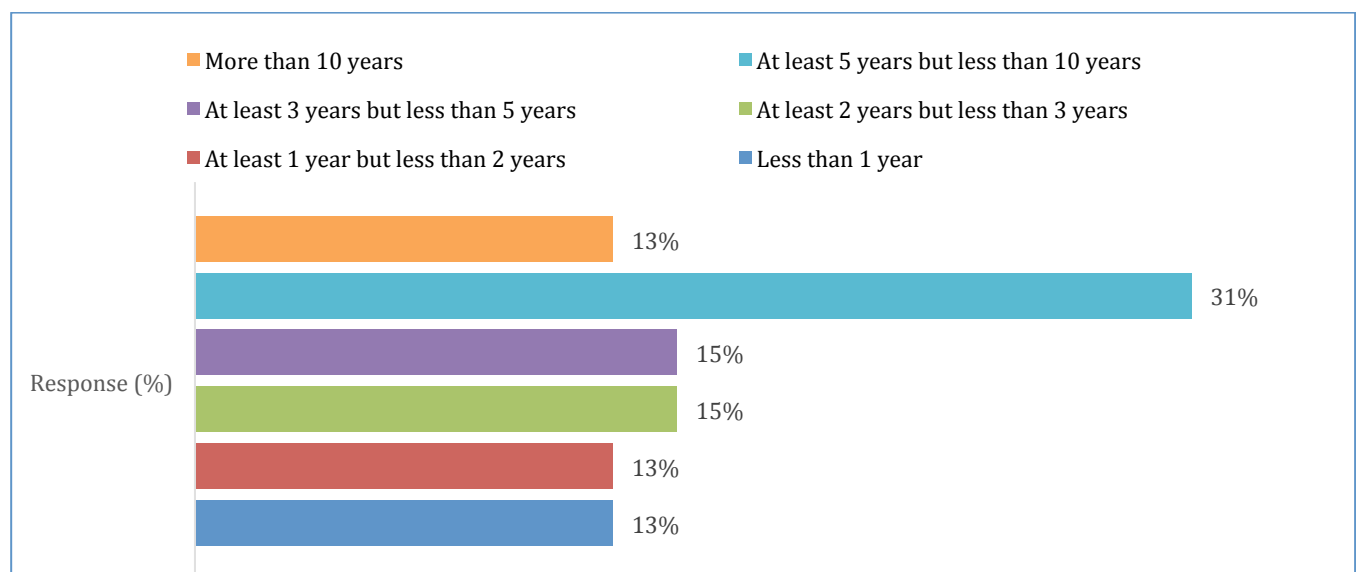
STATEMENTS	Response (%)
I am able to do all chores without slowness, difficulty or impairment	11
I am able to do all chores with some degree of slowness, difficulty and impairment, and am beginning to be aware of difficulty	59
Chores take twice as long and I am conscious of difficulty and slowness	14
Chores take three to four times as long and I spend a large part of the day doing these	3
I can do most chores, but exceedingly slowly and requiring a lot of effort	5
I need help with half the chores and have difficulty with everything	2
I can assist with all the chores, but am only able to do a few on my own	2
I can manage a few chores with some effort, but need a lot of help	2
I do nothing on my own, but can be a slight help with some chores	1
I am totally dependent and helpless	1
I am bedridden	0

1.3. Receiving a diagnosis of Parkinson's disease

1990 was the earliest date that a respondent had been diagnosed with Parkinson's and 2014 the latest (12% had been diagnosed in 2014; the median date of diagnosis was 2010). 99% of respondents had been diagnosed with Parkinson's in Denmark, with the exception of one respondents who had been diagnosed in Africa (exact country not disclosed).

For 56% of respondents, it has been less than 5 years since diagnosis. 13% of respondents were diagnosed over 10 years ago (Figure 1).

Figure 1. Length of time since diagnosis (%)



The symptoms most commonly noticed before diagnosis included changes in the way you move (including the way you walk, dragging a leg, not swinging your arm, etc.), slowness of movement, tremor and fatigue. Interestingly people with these symptoms were more likely to seek help within a year. However with other symptoms, such as bladder and bowel problems and loss of smell or taste and stress, these symptoms could often continue for up to five years before help was sought (Table 2).

Table 2. Reported symptoms, and duration of these symptoms before seeking medical help (%)

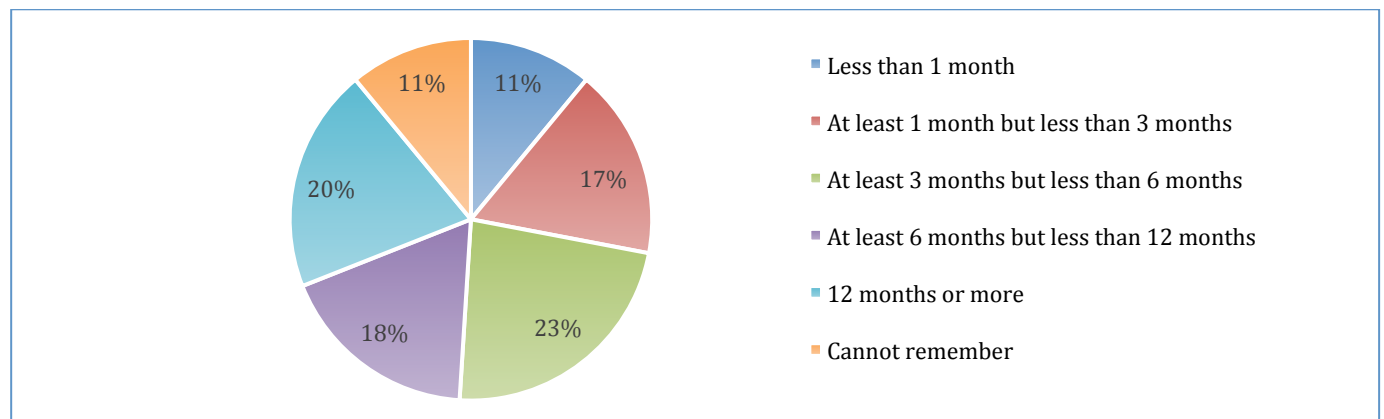
SYMPTOMS/PERCENTAGE OF RESPONDENTS²	Less than 1 year	1 to 2 years	3 to 4 years	5 years or more	Total number of respondents experiencing symptom
Anxiety	7	4	5	1	17
Apathy	4	4	3	1	12
Bladder and bowel problems	5	7	8	10	30
Changes in the way you move (incl. the way you walk, dragging a leg, not swinging your arm, etc.)	16	35	18	5	74
Depression	12	7	3	5	27
Difficulty eating and/or swallowing	7	8	1	3	19
Eye problems	9	6	1	4	20
Falls (balance problems)	13	9	6	3	31
Fatigue	14	18	11	12	55
Freezing	7	7	7	5	26
Loss of smell or taste	11	8	11	15	45
Low blood pressure or dizziness	7	7	5	9	28
Muscle cramps	13	15	8	7	43
Pain	9	13	9	10	41
Rigidity (stiffness)	19	19	7	9	54
Skin and/or sweating problems	6	8	2	8	24
Sleep problems	12	11	5	8	36
Slowness of movement	25	24	11	5	65
Speech and communication problems (incl. small handwriting and reduced facial movements)	20	20	10	4	54
Stress	7	13	7	9	36
Thinking or memory problems	15	17	9	4	45
Tremor (shaking)	26	21	5	7	59

² Respondents could select 'do not apply; and select multiple options

Other symptoms added by the respondents included: cramp while running and violent dreams which involved uncontrolled movement during sleep. One respondent said that one of their first symptoms was: *“Finding it difficult to brush my teeth and stir a pot.”*

When asked how long it was before seeking medical help after first noticing their symptoms, one fifth of respondents waited 12 months or more (20%). 41% of respondents sought help within 3 to 12 months, while 11% sought immediate help (within 1 month) (Figure 2).

Figure 2. Timelines for seeking medical help (%)



1.4. During the first appointment

During the first appointment with a healthcare professional, just over one third of respondents underwent an observation of their symptoms (37%), while less than half underwent a physical examination (42%) and just over one-third (35%) discussed their general medical history. 40% of respondents were told that they might have Parkinson's, although another one fifth of respondents were told that something was wrong; however the healthcare professional was unsure of the exact diagnosis (20%). Over three quarters of respondents (76%) were referred to another doctor or healthcare professional following their first appointment (Table 3).

Table 3. Events during the first appointment with a healthcare professional (%)

EVENTS	Response (%) ³
Discussed your general medical history	35
Carried out a physical examination	42
Observed your symptom(s)	37
Referred you to a specialist, or another doctor / healthcare professional	76
Said nothing was wrong	9
Said it was too early to tell if anything was wrong	10
Said something was wrong, but not sure what	20
Prescribed medication to relieve your symptom(s)	11
Explained that you may have Parkinson's	40
Explained that you may have another disease / condition	11

³ Respondents could select multiple options

A number of respondents detailed other events which happened at the first appointment, including being told that they might have:

- A recurrence of old nerve damage in the arm
- Multiple Sclerosis
- Frozen shoulder

Respondents were asked, if they were referred to another healthcare professional, what the waiting times were. If a referral was made, this was mostly to a neurologist (either general or one specialised in Parkinson's disease). However a significant number of respondents were also referred to a Parkinson's disease nurse specialist or a physiotherapist.

Most of the respondents saw a neurologist (either general or specialised) within two months of referral with a significant proportion of these appointments taking place within one month (Table 4). A significant proportion of respondents also gained access to a physiotherapist within two months of referral.

Table 4. Waiting times to see professionals from referral (%)⁴

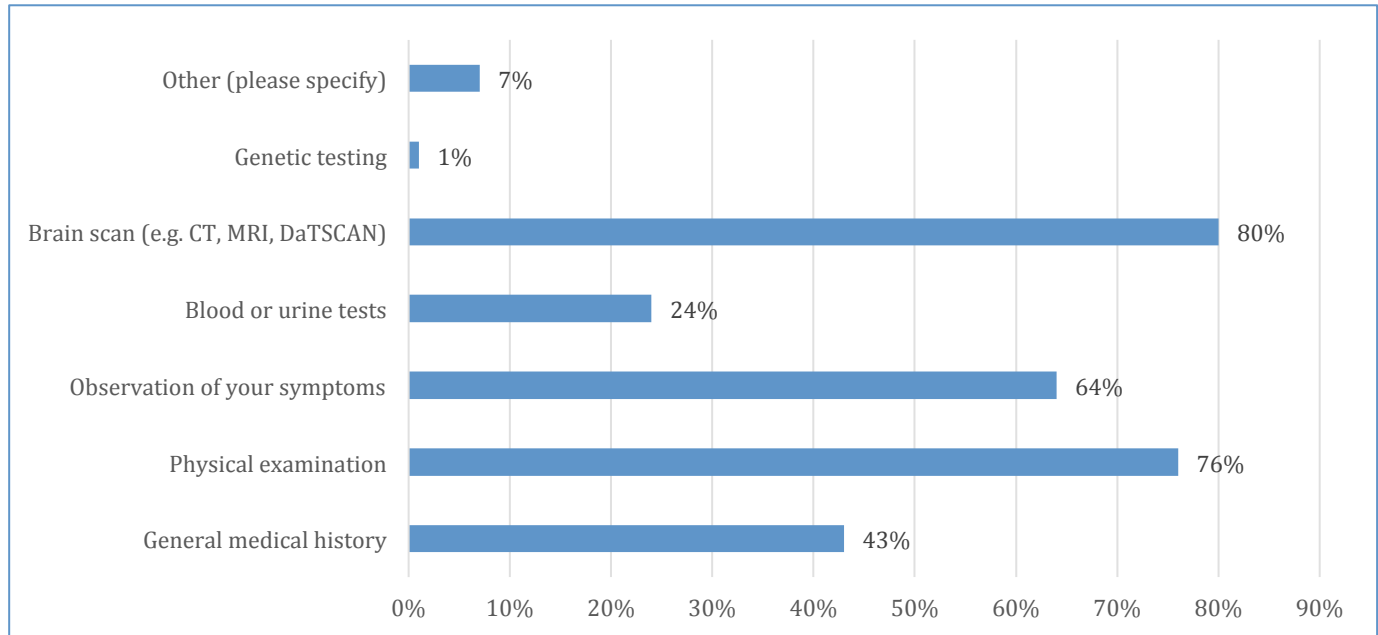
HEALTHCARE PROFESSIONAL	Within 1 month (%)	1-2 months (%)	2-3 months (%)	3-4 months (%)	4 months +	% of respondents referred
General neurologist	34	19	9	6	8	76
Neurologist Specialist in Parkinson's	29	12	11	5	12	69
Geriatrician	1	1	1	0	1	4
Parkinson's disease nurse specialist	6	2	3	0	3	14
Physiotherapist	12	13	7	5	13	50
Occupational therapist	1	1	1	0	1	5
Speech and language therapist	2	1	2	0	10	16

The overwhelming majority of respondents had a brain scan to diagnose their Parkinson's disease (80%). Three-quarters (76%) stated that they underwent a physical examination and just under two-thirds (64%) had their symptoms observed. 7% of respondents mentioned that they also underwent other types of examinations and tests during diagnosis (Figure 3). These included:

- Rheumatology tests
- PET (Positron emission tomography) scan

⁴ Respondents could select multiple options or state that they could not remember

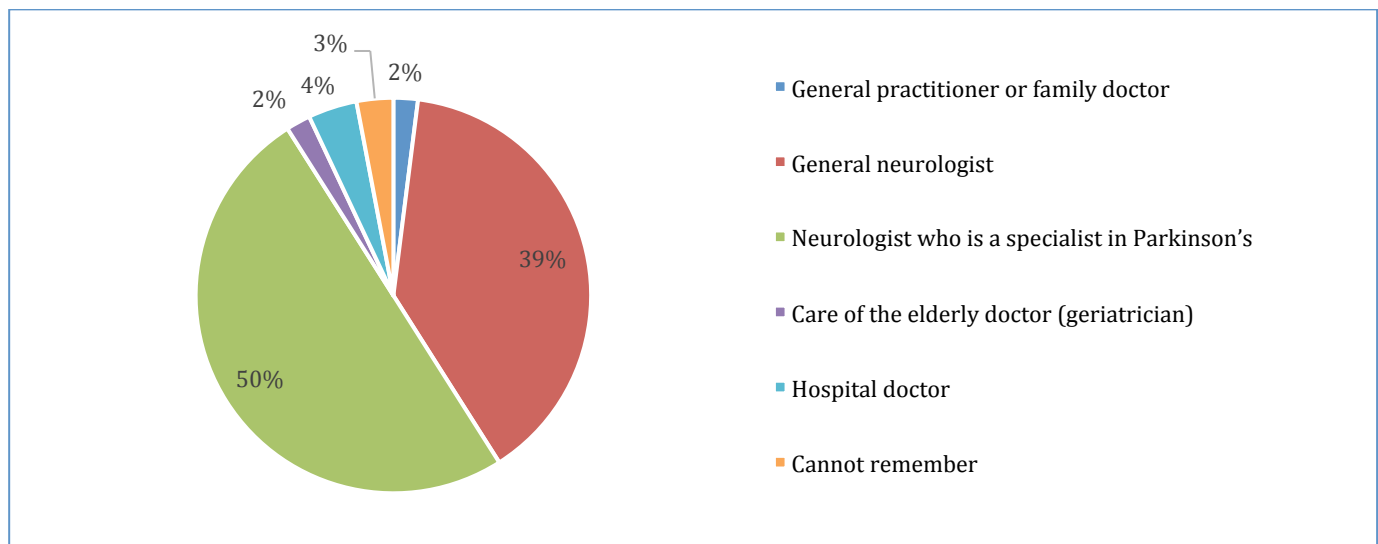
Figure 3. Examinations and tests carried out



1.5. Delivery of the diagnosis

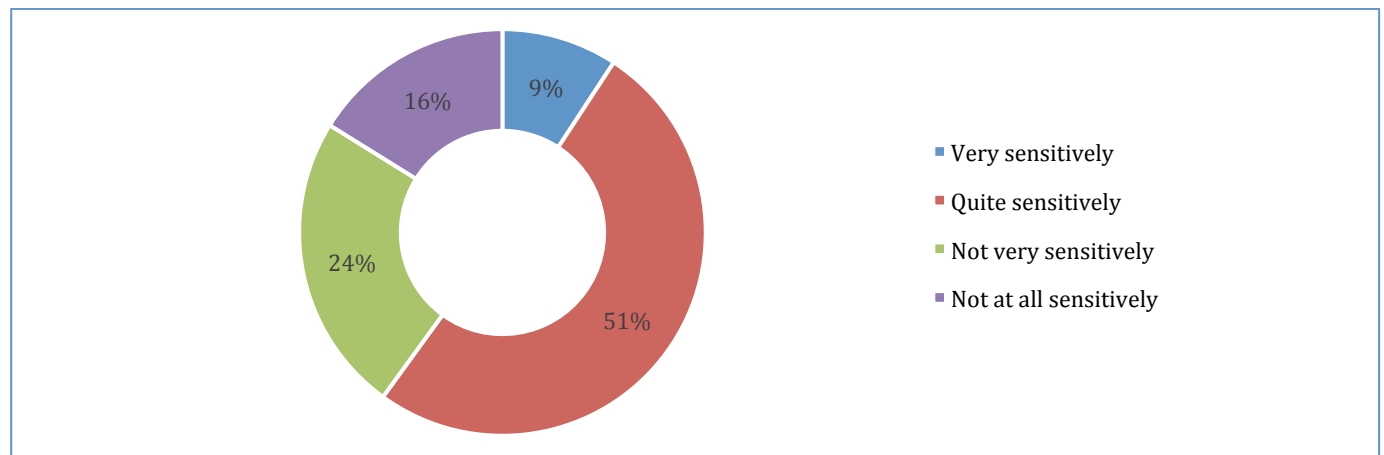
Half of respondents received their diagnosis of Parkinson's from a neurologist specialised in the disease (50%), while a further 39% were diagnosed by a general neurologist. Only 4% received the diagnosis from a hospital doctor and 2% from a geriatrician. Few respondents (2%) were given the diagnosis by their GP (Figure 4).

Figure 4. Healthcare professional diagnosing Parkinson's (%)



Responses were split in relation to the sensitivity in which the diagnosis was given (Figure 5). 60% of respondents feel that they were told either very sensitively or quite sensitively, while the remaining 40% believe that the diagnosis was not given sensitively. However, only 17% feel dissatisfied or very dissatisfied with the consultation where the initial diagnosis was given. In comparison, 19% of respondents have a neutral opinion of their consultation, while 62% said they were satisfied or very satisfied.

Figure 5. Sensitivity of diagnosis (%)



1.6. Information given at diagnosis

At time of diagnosis, one half of the respondents report that they were given information verbally about the symptoms and causes of Parkinson's (50%) while almost 60% were told about medication. Only 9% of respondents were given information about clinical trials either verbally, with hand-outs or through signposting to online information; no respondents said they did not want any information on this subject. Two thirds of respondents (65%) state that they were given either written or verbal information about how to maintain physical wellbeing (e.g. healthy eating or exercise) while over one third (36%) were given advice on maintaining mental wellbeing (Table 5).

Table 5. Information given (%)⁵

TOPIC AREA	Leaflet/ hand-outs/ signposting to online information (%)	Explained verbally (%)	Both hand-outs and verbal information (%)	I did not want any information (%)	No information was provided (%)
Symptoms, diagnosis and causes of Parkinson's	10	50	27	1	10
Medication	8	59	23	1	5
Surgical treatments	1	9	4	2	67
Non-drug treatments	3	39	10	0	35
Maintaining physical wellbeing	5	44	16	0	28
Maintaining emotional wellbeing	4	21	11	1	49
Financial help available	4	13	5	2	61
Support organisations (e.g. patient associations)	9	24	12	1	48
Support for carers	1	5	1	0	72
Where to find more information on Parkinson's	12	25	12	1	37
Taking part in clinical trials	1	6	2	0	72

⁵ Respondents were also able to answer no information was provided or cannot remember.

Amongst respondents who received information, nearly three quarters of them (71%) found the information they were given either very or quite helpful. In contrast, 23% found the information either not very helpful or not helpful.

In relation to the question enquiring whether or not respondents feel as if they had enough time to ask questions and discuss their concerns, nearly half of respondent (47%) feel that they were given enough time compared to the one quarter of respondents (24%) who felt unable to ask questions at that time. A further 8% of respondents stated that they would have liked further time to ask questions while 6% responded that they did not want to ask questions at that time (Table 6).

Table 6. Time to ask questions and discuss concerns – Question responses (%)

RESPONSES	Response (%)
Yes, I was given enough time	47
Yes, but I would have liked more time	8
No, I was not given any time	13
I did not want to ask questions at that time	6
I did not feel able to ask questions or discuss concerns at that time	24
Cannot remember	2

1.7. Link between quality of life, satisfaction, and availability of information

Removing respondents who indicated they did not want information and those who could not remember, a bivariate correlation was conducted to explore the relationship between availability of information and quality of life. To calculate an 'information availability total', responses were coded a '0' for 'no information provided' or '1' for leaflet, verbal, or both (i.e. 'some information provided'). These numbers were then totalled across all the categories respondents were asked to consider (i.e. medication, support for carers), with higher numbers equating to a greater availability of information.

The correlation between the quality of life (QoL) index score (Mean = .69) and the information total (Mean = 4) is in a negative direction. This trend could be interpreted as either those with a Higher QoL also receive (accept) less information or, conversely, more information is received (accepted) by respondents who also report a lower QoL. However, the correlation did not reach a satisfactory level of statistical significance ($n = 61^6$, $r = -.22$, $p = .09$). Although the data displays a trend in a negative direction, the overall correlation between the two variables is not robustly demonstrated.

The relationship between information availability and satisfaction with care received was also explored. A positive relationship is observed ($n = 58$, $r = .42$, $p < .001$), suggesting higher levels of satisfaction with care are associated with receiving more information. Satisfaction with treatment is also explored. Again, a positive relationship emerges between availability of information and satisfaction with treatment ($n = 59$, $r = .52$, $p < .001$), suggesting higher levels of satisfaction with treatment are associated with receiving more information.

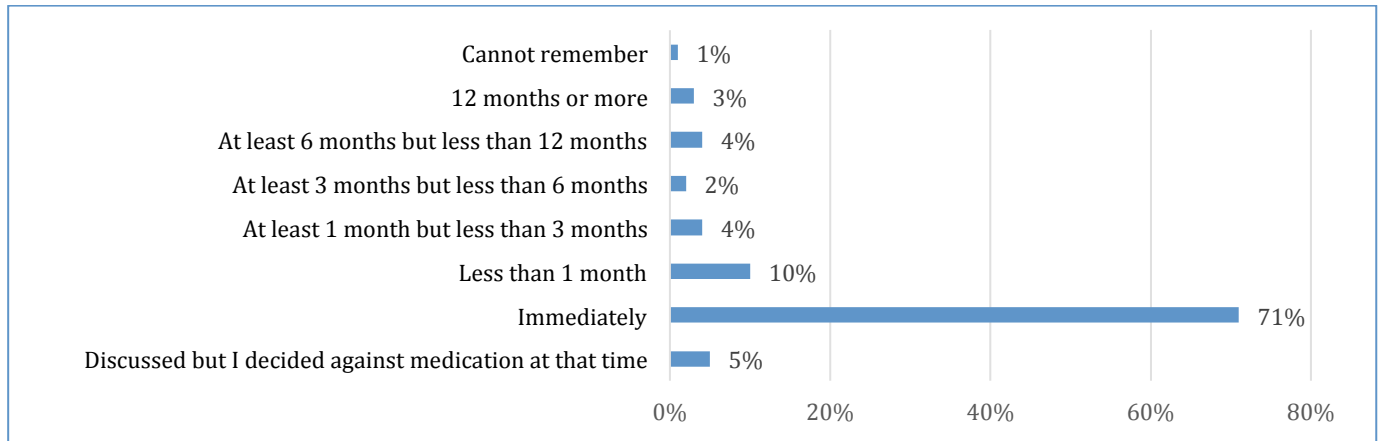
The relationship between satisfaction with the consultation where initial diagnosis was given and the amount of information provided was also explored via a correlation. Results suggest no relationship between the two variables ($n = 61$, $r = .27$, $p = .04$). The amount of information provided (both verbal and written) does not affect how satisfied PwPs are with the initial diagnosis and consultation.

⁶ The sample size number is lower due to respondents who indicated 'I do not want any information' and 'cannot remember' being excluded.

1.8. Treatment

Over 90% of respondents started medication or treatment within the first year after diagnosis, with around 70% of them starting immediately. In comparison, 5% of respondents decided not to take medication at the time of diagnosis (Figure 6).

Figure 6. Medication and treatment timings (%)

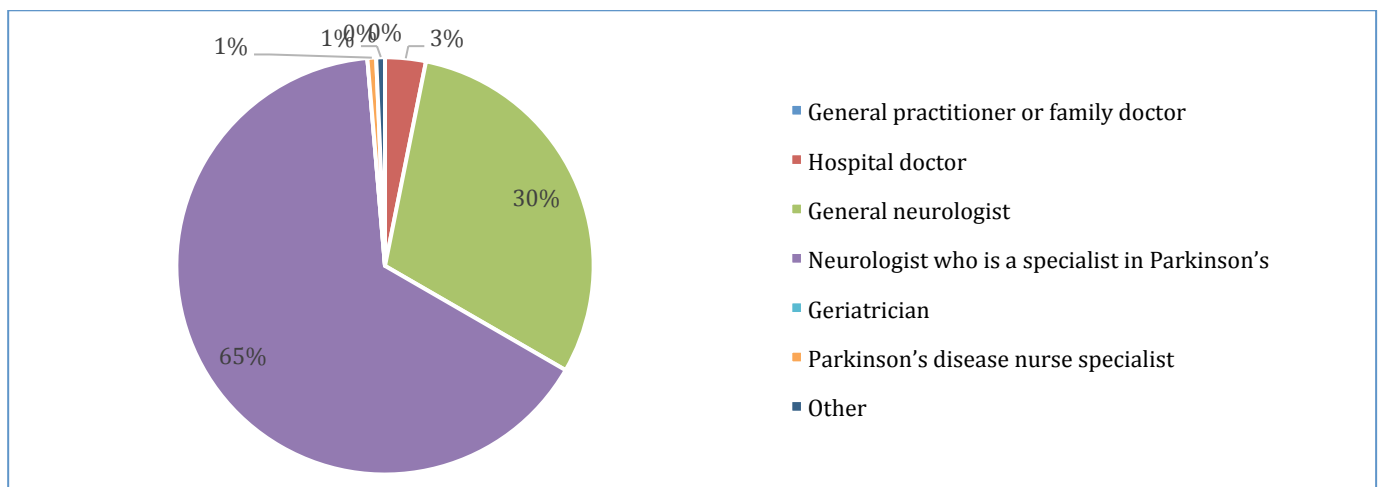


The most frequently taken medications are Sinemet (48% of respondents prescribed this drug), Ropinirole (48%), Rasagaline (40%) and Madopar (37%); these drugs are almost completely prescribed by a general neurologist or a specialist neurologist.

Other medications which are prescribed include⁷: Duodopa (10% of respondents); Entacapone (12%); Pramipexole (34%); Rotigotine (9%); and Stalevo (26%).

As with Sinemet, Ropinirole, Rasagaline and Madopar, for the majority of the time, these medications are almost exclusively prescribed by a general neurologist or a specialist neurologist. Only 3% of respondents mention a hospital doctor prescribing any medication and just 1% a nurse specialist. No respondents report receiving a prescription from a GP or geriatrician (Figure 7).

Figure 7. Healthcare professionals who prescribed the medication (%)



⁷ Presented in alphabetical order

The overwhelming majority of respondents state that they pay for their medication privately (81%). However, 50% also state that the state funds some of their costs while another 26% use insurance.⁸ . None of the respondents say that a Parkinson's organisation pay for the medication and 3% of all respondents do not know who pays for their medication.

The relationship between satisfaction with care and paying for treatment was explored. Responses about paying for treatment were assigned a group based on whether care was state funded or by private/insurance⁹. An independent samples t-test¹⁰ was conducted to investigate whether satisfaction with care differs according to whether respondents pay for the treatment or not. This analysis reveals no statistical difference. Mean levels of satisfaction did not differ between the groups. Respondents who pay for treatment (either through insurance or privately) report similar levels of satisfaction with care (n = 53, Msatisfaction = 14) to those respondents whose treatment is state funded (n = 10, Msatisfaction = 16) (t = .74, p = .46).¹¹

A second independent t-test was conducted to explore if access to health care professionals (as measured by frequency of medication review) differs according to how the health care is funded (i.e. state vs. private). The analysis reveals no significant difference between the two types of funding - whether respondents pay for treatment (n=38) or received state funded care (n= 8) makes no difference to how frequent medicines are reviewed (t= .57, p = .57).

Using length of time to gain access to treatment after diagnosis, as a proxy for availability, a further independent t-test was conducted to establish if length of time differs between state (n=11) versus private funding (n=54). Again, no differences in treatment waiting times are noted between the two groups- Mean waiting times for both are scores as a '3' (Less than 1 month).

Only 11 respondents report being refused care due to cost and seven due to where they lived. These samples are too small to conduct a valid analysis to explore links between Quality of life and refusal of treatment.

1.9. Satisfaction

Amongst respondents, levels of satisfaction with the care they receive is generally high. Over four fifths (82%) of respondents are satisfied or very satisfied by the treatment they receive from specialist neurologists while satisfaction with general neurologists is lower at 70%. Three quarters of respondents are satisfied with the treatment they receive from Parkinson's disease nurse specialists. The highest level of dissatisfaction is with hospital doctors (23%).

Amongst therapists, levels of satisfaction are also high for speech therapists (80%), and physiotherapists (90%). However, in comparison, only 38% are satisfied with the treatment they receive from occupational therapists although the number of respondents receiving occupational therapy treatment is small compared to the other types of therapy.

In relation to treatment and overall care, respondents are most satisfied with both their own and their family's involvement in the decisions made about their treatment (73% satisfied). However there is less satisfaction in relation to other care aspects, in particular in the way the various healthcare professionals work together to deliver the treatment and care (43% satisfied and 21% dissatisfied) (Figure 8).

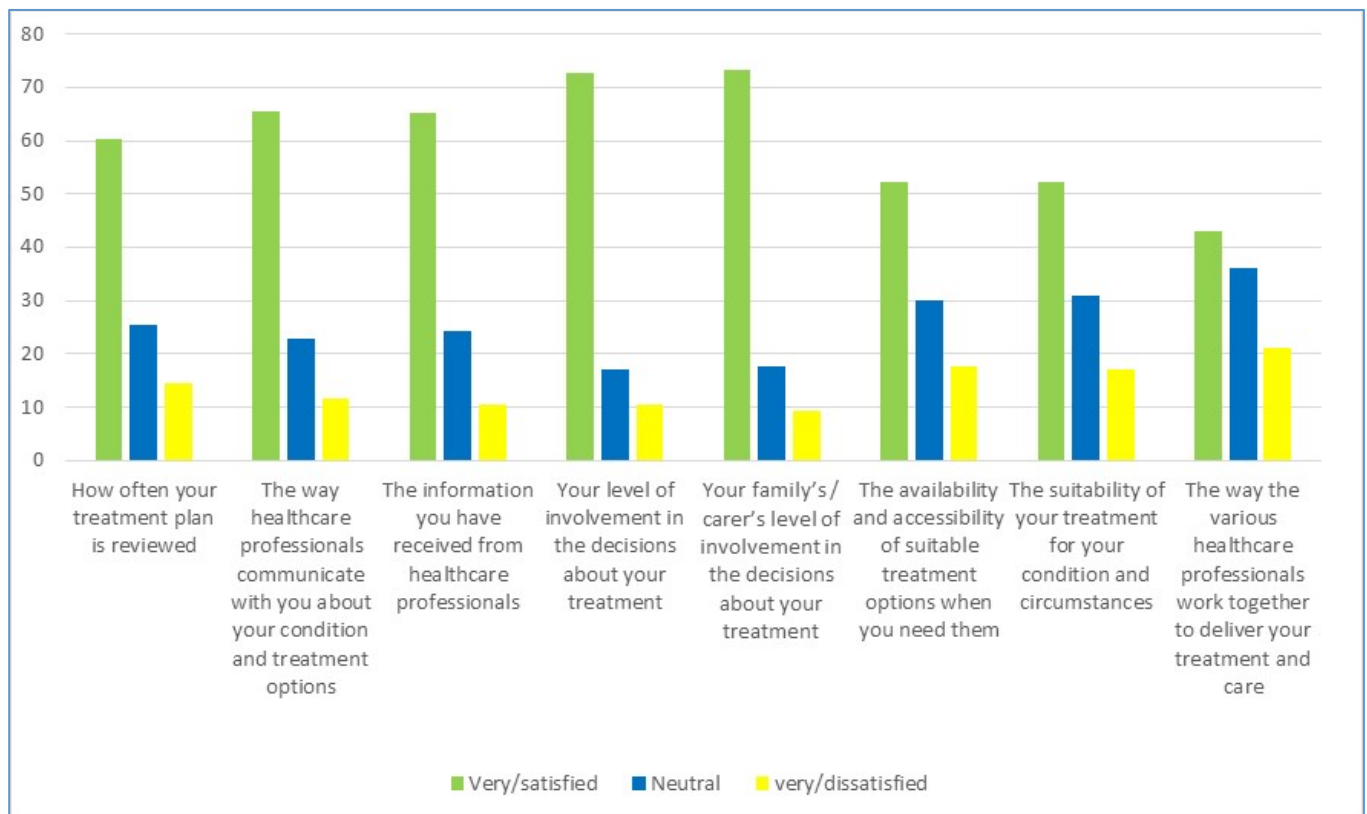
⁸ Respondents could select multiple options

⁹ Insurance and private were joined together to enable a direct comparison between paying vs. non-paying care. Respondents who indicated more than one source of funding were excluded from the analysis so as to ensure valid comparisons between the groups.

¹⁰ The independent-samples t-test (or independent t-test, for short) compares means values (averages) between two unrelated groups on the same continuous variable (i.e. scale scores).

¹¹ Greatly uneven groups are problematic when conducting t-tests; hence the current analysis is shown for information purposes and ideally should be replicated with more balanced groups in each condition.

Figure 8. Satisfaction with treatment and overall care (%)



The relationship between frequency of medication review and satisfaction with care was explored with a bivariate correlation. Responses provided for 'how often is your medication reviewed and by who' were coded so that most frequent reviews ('every 3 months') were assigned the highest number '4', through to '1' for 'once every 2 years'. The correlation reveals a significant large-sized relationship between satisfaction with care and frequency of review. Respondents who benefit from more frequent reviews also report higher levels of satisfaction with care ($n = 98$, $r = .63$, $p < .001$).¹²

Respondents also reported on the frequency of their medication reviews with different healthcare professionals (Table 7); because respondents may have medication reviews with different professionals, numbers in the table do not necessarily add up to 100%.

For the medication reviews, respondents state that a neurologist who is a specialist in Parkinson's reviews their medication either every six months (40%) or once a year (18%). A significant number of respondents also state that their medication is reviewed by a general neurologist either every 6 months (18%) or once a year (6%). Smaller numbers of respondents report having their medication reviewed by GPs or Parkinson's disease nurse specialists. 25% of respondents report that they have their medication reviewed at least every 3 months by a healthcare professional.

¹² Respondents who indicated 'do not know' and 'does not apply' were not included in this analysis

Table 7. Medication reviews (%)¹³

HEALTHCARE PROFESSIONALS	Every 3 months (%)	Every 6 months (%)	Once a year (%)	Once every 2 years or more (%)
General practitioner or family doctor	2	9	4	0
Hospital doctor	2	3	2	1
General neurologist	7	18	6	2
Neurologist who is a specialist in Parkinson's	8	40	18	2
Geriatrician	1	1	1	1
Parkinson's disease nurse specialist	5	8	4	0

A Bivariate correlation was conducted to explore the relationship between quality of life and frequency of medication review. Using the quality of life index and the frequency of review variable, a significant small negative relationship is demonstrated ($n = 99$, $r = -.23$, $p < .05$), suggesting respondents with higher QoL have their medication reviewed less often.

In addition, a second bivariate correlation was run to assess the relationship between quality of life and satisfaction with care. Using the quality of life index and the satisfaction for care index, a significant negative relationship emerges ($n = 127$, $r = -.31$, $p < .001$) suggesting quality of life is influenced by how satisfied respondents are with their care. The direction of the correlation indicates that as QoL scores increase, satisfaction with the care they receive decreases.

1.10. Advanced treatments

Only five of the respondents have received surgical treatment in the form of “*Deep Brain Stimulation*”. One of the respondents had the surgery within 5 years of diagnosis, while the others answered between 6 to 10 years after diagnosis. Respondents have a mixed view on the effectiveness of the surgery - one respondent is awaiting a repeat operation while another notes that despite an initial improvement in their condition, their Parkinson's is getting worse again. However another respondent is more positive:

“I am as free as a bird!”

The research team were not able to look at the correlations between receiving advanced treatments and QoL/satisfaction variables as there are too few respondents who have received advanced treatments.

1.11. Findings in relation to the national guidelines

National guidelines are due shortly on the diagnosis and treatment of Parkinson's disease in Denmark. In the meantime the most detailed Danish clinical guidance available are those produced by the Danish Neurological Society in 2011. Although, this guidance contains detailed advice on the diagnosis and treatment of the disease, it is underpinned by a number of key principles:

- Diagnosis should be carried out by a neurologist;
- The initial treatment should be prescribed by a neurologist and followed up and monitored in cooperation with the patient's GP;

¹³ Respondents could have reviews from more than one healthcare professional and were also able to state that they did not know or that it did not apply for them.

- Treatment should commence as early as possible after diagnosis;
- Treatment plans should be individually tailored for each patient;
- Treatment should be interdisciplinary in nature and involve a range of health professionals;
- For most patients, adjustments to medication should be gradual and cautious; and
- Care-givers should be involved in the treatment.

Just under 90% of respondents report having their diagnosis confirmed by a neurologist (89%) and although it was not possible to find out the recommended referral time to see a neurologist, the study shows that 53% and 41% of respondents saw, respectively, a general or specialist neurologist within two months of referral. This would suggest that for the majority of patients, the six-week target that is common in other European countries, is also being achieved in Denmark.

70% of respondents report beginning their treatment immediately on diagnosis, with this rising to over 90% by the end of one year. In line with the above recommendations, nearly all respondents had their initial medication prescribed by a neurologist (95%).

31% of respondents report having their medication reviewed at least annually by a general neurologist and 66% by a specialist neurologist. Therefore, in terms of follow-up, the survey strongly suggests that most respondents undergo an annual medication review with a neurologist. However, few respondents report having a medication review with their GP at least every year (15%).

The Danish guidelines emphasise the importance of adopting a multi-disciplinary approach to treatment but from the survey we cannot determine what access there is to healthcare professionals such as physiotherapists and occupational therapists. However, the survey does show that referrals across these services vary. For example, although around one half of respondents report being referred to physiotherapist (50%), only 5% have seen a speech and language therapist and 4% an occupational therapist.

In terms of the quality of the overall collaborative care achieved by patients, less than a half of respondents are satisfied with this aspect of their care (43%) and nearly a quarter are dissatisfied (21%). This is the lowest level of satisfaction and highest level of dissatisfaction amongst all the categories of treatment surveyed.

The guidelines also emphasise the importance of ensuring that each patient has an individually tailored package of treatments to meet their needs. However just over a half of respondents are satisfied that their treatment is suitable for their condition and circumstances (53%).

The Danish guidelines also emphasise the importance of involving care-givers in treatment plans and in this area, levels of satisfaction are much higher. Nearly three quarters of respondents state that they are satisfied with this aspect of their care (73%) and only 9% are dissatisfied.

APPENDIX II-B: SURVEY FINDINGS FOR FRANCE

1.1. Sample profile

In total 47 respondents completed the survey from France. 57% of respondents are male and the average age of respondents was 55 years when they were diagnosed with Parkinson's, with the youngest aged 32 and the oldest aged 76 years. Only 21% are currently employed. When asked to describe the area in which they live, 34% state rural, 57% town, with the remaining 9% living in cities.

1.2. Quality of life and disability scores

To explore quality of life, EuroQol's EQ-5D measure was utilised. This is a standardised instrument for the measuring of health status and requires respondents to answer five questions focusing on **mobility**, **self-care**, **usual activities**, **pain**, and **anxiety/depression**.

Regarding **mobility**, 24% report no problems walking, 71% report some problems while 4% of respondents indicate that they were confined to a bed¹⁴.

Moving on to **self-care**, 7% report they are unable to wash or dress themselves and 42% that they have some problems with washing or dressing. However, just over half of respondents- 51%- indicate no problems with self-care.

When asked about their current ability to perform **everyday activities** such as work and leisure, 66% of respondents experienced some problems performing these activities, while 27% indicate no problems at all. Those who are unable to perform any everyday activities were the smallest group, accounting for 7% of the sample.

When discussing current levels of **pain and discomfort**, the majority of the sample- 78%- indicate that they suffer from moderate pain, while 11% indicate having no pain or discomfort. Those who suffer from extreme pain also represent 11% of the sample.

The final question assessing current quality of life focuses on levels of **anxiety and depression**. Nearly a third of respondents indicate that they are not anxious or depressed (31%), while over a half (53%) indicate moderate levels of anxiety or depression. 15% of the sample report feelings of extreme anxiety or depression.

Compared with their general health over the last 12 months, only 15% of respondents state that their health is *better*. The majority of respondents feel that their health is *much the same* (53%) while 31% of respondents feel that their health is *worse*.

When asked to rate which statement best describes how they feel about their independence, none of the respondents report to being bed bound. The most commonly recorded response is '*I am able to do all chores with some degree of slowness, difficulty and impairment, and am beginning to be aware of difficulty*' (38%) (Table 1).

¹⁴ Results based on the number of respondents answering Question 7. This result may not tally with the number stating they are bedridden in Question 13, the results of which are shown in Table 1.

Table 1. Self-reported disability score (%)

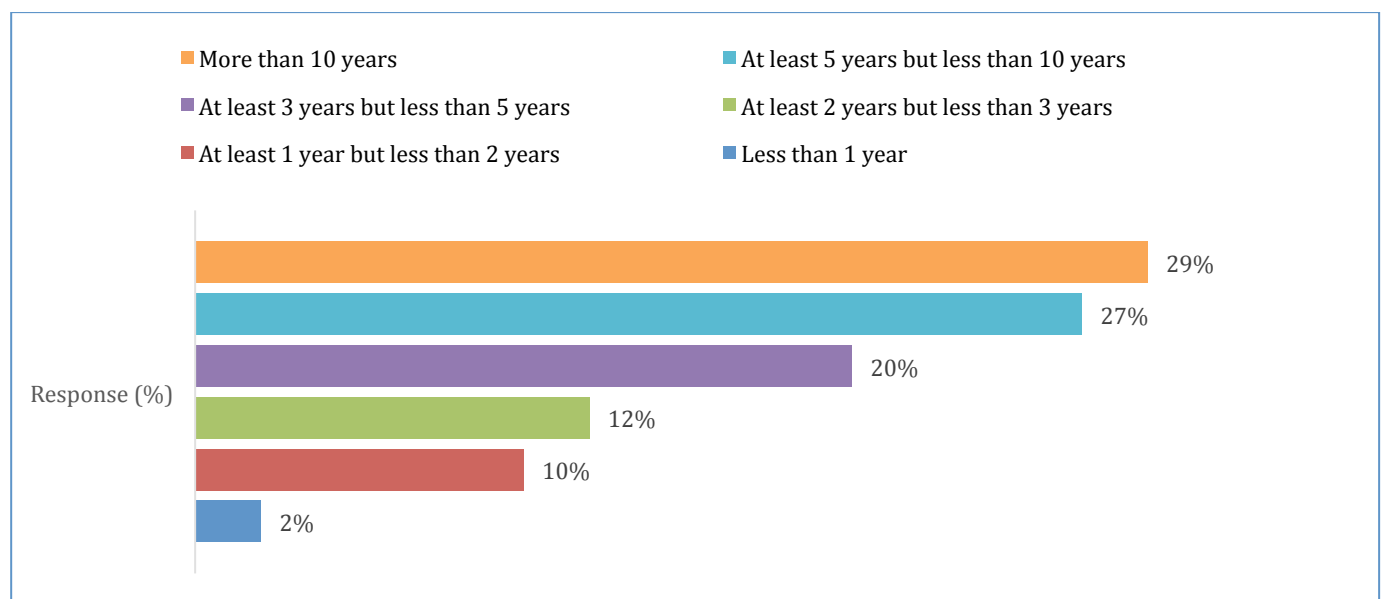
STATEMENTS	Response (%)
I am able to do all chores without slowness, difficulty or impairment	9
I am able to do all chores with some degree of slowness, difficulty and impairment, and am beginning to be aware of difficulty	38
Chores take twice as long and I am conscious of difficulty and slowness	20
Chores take three to four times as long and I spend a large part of the day doing these	4
I can do most chores, but exceedingly slowly and requiring a lot of effort	11
I need help with half the chores and have difficulty with everything	4
I can assist with all the chores, but am only able to do a few on my own	2
I can manage a few chores with some effort, but need a lot of help	4
I do nothing on my own, but can be a slight help with some chores	4
I am totally dependent and helpless	2
I am bedridden	0

1.3. Receiving a diagnosis of Parkinson's disease

1970 was the earliest date that a respondent had been diagnosed with Parkinson's and 2014 the latest (8% had been diagnosed in 2014; the median date of diagnosis was 2006). 96% of respondents had been diagnosed with Parkinson's in France, although two had been diagnosed in Italy.

For 44% of respondents, it has been less than 5 years since diagnosis. 29% of respondents were diagnosed over 10 years ago (Figure 1).

Figure 1. Length of time since diagnosis (%)



The symptoms most commonly noticed before diagnosis included changes in the way you move (including the way you walk, dragging a leg, not swinging your arm, etc.), fatigue, muscle cramps and slowness of movement. People with these symptoms were more likely to seek help within a year. However with other symptoms, such as depression and sleep problems, these symptoms could often continue for up to five years before help was sought (Table 2).

Table 2. Reported symptoms, and duration of these symptoms before seeking medical help (%)

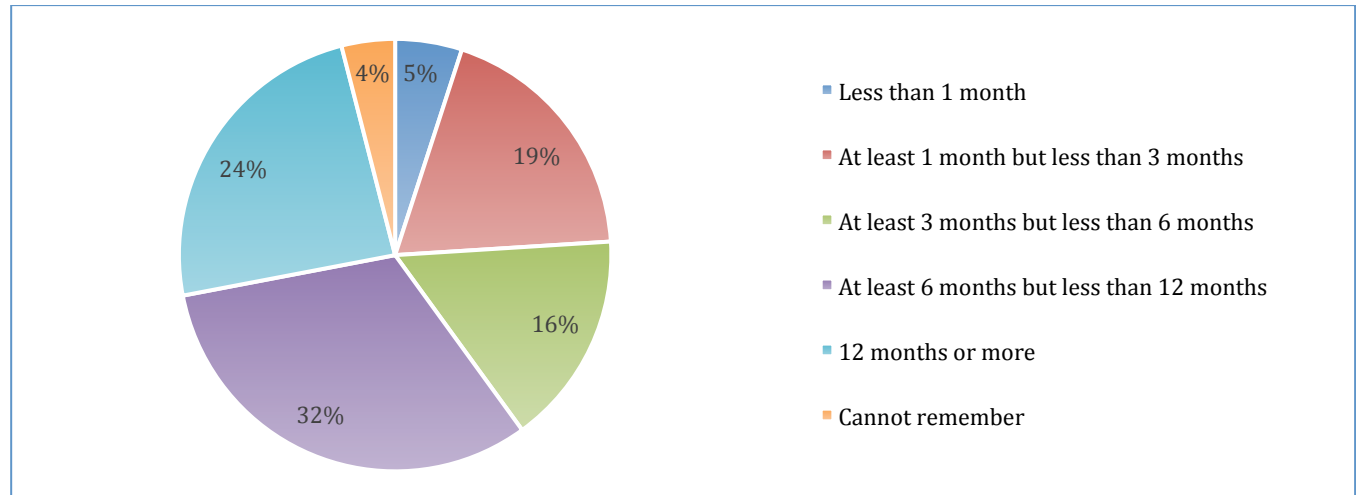
SYMPTOMS/PERCENTAGE OF RESPONDENTS¹⁵	Less than 1 year	1 to 2 years	3 to 4 years	5 years or more	Total percentage of respondents experiencing symptom
Anxiety	8	27	3	14	52
Apathy	8	30	3	5	46
Bladder and bowel problems	8	35	8	11	62
Changes in the way you move (incl. the way you walk, dragging a leg, not swinging your arm, etc.)	32	43	8	3	86
Depression	11	19	5	16	51
Difficulty eating and/or swallowing	11	19	0	3	33
Eye problems	14	19	3	5	41
Falls (balance problems)	16	22	5	5	48
Fatigue	16	35	16	11	78
Freezing	8	24	5	0	37
Loss of smell or taste	11	27	5	5	48
Low blood pressure or dizziness	8	19	11	0	38
Muscle cramps	14	32	16	11	73
Pain	11	27	19	11	68
Rigidity (stiffness)	22	32	5	5	64
Skin and/or sweating problems	16	14	5	11	46
Sleep problems	11	19	27	14	71
Slowness of movement	24	38	3	5	70
Speech and communication problems (incl. small handwriting and reduced facial movements)	24	41	11	5	81
Stress	14	27	8	11	60
Thinking or memory problems	16	22	5	3	46
Tremor (shaking)	22	24	5	5	56

Other symptoms added by the respondents included tendonitis and hyper salivation.

¹⁵ Respondents could select “do not apply”; and select multiple options

When asked how long it was before seeking medical help after first noticing their symptoms, one quarter of respondents waited 12 months or more (24%). Nearly one half of respondents sought help within 3 to 12 months (48%), while 5% sought immediate help (within 1 month) (Figure 2).

Figure 2. Timelines for seeking medical help (%)



1.4. During the first appointment

During the first appointment with a healthcare professional, just over one half of respondents underwent an observation of their symptoms (51%), while just over one third underwent a physical examination (35%) and one fifth (21%) discussed their general medical history. One-third of respondents were told that they might have Parkinson's (32%), although another 14% of respondents were told that something was wrong; however the healthcare professional was unsure of the exact diagnosis. One half of respondents (51%) were referred to another doctor or healthcare professional following their first appointment (Table 3).

Table 3. Events during the first appointment with a healthcare professional (%)

EVENTS	Response (%) ¹⁶
Discussed your general medical history	21
Carried out a physical examination	35
Observed your symptom(s)	51
Referred you to a specialist, or another doctor / healthcare professional	51
Said nothing was wrong	5
Said it was too early to tell if anything was wrong	8
Said something was wrong, but not sure what	14
Prescribed medication to relieve your symptom(s)	8
Explained that you may have Parkinson's	32
Explained that you may have another disease / condition	5

¹⁶ Respondents could select multiple options

A number of respondents detailed other events which had happened at the first appointment. These included:

- Being referred to a psychiatrist
- Told they might have Multiple Sclerosis
- Told they might have Depression

Respondents were asked, if they were referred to another healthcare professional, what the waiting times were. If a referral was made, this was mostly to a neurologist (either general or one specialised in Parkinson's disease). However a significant number of respondents were also referred to a physiotherapist, occupational therapist or speech and language therapist.

Most of the respondents saw a neurologist (either general or specialised) within three months of referral with a significant proportion of these appointments taking place within one month. (Table 4). A significant proportion of respondents also gained access to a therapist within two months of referral.

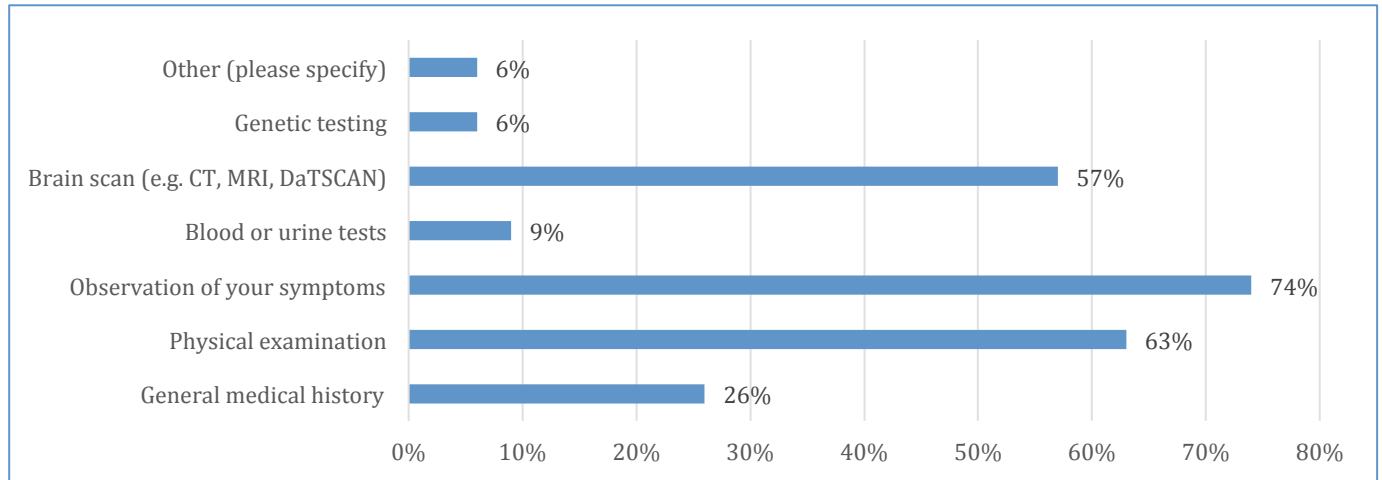
Table 4. Waiting times to see professionals from referral (%)¹⁷

Healthcare professional	Within 1 month (%)	1-2 months (%)	2-3 months (%)	3-4 months (%)	4 months + (%)	% of respondents referred
General neurologist	26	20	23	6	3	77
Neurologist Specialist in Parkinson's	17	26	11	9	9	71
Geriatrician	6	11	3	0	0	20
Parkinson's disease nurse specialist	9	9	3	0	0	21
Physiotherapist	11	9	3	0	0	23
Occupational therapist	11	9	3	0	0	23
Speech and language therapist	11	9	6	0	6	32

To diagnose their Parkinson's Disease three quarters of respondents stated that they had their symptoms observed (74%) while just under two thirds underwent a physical examination (63%). 57% of respondents had a brain scan. 6% of respondents also mentioned that they also underwent other types of examinations and tests during diagnosis. This included one respondent undergoing an eye examination in connection with Wilson's Disease (Figure 3).

¹⁷ Respondents could select all that applied or state that they could not remember

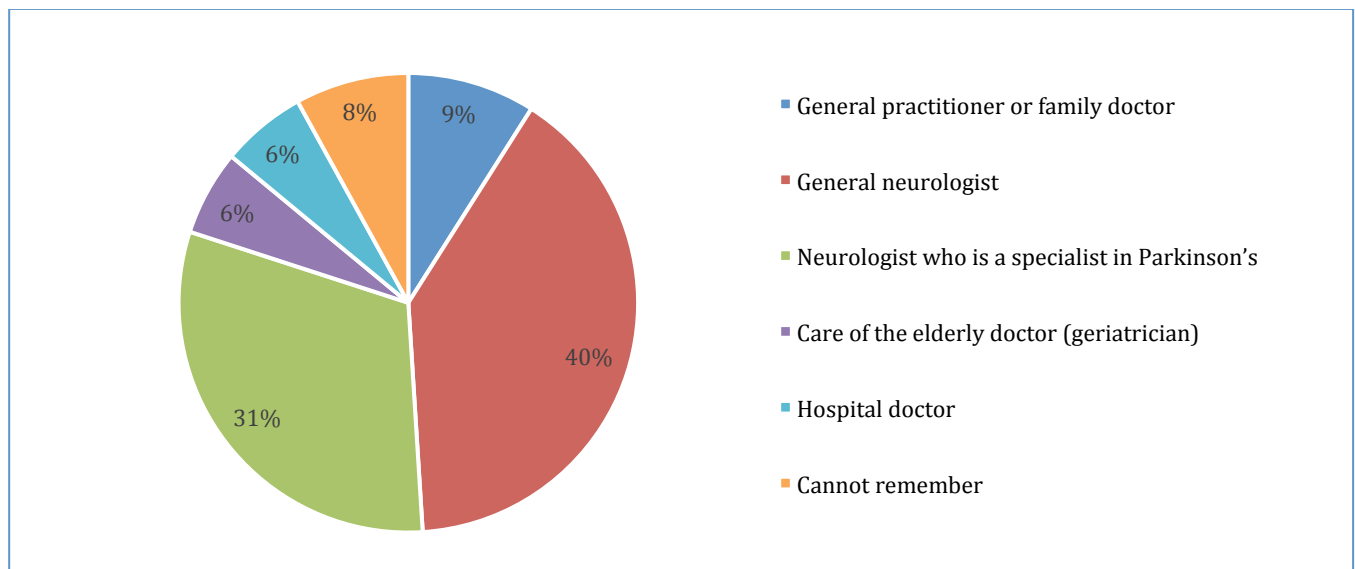
Figure 3. Examinations and tests carried out



1.5. Delivery of the diagnosis

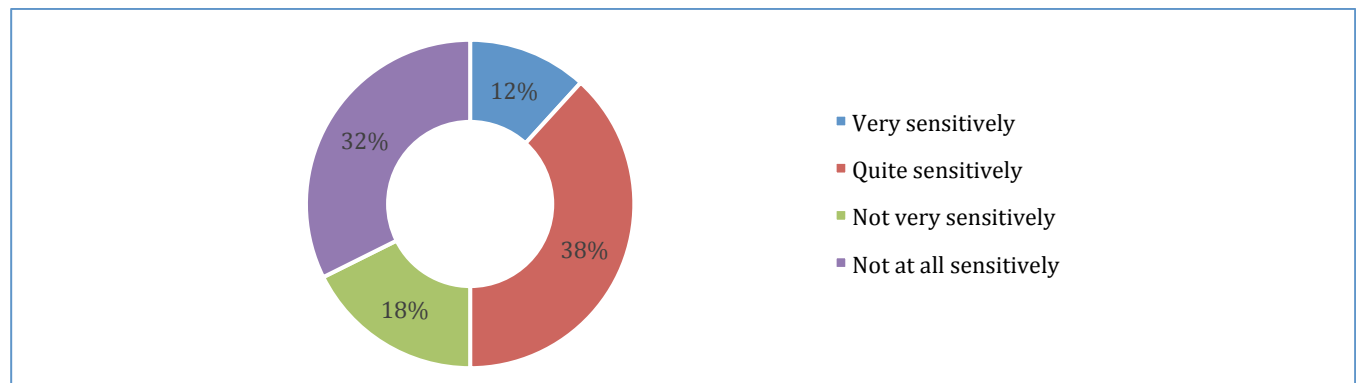
Just under one third of respondents received their diagnosis of Parkinson's from a neurologist specialised in the disease (31%), while a further 40% were diagnosed by a general neurologist. 6% of respondents received the diagnosis from a hospital doctor and another 6% from a geriatrician. 9% were given the diagnosis by their GP or family doctor (Figure 4).

Figure 4. Healthcare professional diagnosing Parkinson's (%)



Responses were polarised in relation to the sensitivity in which the diagnosis was given. (Figure 5). 50% of respondents feel that they were told either very sensitively or quite sensitively, while the other 50% believe that the diagnosis was not given sensitively. However, despite half of the respondents not feeling as if the diagnosis was given sensitively, only 25% feel dissatisfied or very dissatisfied with the consultation where the initial diagnosis was given. In comparison, 34% of respondents have a neutral opinion of their consultation, while 44% said they were satisfied or very satisfied.

Figure 5. Sensitivity of diagnosis (%)



1.6. Information given at diagnosis

At time of diagnosis, 41% of the respondents report that they were given information verbally about the symptoms and causes of Parkinson's while just under one half were told about medication (47%). 22% of respondents were given information about clinical trials either verbally, with hand-outs or through signposting to online information. No respondents report that they did not want any information on this subject. Less than one half of respondents (45%) state that they were given either written or verbal information about how to maintain physical wellbeing (e.g. healthy eating or exercise) while 40% were given advice on maintaining mental wellbeing. (Table 5).

Table 5. Information given (%)¹⁸

TOPIC AREA	Leaflet/ handouts/ signposting to online information (%)	Explained verbally (%)	Both handouts and verbal information (%)	I did not want any information (%)	No information was provided (%)
Symptoms, diagnosis and causes of Parkinson's	9	41	18	0	29
Medication	6	47	12	3	29
Surgical treatments	15	18	9	3	52
Non-drug treatments	9	13	9	3	59
Maintaining physical wellbeing	12	24	9	0	48
Maintaining emotional wellbeing	9	25	6	3	53
Financial help available	13	6	6	3	66
Support organisations (e.g. patient associations)	15	15	6	0	61
Support for carers	13	20	3	0	60
Where to find more information on Parkinson's	15	15	3	0	58
Taking part in clinical trials	6	13	3	0	71

¹⁸ Respondents were also able to answer no information was provided or cannot remember. 2-3% of respondents answered 'cannot remember' consistently

Amongst respondents who received information, 61% found the information they were given either very or quite helpful. In contrast, 39% found the information either not very helpful or not helpful.

In relation to the question enquiring whether or not respondents feel as if they had enough time to ask questions and discuss their concerns, less than one third of respondent (29%) feel that they were given enough time compared to over one third (35%) who were not given time to ask questions. A further 18% felt unable to ask questions at that time while 6% did not want to ask questions at that time (Table 6).

Table 6. Time to ask questions and discuss concerns – Question responses (%)

RESPONSES	Response (%)
Yes, I was given enough time	29
Yes, but I would have liked more time	12
No, I was not given any time	35
I did not want to ask questions at that time	6
I did not feel able to ask questions or discuss concerns at that time	18
Cannot remember	0

1.7. Link between quality of life, satisfaction, and availability of information

Removing respondents who indicated they did not want information and those who could not remember, a bivariate correlation was conducted to explore the relationship between availability of information and quality of life. To calculate an 'information availability total', responses were coded a '0' for 'no information provided' or '1' for leaflet, verbal, or both (i.e. 'some information provided'). These numbers were then totalled across all the categories respondents were asked to consider (i.e. medication, support for carers), with higher numbers equating to a greater availability of information.

The correlation between the quality of life (QoL) index score (Mean = .52) and the information total (Mean = 4) is in a negative direction. This trend could be interpreted as either those with a Higher QoL also receive (accept) less information or, conversely, more information is received (accepted) by respondents who also report a lower QoL. However, the correlation did not reach a satisfactory level of statistical significance ($n = 26^{19}$, $r = -.25$, $p = .23$).

The relationship between information availability and satisfaction with care received was also explored. A positive relationship is observed ($n = 24$, $r = .55$, $p < .01$), suggesting higher levels of satisfaction with care are associated with receiving more information. Satisfaction with treatment was also explored. No relationship emerges between availability of information and satisfaction with treatment ($n = 24$, $r = .16$, $p = .45$), suggesting levels of satisfaction with treatment are not associated with availability of information.

The relationship between satisfaction with consultation when initial diagnosis was given and the amount of information provided was also explored via a correlation. Results suggest a relationship between the two variables ($n = 26$, $r = .59$, $p < .01$). – the amount of information provided (both verbal and written) appears to affect how satisfied PwP are with the initial diagnosis and consultation. This indicates that the level of information provided is related to increased satisfaction with the initial diagnosis.

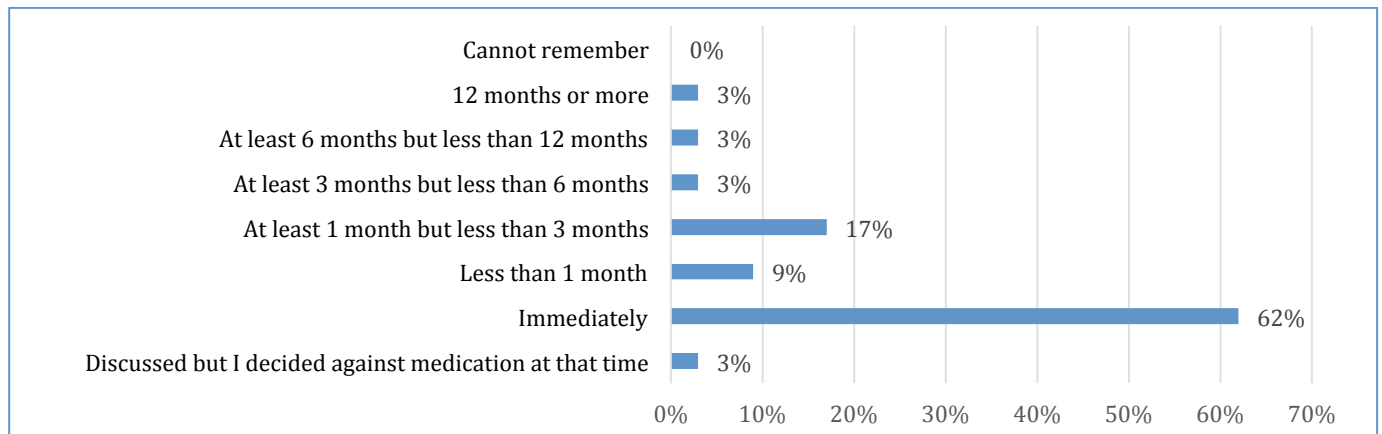
¹⁹ The sample size number is lower due to respondents who indicated 'I do not want any information' and 'cannot remember' being excluded.

It should be noted the four correlations discussed were all based on sample sizes that are statistically too small to produce a valid relationship; hence any conclusions drawn should be made tentatively.

1.8. Treatment

Nearly 95% of respondents started medication or treatment within the first year after diagnosis, with just under two thirds of them starting immediately (62%). In comparison, 3% of respondents decided not to take medication at the time of diagnosis (Figure 6).

Figure 6. Medication and treatment timings (%)

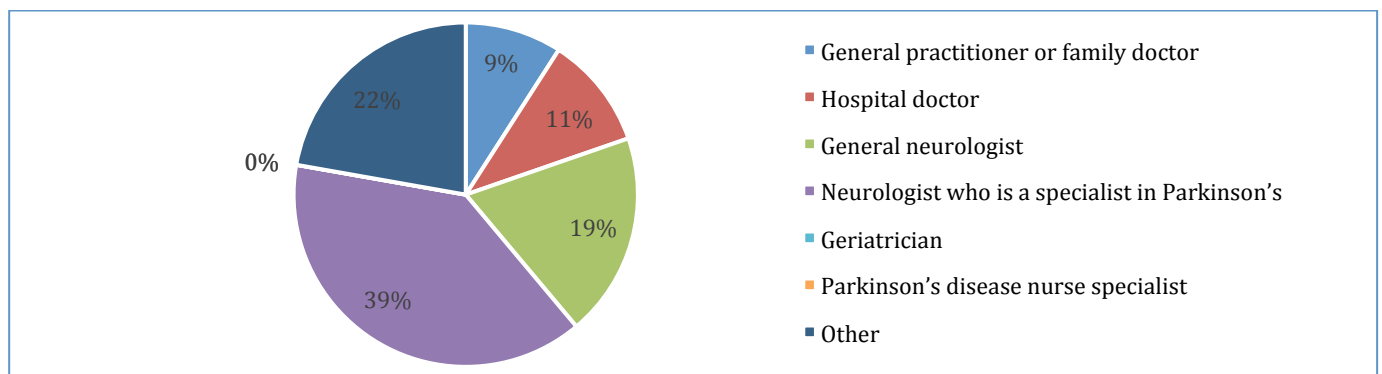


The most frequently taken medications are Madopar (68% of respondents prescribed this drug), Rasagaline (61%), Sinemet (48%) and Stalevo (42%); these drugs are predominantly prescribed by a general neurologist or a specialist neurologist.

Other medications which are prescribed include²⁰: Amantadine (30% of respondents); Duodopa (30%); Entacapone (27%); and Rotigotine (33%).

As with Madopar, Rasagaline, Sinemet and Stalevo, for the majority of the time, these medications are prescribed by a general neurologist or a specialist neurologist. However 11% of respondents mention a hospital doctor prescribing medication and 9% a GP. No respondents report receiving a prescription from a Parkinson's disease nurse specialist or geriatrician. 22% of respondents mention that they were prescribed medication from another source but further details of these sources was not provided (Figure 7).

Figure 7. Healthcare professionals who prescribed the medication (%)



²⁰ Presented in alphabetical order

Nearly one half of respondents state that the state funds their medication (46%) while over one third use insurance (35%). A further 9% of respondents mention that they or their families pay for medication privately (9%)²¹. 3% of the respondents say that a Parkinson's organisation pay for the medication and 6% do not know who pays for their medication.

The relationship between satisfaction with care and paying for treatment was explored. Responses about paying for treatment were assigned a group based on whether care was state funded or by private/insurance²². An independent samples t-test²³ was conducted to investigate whether satisfaction with care differs according to whether respondents pay for the treatment or not. This analysis reveals no statistical difference. Mean levels of satisfaction did not differ between the groups. Respondents who pay for treatment (either through insurance or privately) report similar levels of satisfaction with care ($n = 13$, $M_{\text{satisfaction}} = 19$) to those respondents whose treatment is state funded ($n = 15$, $M_{\text{satisfaction}} = 15$) ($t = 1.00$, $p = .32$).²⁴ There is a relatively large difference between the mean values for each group and it may be reasonable to expect that a significant difference would emerge; however the relatively small sample sizes in each reduce the power behind the analysis and hinder a robust testing of the differences.

A second independent t-test was conducted to explore if access to health care professionals (as measured by frequency of medication review) differs according to how the health care is funded (i.e. state vs. private). Respondents who receive state funded care ($n=14$, $M_{\text{review}} = 3$) report less frequent reviews of medication, compared to respondents who pay for treatment ($n=12$, $M_{\text{review}} = 7$); however, the comparison between the two groups reveals no significant difference according to the two types of funding ($t = 1.91$, $p = .07$).

Using length of time to gain access to treatment after diagnosis, as a proxy for availability, a further independent t-test was conducted to establish if length of time differs between state ($n=15$, $M_{\text{time}} = 3$) versus private funding ($n=14$, $M_{\text{review}} = 3$). Again, no differences in treatment waiting times are noted between the two groups ($t = 1.04$, $p = .31$).

Only 6 respondents reported being refused care due to cost and none due to where they lived. These sample are too small to conduct a valid analysis to explore links between Quality of life and refusal of treatment.

1.9. Satisfaction

Across nearly all healthcare professions, at least two thirds of respondents state that they are satisfied with the care they are receiving. The one exception is with general neurologists where only 56% of respondents are satisfied. The highest level of satisfaction is with occupational therapists (82%).

Very few respondents are actually dissatisfied with the care they are receiving, with the exception again, of general neurologists where 33% are dissatisfied. Within most other professional categories, those not satisfied tend to have a neutral, rather than negative, opinion of the care they are receiving.

The majority of respondents are satisfied with most aspects of their treatment and overall care. Respondents are most satisfied with how often their treatment plans are reviewed (83%), the information they receive (80%) and their involvement in the decisions made about treatment (80%). The highest level of dissatisfaction is recorded in the availability and accessibility of suitable treatment options where 14% of respondents state that they are

²¹ Respondents could select multiple options

²² Insurance and private were joined together to enable a direct comparison between paying vs. non-paying care. Respondents who indicated more than one source of funding were excluded from the analysis so as to ensure valid comparisons between the groups.

²³ The independent-samples t-test (or independent t-test, for short) compares means values (averages) between two unrelated groups on the same continuous variable (i.e., scale scores).

²⁴ Greatly uneven groups are problematic when conducting t-tests; hence the current analysis is shown for information purposes and ideally should be replicated with more balanced groups in each condition.

dissatisfied. No respondent states that they are dissatisfied with the suitability of their treatment for their condition and circumstances (Figure 8).

The relationship between frequency of medication review and satisfaction with care was explored with a bivariate correlation. Responses provided for 'how often is your medication reviewed and by who' were coded so that most frequent reviews ('every 3 months') were assigned the highest number '4', through to '1' for 'once every 2 years'. The correlation reveals a significant large-sized relationship between satisfaction with care and frequency of review. Respondents who benefit from more frequent reviews also report higher levels of satisfaction with care ($n = 28$, $r = .56$, $p < .01$).²⁵

Respondents also reported on the frequency of their medication reviews with different healthcare professionals (Table 7); because respondents may have medication reviews with different professionals, numbers in the table do not necessarily add up to 100%.

For the medication reviews, respondents state that a neurologist who is a specialist in Parkinson's reviews their medication either every six months (55%) or once a year (10%). A significant number of respondents also state that their medication is reviewed by a general neurologist either every 6 months (26%) or once a year (6%). A number of respondents also report having their medication reviewed by either their GP or a hospital doctor. Two thirds of respondents (66%) report that they have had their medication reviewed at least every 3 months by a healthcare professional, with GPs being the most likely to carry out this frequency of review.

Figure 8. Satisfaction with treatment and overall care (%)

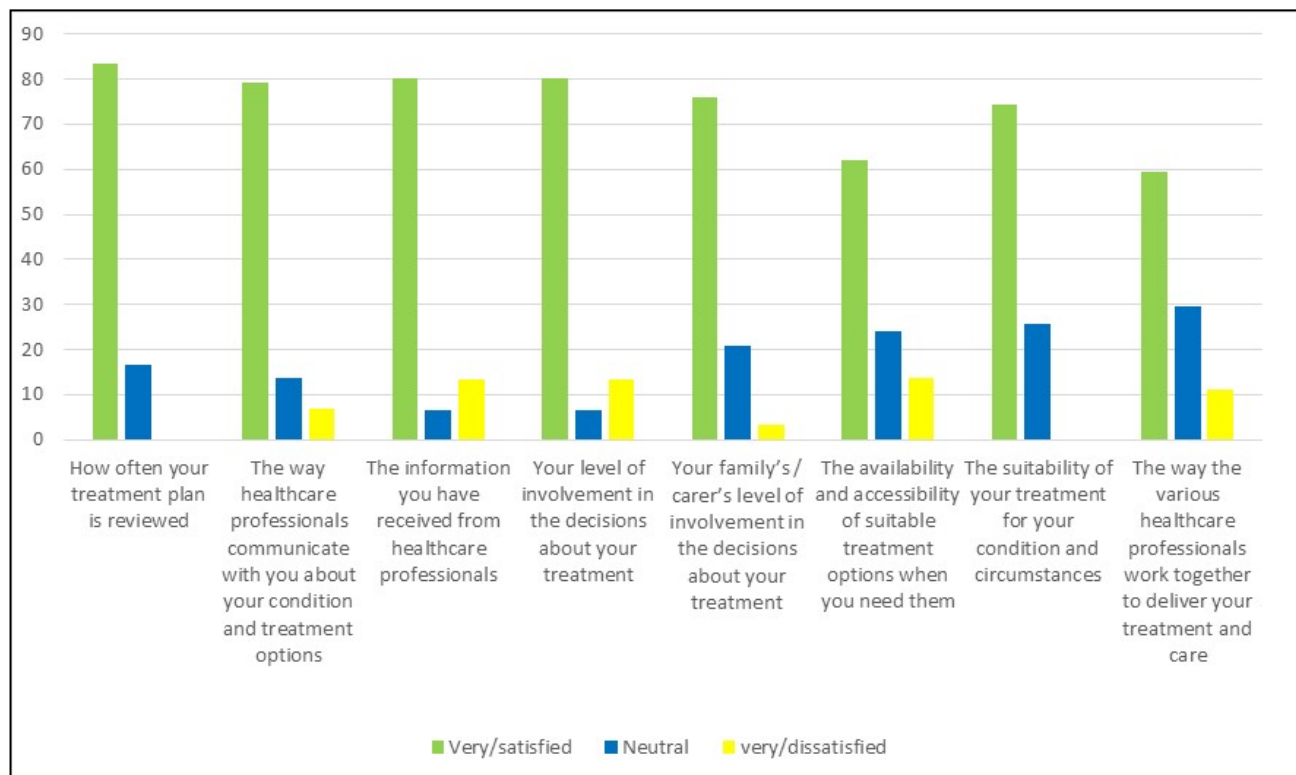


Table 7. Medication reviews (%)²⁶

²⁵ Respondents who indicated 'do not know' and 'does not apply' were not included in this analysis

²⁶ Respondents could have reviews from more than one healthcare professional and were also able to state that

HEALTHCARE PROFESSIONALS	Every 3 months (%)	Every 6 months (%)	Once a year (%)	Once every 2 years or more (%)
General practitioner or family doctor	29	10	10	0
Hospital doctor	6	10	13	0
General neurologist	6	26	6	0
Neurologist who is a specialist in Parkinson's	13	55	10	0
Geriatrician	6	6	6	0
Parkinson's disease nurse specialist	6	3	6	3

A Bivariate correlation was conducted to explore the relationship between quality of life and frequency of medication review. Using the quality of life index and the frequency of review variable, no relationship is demonstrated ($n = 28$, $r = -.23$, $p = .25$), suggesting that there is no relationship between QoL and frequency of medication review.

In addition, a second bivariate correlation was run to assess the relationship between quality of life and satisfaction with care. Using the quality of life index and the satisfaction for care index, again no significant relationship emerges ($n = 30$, $r = -.07$, $p = .68$) suggesting QoL is not influenced by how satisfied respondents are with their care.

1.10. Advanced treatments

Four out of 31 respondents have received surgical treatment in the form of “*Deep Brain Stimulation*”; however it is not possible to determine when respondents underwent this treatment. Two respondents are enthusiastic in their praise of the treatment:

“Beyond my expectations!”

“I was able to maintain my professional activities until the age of retirement.”

The research team were not able to look at the correlations between receiving advanced treatments and QoL/satisfaction variables as there are too few respondents who have received advanced treatments.

1.11. Findings in relation to the national guidelines

The official “*Guide parcours de soins maladie de Parkinson*” addresses the pathway care, the role, place and manner of different professionals, accompanied by a summary of critical points and a diagram of the patient journey. This guide, which was revised in 2014, states:

- People with suspected Parkinson's disease should be referred untreated to a neurologist for diagnosis and treatment (referral time not stated);
- GPs have an important role to play in providing patients with information on the disease and advising them on quality of life issues such as ensuring physical and social activities take place;
- A collaborative treatment programme is recommended with the GP liaising regularly with the neurologist and, if required, ensuring that patients have access to physiotherapists and speech and language therapists.
- GPs should monitor patients on a regular basis to check medication and check for symptoms such as depression, anxiety and sleep disorders. The guidelines recommend that GP consultations should occur at least every 3 months;
- Consultations with neurologists should take place at least every 6 months.

they did not know or that it did not apply for them.

- It is the GP's responsibility to intensify and coordinate the care of the patient in the final stage or palliative phase of the condition.

Although it was not possible to find out the recommended referral time to see a neurologist, the study shows that nearly 90% of respondents saw a neurologist within two months of referral (89%). This would suggest that for most patients, the six-week target that is common in other European countries, is also being achieved in France.

In contrast, only 29% of respondents report having their medication reviewed by their GP at the recommended interval of at least every 3 months although the results of the survey show that all respondents meet with their neurologist at least every 6 months.

The guidelines also provide detailed information on the recommended frequency and length of treatments provided by healthcare professionals such as speech and language therapists and psychologists. However, information on these aspects of treatment were not collected in this study.

Like the guidelines for many other European countries, the French guidelines stress the importance of collaborative care between the different healthcare specialists when treating patients. The results of this survey indicate that less than 60% of respondents are satisfied by this aspect of their treatment – this is the lowest level of satisfaction amongst all the categories of treatment surveyed.

APPENDIX II-C: SURVEY FINDINGS FOR GERMANY

1.1. Sample profile

In total 84 respondents completed the survey from Germany. Just over one-third (39%) of respondents are male and the average age of respondents was 47 years when they were diagnosed with Parkinson's, with the youngest aged 34 and oldest aged 69 years. One third of respondents state that they are currently employed. When asked to describe the area in which they live, there is a relatively even split between those living in rural areas (31%) and those living in towns (26%) or cities (43%).

1.2. Quality of life and disability scores

To explore quality of life EuroQol's EQ-5D measure was utilised. This is a standardised instrument for measuring health status and requires respondents to answer five questions focusing on **mobility**, **self-care**, **usual activities**, **pain**, and **anxiety/depression**.

Regarding **mobility**, 26% report no problems walking, while 74% report some problems. No respondents indicate that they are confined to a bed²⁷.

Moving on to **self-care**, only 1% report they are unable to wash or dress themselves and 31% that they have some problems with washing or dressing. The majority of respondents (68%) indicate no problems with self-care.

When asked about their current ability to perform **everyday activities** such as work and leisure, 68% of respondents experience some problems performing these activities, while 27% indicate no problems at all. Those who were unable to perform any everyday activities are the smallest group, accounting for 5% of the sample.

When discussing current levels of **pain and discomfort**, the majority of the sample- 68%- indicate that they suffer from moderate pain, while 20% indicate having no pain or discomfort. Those who suffer from extreme pain represent 12% of the sample.

The final question assessing current quality of life focuses on levels of **anxiety and depression**. Over half of respondents (54%) indicate moderate levels of anxiety or depression, while 42% report no feelings of anxiety or depression. The smallest proportion of the sample (4%), report feelings of extreme anxiety or depression.

Compared with their general health over the last 12 months, 40% of respondents feel that it has improved although 55% say it has worsened. Only 5% state that their health is *much the same*.

When asked to rate which statement best describes how they feel about their independence, none of the respondents report to being bed bound or totally dependent and helpless. The most commonly recorded response is '*I am able to do all chores with some degree of slowness, difficulty and impairment, and am beginning to be aware of difficulty*' (41%) (Table 1). Positively, 10% state that they are able to do all chores without slowness, difficulty or impairment.

²⁷ Results based on the number of respondents answering Question 7. This result may not tally with the number stating they are bedridden in Question 13, the results of which are shown in Table 1.

Table 1. Self-reported disability score (%)

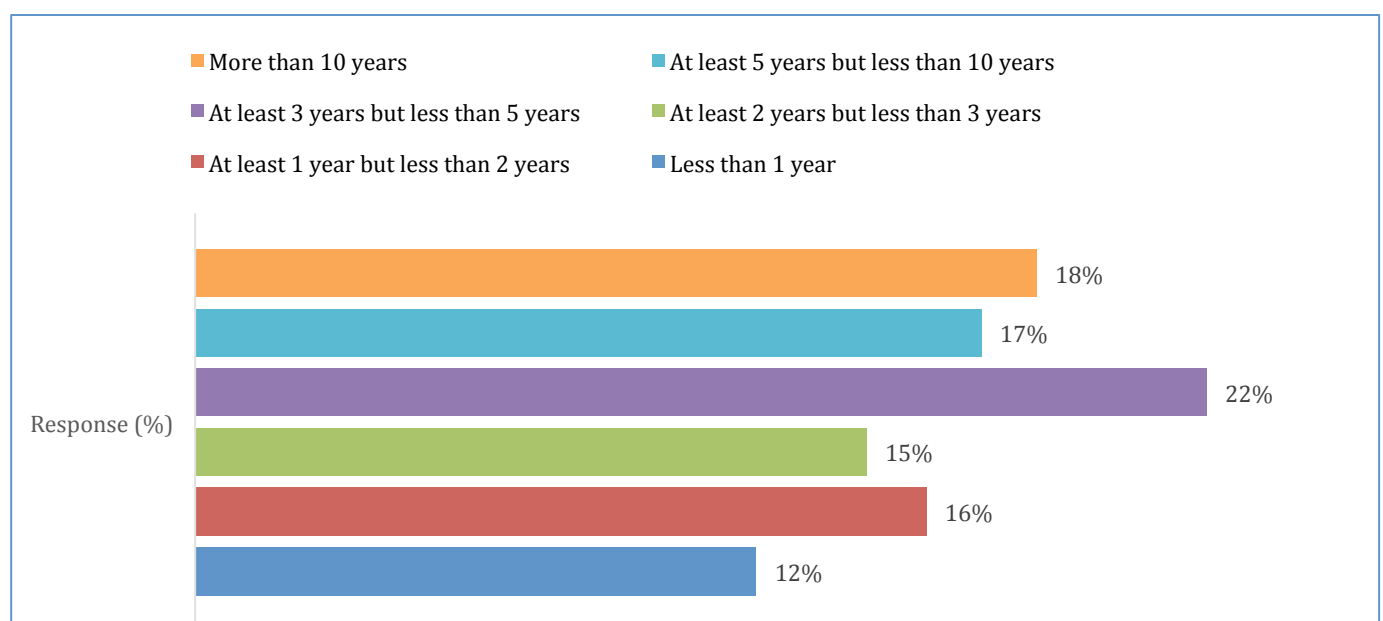
STATEMENTS	Response (%)
I am able to do all chores without slowness, difficulty or impairment	10
I am able to do all chores with some degree of slowness, difficulty and impairment, and am beginning to be aware of difficulty	41
Chores take twice as long and I am conscious of difficulty and slowness	19
Chores take three to four times as long and I spend a large part of the day doing these	5
I can do most chores, but exceedingly slowly and requiring a lot of effort	13
I need help with half the chores and have difficulty with everything	6
I can assist with all the chores, but am only able to do a few on my own	0
I can manage a few chores with some effort, but need a lot of help	4
I do nothing on my own, but can be a slight help with some chores	2
I am totally dependent and helpless	0
I am bedridden	0

1.3. Receiving a diagnosis of Parkinson's disease

1970 was the earliest date that a respondent had been diagnosed with Parkinson's and 2014 the latest (the median date of diagnosis was 2011). All of the respondents had been diagnosed with Parkinson's in Germany, with the exception of two who had been diagnosed in Switzerland or Austria.

For most of the respondents, it has been over three years since diagnosis (57%). 18% of respondents were diagnosed over 10 years ago (Figure 1).

Figure 1. Length of time since diagnosis (%)



The symptoms most commonly noticed before diagnosis included changes in the way you move (including the way you walk, dragging a leg, not swinging your arm, etc.) and slowness of movement. Interestingly people with these symptoms were more likely to seek help within two years. The main symptom where people sought help later was stress (Table 2).

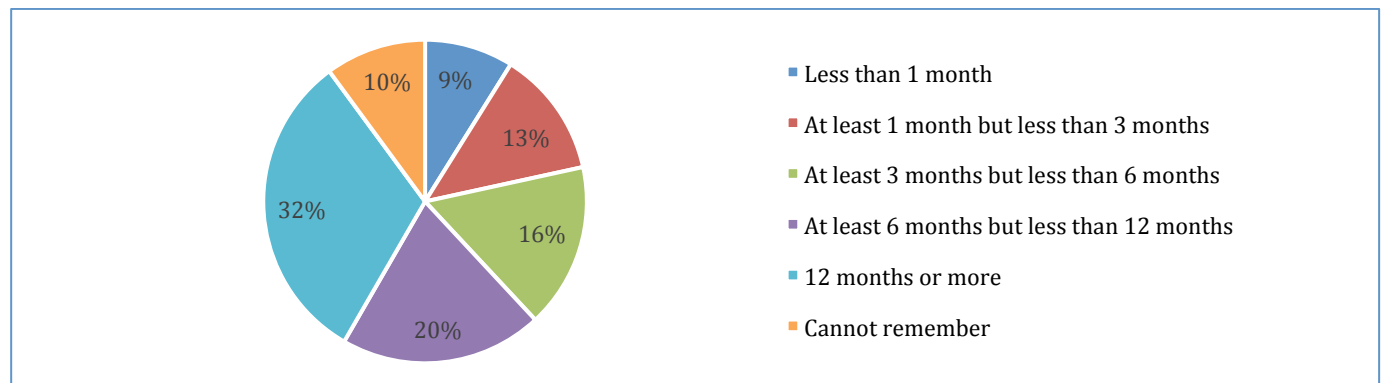
Table 2. Reported symptoms, and duration of these symptoms before seeking medical help (%)

SYMPTOMS/PERCENTAGE OF RESPONDENTS¹	Less than 1 year (%)	1 to 2 years (%)	3 to 4 years (%)	5 years or more (%)	Total number of respondents experiencing symptom
Anxiety	10	6	6	19	42
Apathy	8	9	5	9	30
Bladder and bowel problems	9	11	9	11	41
Changes in the way you move (incl. the way you walk, dragging a leg, not swinging your arm, etc.)	25	33	14	22	94
Depression	8	11	4	27	49
Difficulty eating and/or swallowing	9	10	1	8	28
Eye problems	13	13	9	8	42
Falls (balance problems)	15	13	5	8	41
Fatigue	14	23	5	24	66
Freezing	11	9	8	0	28
Loss of smell or taste	15	11	8	20	54
Low blood pressure or dizziness	15	11	5	15	47
Muscle cramps	15	23	13	13	63
Pain	14	16	10	20	61
Rigidity (stiffness)	18	18	10	11	57
Skin and/or sweating problems	11	8	10	25	54
Sleep problems	13	15	11	25	65
Slowness of movement	30	24	10	13	77
Speech and communication problems (incl. small handwriting and reduced facial movements)	18	29	10	11	68
Stress	14	11	11	30	67
Thinking or memory problems	18	11	5	11	46
Tremor (shaking)	28	19	6	13	42

Other symptoms added by the respondents included: Disorientation; shoulder pain; violent dreams/sleep problems; slowed digestion; tingling in limbs and sweats; back problems; and constipation.

When asked how long it was before seeking medical help after first noticing their symptoms, nearly one-third waited 12 months or more (31%) and only 9% sought help within one month. The majority sought help within three to 12 months (Figure 2). 10% could not remember.

Figure 2. Timelines for seeking medical help (%)



1.4. During the first appointment

For just over half of the respondents, during the first appointment with a healthcare professional, their medical history was discussed (51%), as well as a physical examination conducted (52%). 57% were referred to a specialist or another doctor. Worryingly, 18% were informed that nothing was wrong whilst for 15% they were told that they had another disease/condition. Over one third of respondents were told at their first appointment that they may have Parkinson's disease (34%) (Table 3).

Table 3. Events during the first appointment with a healthcare professional (%)

EVENTS	Response (%) ¹
Discussed your general medical history	51
Carried out a physical examination	52
Observed your symptom(s)	47
Referred you to a specialist, or another doctor / healthcare professional	57
Said nothing was wrong	18
Said it was too early to tell if anything was wrong	9
Said something was wrong, but not sure what	13
Prescribed medication to relieve your symptom(s)	22
Explained that you may have Parkinson's	34
Explained that you may have another disease / condition	15

A number of the respondents detailed over events which happened at the first appointment:

- "I asked if it could be Parkinson's, and they just smiled and then laughed at me!"
- "[Told that I] should exercise more."
- "Told 'You are a mystery to me!'"
- "I was asked/told: 1) 'You are still too young'; 2) 'Do you drink three cups of coffee in the morning?' and 3) 'Do you have problems with your wife?'"
- "I asked if it could be Parkinson's and the neurologist said 'No, I was far too young for that'. I was 32 years old. She prescribed stress and put me on beta-blockers which I did not take."
- "Asked if I was an alcoholic."

Respondents were asked, if they were referred to another healthcare professional, what the waiting times were. If a referral was made, this was mostly to a neurologist (general; 71%, specialist; 49%) or a physiotherapist (57%). Only 5% were referred to a geriatrician.

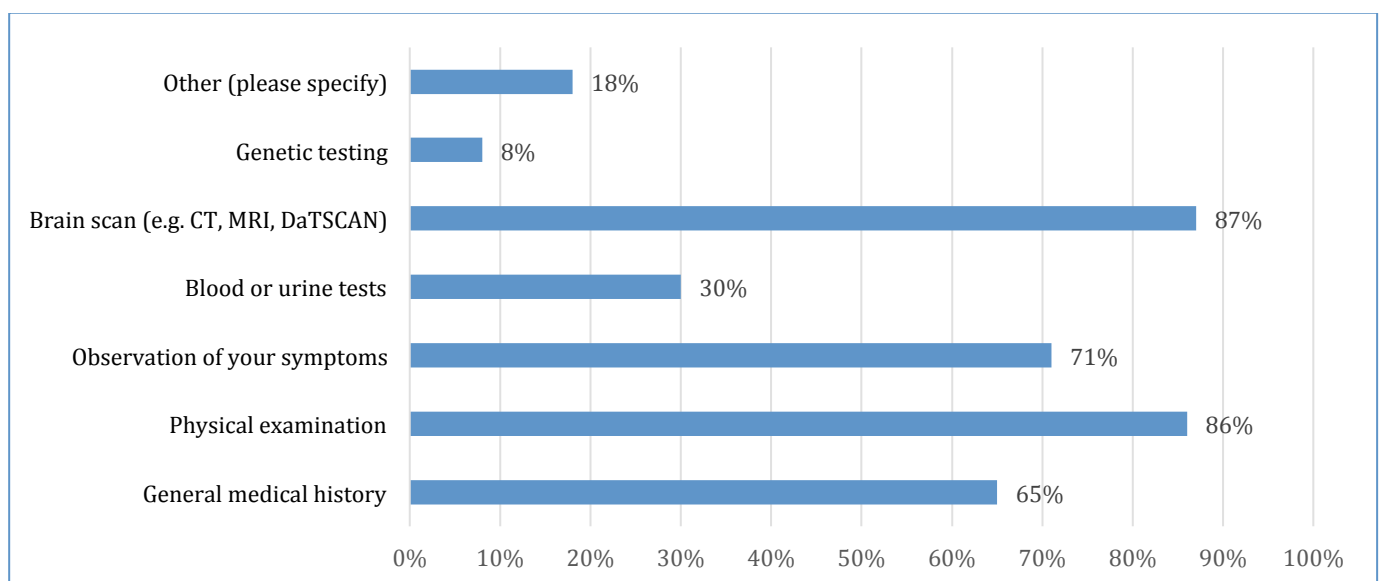
The waiting time were, on the whole, very consistent for all the healthcare professionals, with many respondents being seen within one month. The overwhelming majority of respondents who were referred to a general neurologist were seen within two months (79%) and half were seen within one month (50%). Over half of the respondents (60%) referred to a physiotherapist were seen within one month (Table 4).

Table 4. Waiting times to see professionals from referral (%)¹

Healthcare professional	Within 1 month (%)	1-2 months (%)	2-3 months (%)	3-4 months (%)	4 months +	% of respondents referred
General neurologist	37	21	8	3	3	71
Neurologist Specialist in Parkinson's	24	9	4	7	5	49
Geriatrician	3	1	1	0	0	5
Parkinson's disease nurse specialist	4	3	3	0	0	9
Physiotherapist	36	7	5	5	4	57
Occupational therapist	12	4	3	3	1	22
Speech and language therapist	9	3	1	1	0	14

The overwhelming majority of respondents had a brain scan to diagnose their Parkinson's (87%) along with a physical examination (86%) and an observation of their symptoms (71%). Two thirds (65%) state that their general medical history was taken. 18% of respondents also state that other tests were carried out – the most reported of these is an “L Dopa Test” (Figure 3).

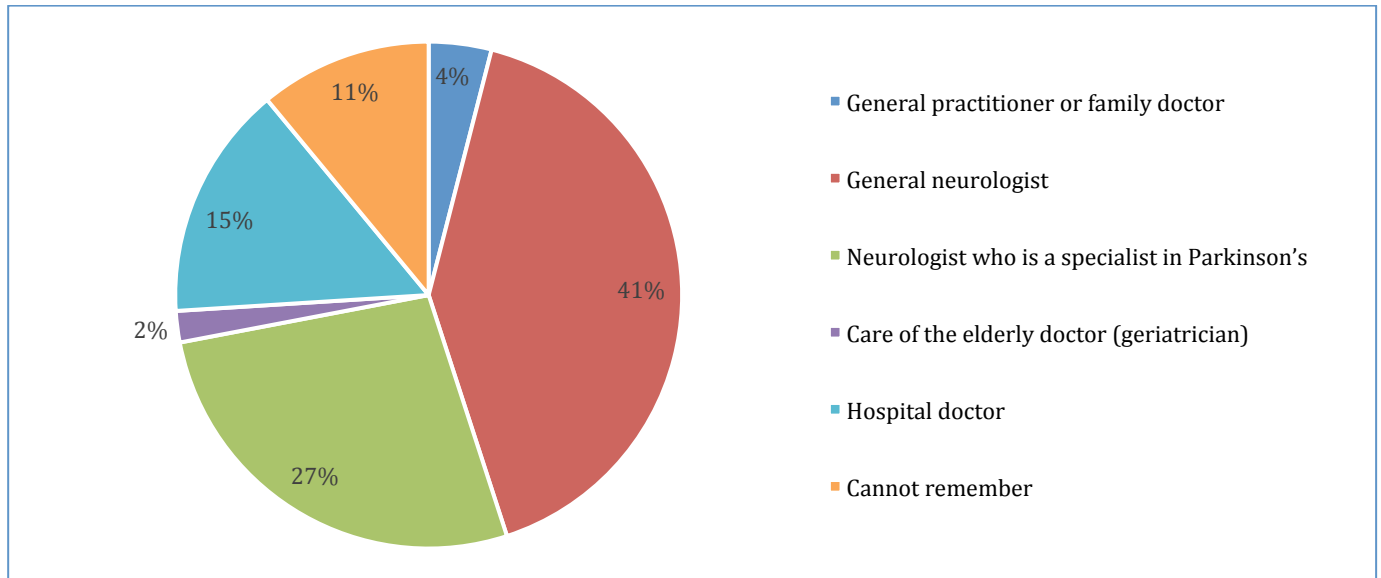
Figure 3. Examinations and tests carried out



1.5. Delivery of the diagnosis

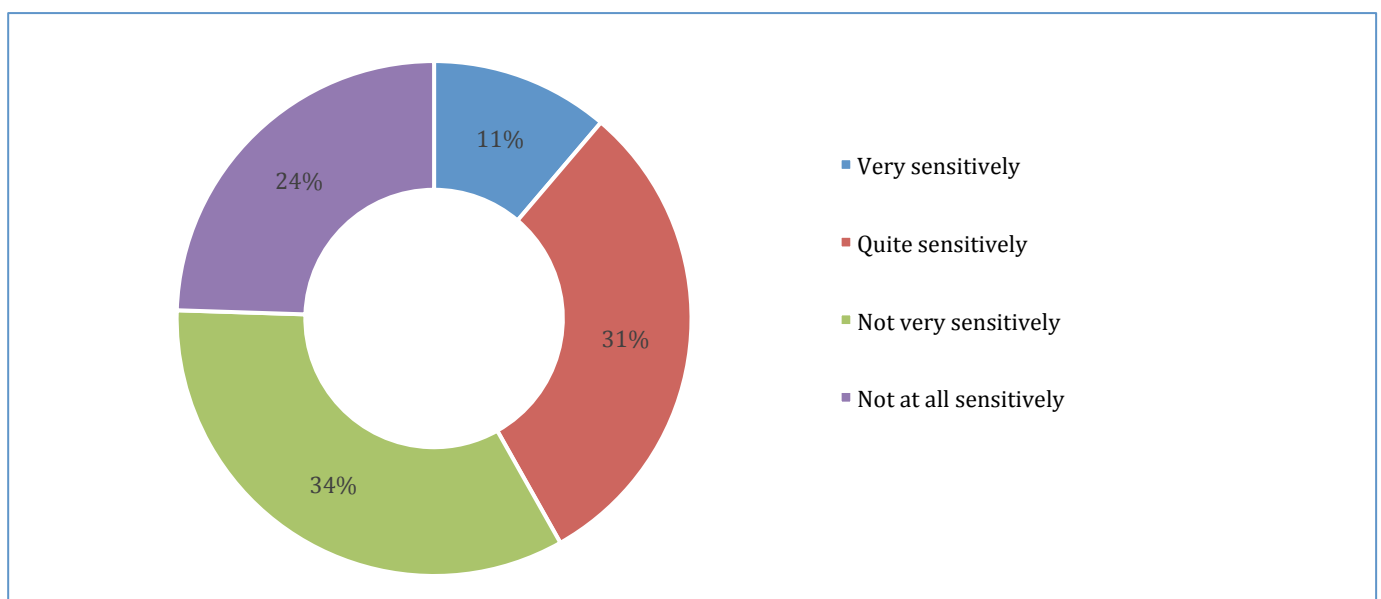
A general neurologist was the health professional who most frequently made the diagnosis of Parkinson's (41%), followed by a specialist neurologist (27%). 15% of respondents state that they were diagnosed by a hospital doctor (Figure 4).

Figure 4. Healthcare professional diagnosing Parkinson's (%)



More respondents feel that the diagnosis was not given sensitively. 42% of respondents feel that they were told either very sensitively or quite sensitively, while 58% feel the opposite (Figure 5). Despite over half of the respondents not feeling as if the diagnosis was given sensitively only 25% feel dissatisfied or very dissatisfied with the consultation where the initial diagnosis was given. In comparison, 37% have a neutral opinion of their consultation, while 38% say they are either very satisfied or satisfied.

Figure 5. Sensitivity of diagnosis (%)



1.6. Information given at diagnosis

At time of diagnosis, 32% of the respondents report that they were given information verbally about the symptoms and causes of Parkinson's while 38% were told about medication. 26% of the respondents were given information about clinical trials either verbally, with hand-outs or through signposting to online information 39% of respondents state that they were given either written or verbal information about how to maintain physical wellbeing and 29% were given advice on maintaining mental wellbeing (Table 5).

Table 5. Information given (%)¹

TOPIC AREA	Leaflet/ Hand-outs/ signposting to online information (%)	Explained verbally (%)	Both hand- outs and verbal information (%)	I did not want any information (%)	No Information was provided
Symptoms, diagnosis and causes of Parkinson's	22	32	12	1	28
Medication	17	38	11	3	28
Surgical treatments	4	14	7	3	61
Non-drug treatments	5	31	9	3	43
Maintaining physical wellbeing	9	22	8	4	49
Maintaining emotional wellbeing	8	14	7	1	57
Financial help available	3	4	0	1	75
Support organisations (e.g. patient associations)	10	11	4	3	58
Support for carers	4	3	0	4	67
Where to find more information on Parkinson's	14	10	4	3	56
Taking part in clinical trials	13	10	3	1	56

Nearly half of the respondents found the information they were given either very or quite helpful (43%). However, 28% found the information not very helpful or not helpful. The remaining respondents had either not been given any information (21%) or could not remember (8%).

In relation to the question enquiring whether or not respondents feel as if they had enough time to ask questions and discuss their concerns, around one third feel that they were given enough time (34%). In comparison 30% did not feel able to ask questions or discuss concerns at that time. Disappointingly, 18% say they were not given any time to ask questions (Table 6).

Table 6. Time to ask questions and discuss concerns – Question responses (%)

REPONSES	Response (%)
Yes, I was given enough time	34
Yes, but I would have liked more time	11
No, I was not given any time	18
I did not want to ask questions at that time	5
I did not feel able to ask questions or discuss concerns at that time	30
Cannot remember	3

1.7. Link between quality of life, satisfaction, and availability of information

A bivariate correlation was conducted to explore the relationship between availability of information and quality of life. To calculate an 'information availability total', responses were coded '1' for leaflet, verbal, or both (i.e. 'some information provided'). These numbers were then totalled across all the categories respondents were asked to consider (i.e. medication, support for carers), with higher numbers equating to a greater availability of information.

The correlation between the quality of life (QoL) index score (Mean = .60) and the information total (Mean = 3) is in a positive direction; however it does not reach a satisfactory level of statistical significance ($n = 84$, $r = .07$, $p = .56$). Therefore we are unable to conclude that QoL is affected by the availability of information.

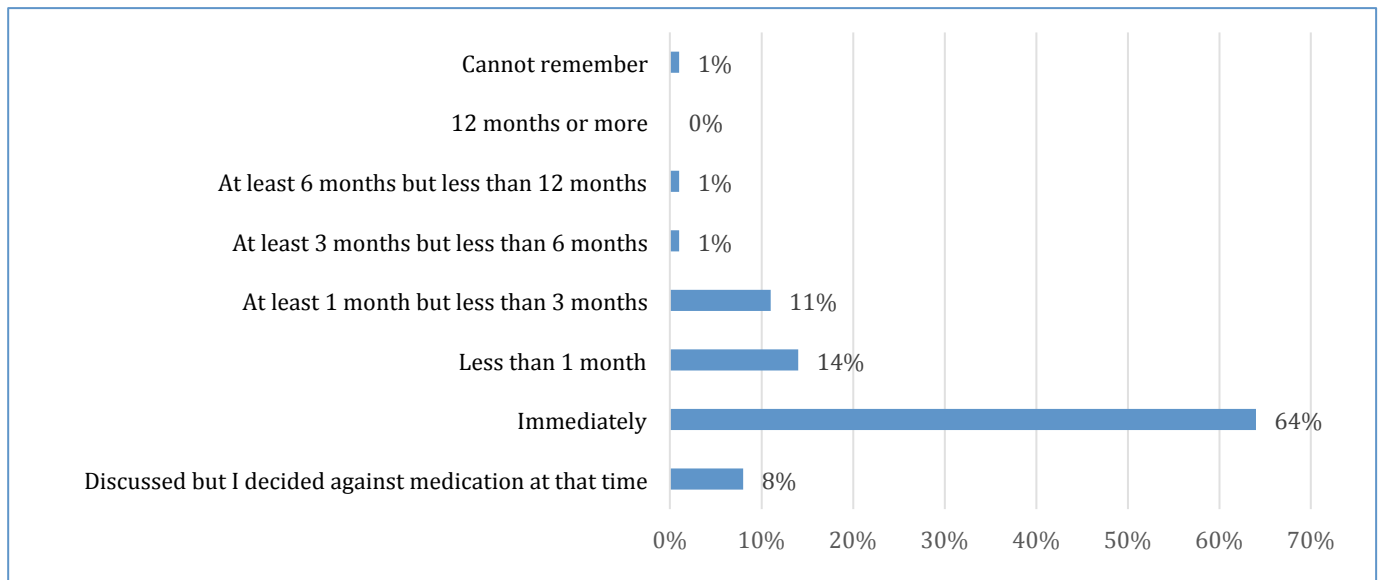
The relationship between information availability and satisfaction with care received was also explored via a correlation. No statistically significant relationship was observed ($n = 69$, $r = .10$, $p = .40$), suggesting levels of satisfaction with care are not associated with the availability of information. The relationship between satisfaction with treatment and information was also explored. Again, no relationship emerges between availability of information and satisfaction with treatment ($n = 67$, $r = .20$, $p = .11$), suggesting levels of satisfaction with treatment are not associated with availability of information.

Finally, the relationship between satisfaction with consultation where the initial diagnosis was given and the amount of information provided was also explored via a correlation. Replicating the previous correlations, results suggest no relationship between the two variables ($n = 76$, $r = .21$, $p = .07$). – the amount of information provided (both verbal and written) does not affect how satisfied PwP are with the initial diagnosis and consultation.

1.8. Treatment

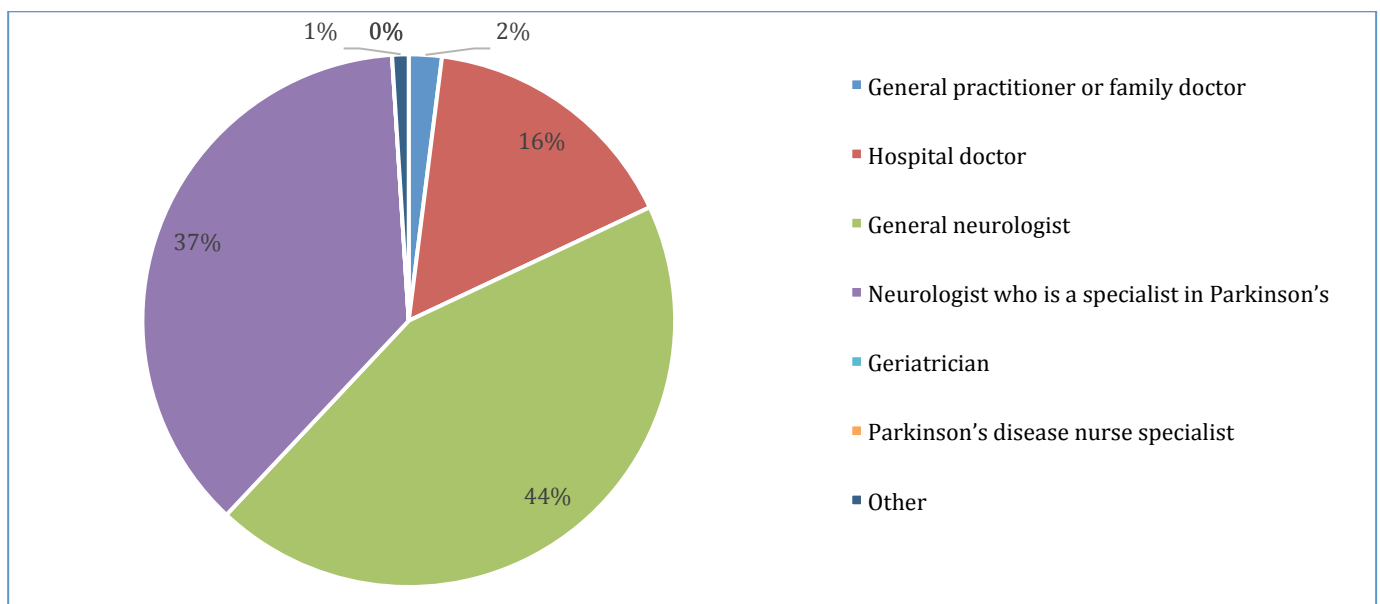
Around 90% of respondents started medication or treatment within the first year after diagnosis with the majority of them starting immediately (64%). In comparison, 8% of respondents decided not to take medication at the time of diagnosis (Figure 6).

Figure 6. Medication and treatment timings (%)



The medication most frequently prescribed is Rasagiline (58%), followed by Pramipexole (56%) and Madopar® (49%). All are predominantly prescribed by a general neurologist or a specialist neurologist, although 12% of the Pramipexole prescriptions are made by hospital doctors. The least prescribed medications are Tolcapone and Apomorphine; both only prescribed to one participant by a neurologist specialising in Parkinson's (Figure 7).

Figure 7. Healthcare professionals who prescribed the medication (%)



The majority of respondents report that the state currently pays for their medication (82%). None of the respondents state that they pay for medication privately (themselves/family) while 18% say that their insurance pays for their medication¹. None of the respondents report a Parkinson's organisation paying for their medication and only one of the respondents does not know who pays.

The relationship between satisfaction with care and paying for treatment was explored. Responses about paying for treatment were assigned a group based on whether care was state funded or by private/insurance¹. An independent samples t-test¹ was conducted to investigate whether satisfaction with care differed according to whether respondents paid for the treatment or not. This analysis reveals no statistical difference. Mean levels of satisfaction do not differ between the groups. Respondents who pay for treatment (either through insurance or privately) report similar levels of satisfaction with care ($n = 12$, $M_{\text{satisfaction}} = 19$) to those respondents whose treatment is state funded ($n = 57$, $M_{\text{satisfaction}} = 23$) ($t = 1.64$, $p = .11$).¹

A second independent t-test was conducted to explore if access to health care professionals (as measured by frequency of medication review) differs according to how the health care is funded (i.e. state vs. private). Respondents who receive state funded care ($n=58$, $M_{\text{review}} = 2$) report less frequent reviews of medication, compared to respondents who pay for treatment ($n=13$, $M_{\text{review}} = 4$); however, the comparison between the two groups reveals no significant difference according to the two types of funding ($t = 1.16$, $p = .25$).

Using length of time to gain access to treatment after diagnosis, as a proxy for availability, a further independent t-test was conducted to establish if length of time differed between state ($n=58$, $M_{\text{time}} = 2$) versus private funding ($n=13$, $M_{\text{time}} = 2$). Again, no differences in treatment waiting times are noted between the two groups ($t = .30$, $p = .76$).

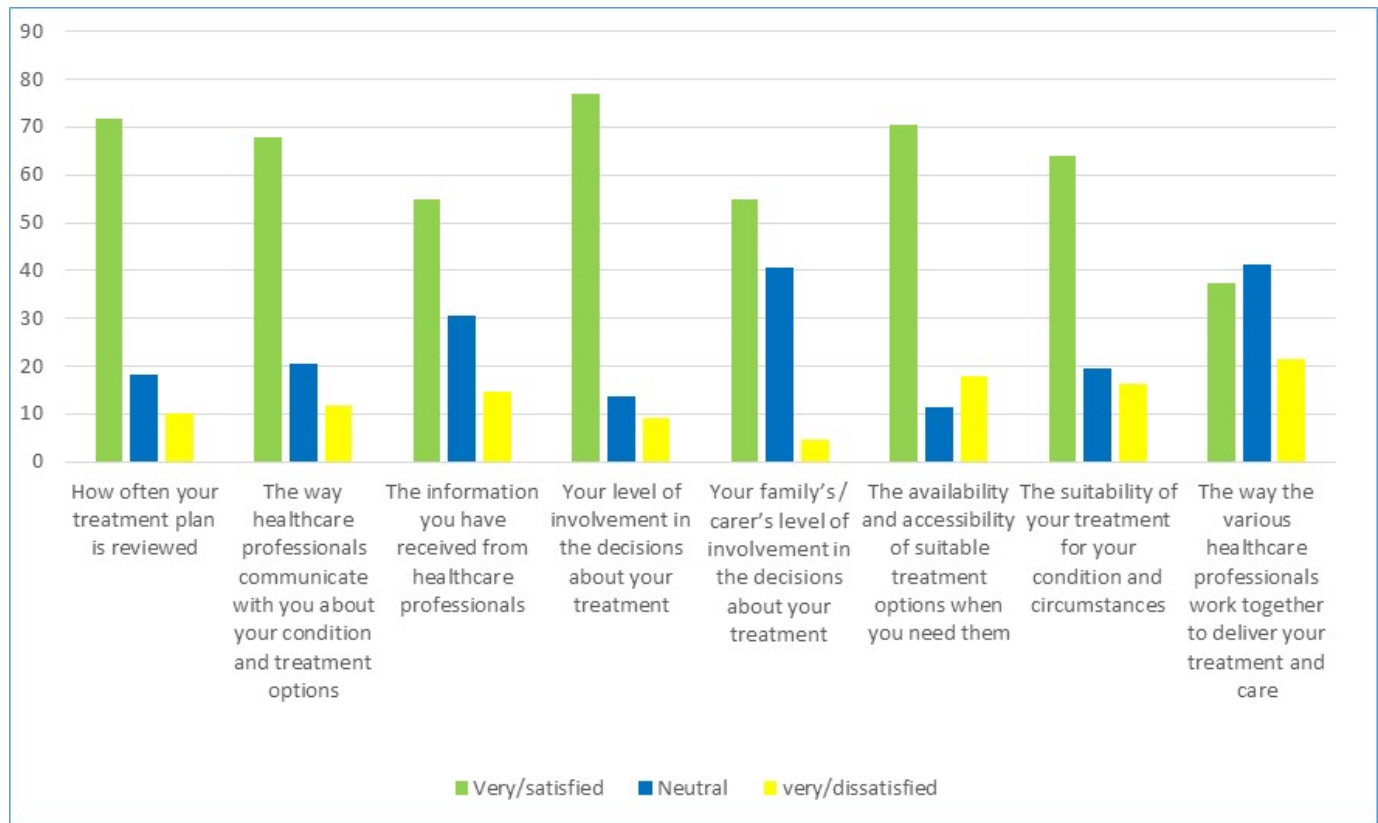
Only 18 respondents report being refused care due to cost and none due to where they lived; hence the samples are too small to conduct a valid analysis to explore links between QoL and refusal of treatment.

1.9. Satisfaction

Most of the respondents are satisfied or very satisfied with the care they are receiving from all of the healthcare professionals they were asked to comment on (including clinical practitioners in both primary and secondary care, as well as therapists). In particular respondents are very satisfied with the care they receive from physiotherapists with only one person saying they were dissatisfied. Respondents were least satisfied with general neurologists, although the level of dissatisfaction is just 15%.

In relation to treatment and overall care, respondents are most satisfied with how often their treatment plan is reviewed (72%) and their level of involvement in decisions about treatment (77%). However, there is less satisfaction in relation to other care aspects, in particular the way the various healthcare professionals work together to deliver the treatment and care where only 37% of respondents are satisfied and 22% are dissatisfied (Figure 8).

Figure 8. Satisfaction with treatment and overall care (%)



The relationship between frequency of medication review and satisfaction with care was explored with a bivariate correlation. Responses provided for 'how often is your medication reviewed and by who' were coded so that most frequent reviews ('every 3 months') were assigned the highest number '4', through to '1' for 'once every 2 years'. The correlation reveals a significant small sized relationship between satisfaction with care and frequency of review. This result suggests that respondents who benefit from more frequent reviews also report higher levels of satisfaction with care ($n = 69$, $r = .27$, $p < .05$).¹

Respondents also reported on the frequency of their medication reviews with different healthcare professionals (Table 7); because respondents may have more than one medication review a year, numbers in the table do not necessarily add up to 100%.

For the medication reviews, most respondents state that either a specialist or general neurologist reviews their medication. A smaller proportion of respondents report that either a GP or hospital doctor reviews their medication. 91% of respondents report that they have their medication reviewed at least every three months.

Table 7. Medication reviews (%)¹

Healthcare professionals	Every 3 months (%)	Every 6 months (%)	Once a year (%)	Once every 2 years or more (%)
General practitioner or family doctor	17	7	3	1
Hospital doctor	6	4	9	1
General neurologist	44	7	6	0
Neurologist who is a specialist in Parkinson's	23	14	6	1
Geriatrician	0	1	1	1
Parkinson's disease nurse specialist	1	1	1	0

A Bivariate correlation was conducted to explore the relationship between quality of life and frequency of medication review. No significant relationship is observed ($n = 84$, $r = .16$, $p = .16$), suggesting QoL is not associated with frequency of medication review.

In addition, a second bivariate correlation was run to assess the relationship between quality of life and satisfaction with care. Using the quality of life index and the satisfaction for care index, again no significant relationship emerges ($n = 69$, $r = .09$, $p = .46$) suggesting QoL is not influenced by how satisfied respondents are with their care.

1.10. Advanced treatments

Only five of the respondents report receiving surgical treatments, all of which were “Deep Brain Stimulation”.

All except for one of the respondents had the surgery within the first ten years after diagnosis; the remaining respondent had the surgery between 11 to 15 years after diagnosis. All of the respondents say that the surgery has met their expectations and one of the respondents gave further explanation

“The actual installation of the THS (Tiefe Hirnstimulation; translated as DBS) was perfectly ok. Only after 4 years the battery had to be renewed. Thereupon, I had to get along so about 6 weeks without a battery.”

The research team were not able to look at the correlations between receiving advanced treatments and QoL/satisfaction variables as there are too few respondents who have received these treatments.

1.11. Findings in relation to the national guidelines

For Germany, the Guidelines for Diagnosis and Therapy in Neurology were published in 2012. In summary, the guidelines state that:

- Pharmaceutical treatment must be initiated immediately after diagnosis as it positively influences the course of the disease;
- Initial treatment with dopamine agonists compared to L-Dopa-Monotherapy reduces the occurrence of Dyskinesia for at least three to five years. In contrast, L-Dopa has proven to have a better symptomatic effect as well as fewer non motoric side-effects. In particular with patients who develop Parkinson's late, the medical treatment should be initiated with L-Dopa, as it has proven to be the most efficient and compatible. In elderly patients, monotherapy with L-Dopa should be continued as long as no complications occur;
- Parkinson's patients with an early onset have a higher risk of developing dyskinesia under L-Dopa treatment;

- Deep Brain Stimulation is used in patients with advanced Parkinson with dopa sensitive fluctuations and has proven more effective in improving quality of life, symptoms and daily activity, than oral medical treatment. There is not sufficient data currently in existence about the use of Deep Brain Stimulation in early or mid-term phases of Parkinson;
- There is no indication for the use of COMT-blockers with L-Dopa first time users or with patients with a stable L-Dopa response; and
- Patients who receive medical treatment for fluctuations, benefit from deep brain stimulation, positively affecting movement and quality of life.

The findings from the survey demonstrate that, in line with the guidelines, nearly two-thirds of the respondents started medication immediately (64%). Although a further 8% discussed starting medication immediately, the PwPs decided against it.

In addition to this, the most commonly prescribed drugs are the L-dopa ones, such as Rasagiline (Azilect®) (58%), followed by Pramipexole (MIRAPEXIN®/SIFROL®) (56%) and Madopar® (49%). When asked what other tests were used to diagnose Parkinson's, respondents frequently stated an "L-Dopa Test".

APPENDIX II-D: SURVEY FINDINGS FOR HUNGARY

1.1. Sample profile

In total 66 respondents completed the survey from Hungary. 62% of respondents are female and the average age of respondents was 60 years when they were diagnosed with Parkinson's, with the youngest aged 25 and oldest aged 82 years. Only 20% are currently employed. When asked to describe the area in which they live, 11% state rural, 14% town, with the remaining 75% living in cities.

1.2. Quality of life and disability scores

To explore quality of life, EuroQol's EQ-5D measure was utilised. This is a standardised instrument for measuring health status and requires respondents to answer five questions focusing on **mobility**, **self-care**, **usual activities**, **pain**, and **anxiety/depression**.

Regarding **mobility**, 23% report no problems walking, while 76% report some problems. Only 2% of respondents indicate that they are confined to a bed²⁸.

Moving on to **self-care**, 5% report they are unable to wash or dress themselves and 50% that they have some problems with washing or dressing, with 46% indicating no problems with self-care.

When asked about their current ability to perform **everyday activities** such as work and leisure, the majority (76%) experience some problems performing these activities, while 21% indicate no problems at all. Those who were unable to perform *any* everyday activities are the smallest group, accounting for 3% of the sample.

When discussing current levels of **pain and discomfort**, a high percentage of the sample - 70% - indicate that they suffer from moderate pain, while 23% indicate having no pain or discomfort. Again, those who suffer from extreme pain represent a relatively small proportion of the sample at 7%.

The final question assessing current quality of life focuses on levels of **anxiety and depression**. 36% respondents indicate they are not anxious or depressed, while 59% indicate moderately so. The remaining 5% of the sample report feelings of extreme anxiety or depression.

Compared with their general health over the last 12 months, 19% of respondents state that their health is *better*. Most respondents feel that their health is *much the same* (44%) while 37% state that it is *worse*.

When asked to rate which statement best describes how they feel about their independence, one of the respondents reports to being bed bound. However, the most commonly recorded response is '*I am able to do all chores with some degree of slowness, difficulty and impairment, and am beginning to be aware of difficulty*' (42%) (Table 1).

²⁸ Results based on the number of respondents answering Question 7. This result may not tally with the number stating they are bedridden in Question 13, the results of which are shown in Table 1.

Table 1. Self-reported disability score (%)

STATEMENTS	Response (%)
I am able to do all chores without slowness, difficulty or impairment	0
I am able to do all chores with some degree of slowness, difficulty and impairment, and am beginning to be aware of difficulty	42
Chores take twice as long and I am conscious of difficulty and slowness	30
Chores take three to four times as long and I spend a large part of the day doing these	6
I can do most chores, but exceedingly slowly and requiring a lot of effort	12
I need help with half the chores and have difficulty with everything	2
I can assist with all the chores, but am only able to do a few on my own	2
I can manage a few chores with some effort, but need a lot of help	2
I do nothing on my own, but can be a slight help with some chores	2
I am totally dependent and helpless	0
I am bedridden	2

1.3. Receiving a diagnosis of Parkinson's disease

1993 was the earliest date that a respondent had been diagnosed with Parkinson's and 2013 the latest (the median date of diagnosis was 2007). Almost all of the respondents had been diagnosed with Parkinson's in Hungary, with the exception of one who had been diagnosed in Germany.

Respondents were asked how much time has passed since their diagnosis of Parkinson's and the majority of respondents (76%) answer less than a year. However, this response does not tally with the answers given to the earlier question on year of diagnosis where 9% said they were diagnosed in 2013. Therefore, due to this inconsistency, the answers to the question on length of time since diagnosis have been excluded from this report.

The symptoms most commonly noticed before diagnosis includes slowness of movement, tremor, changes in the way you move (including the way you walk, dragging a leg, not swinging your arm, etc.), tremor, fatigue and loss of smell or taste. Interestingly people with these symptoms were more likely to seek help within a year. However with other symptoms, such as speech and communication problems (incl. small handwriting and reduced facial movements), stress, rigidity (stiffness), bladder or bowel problems, anxiety, freezing, falls (balance problems), difficulty eating and/or swallowing, these symptoms could often continue for over five years before help was sought (Table 2).

Table 2. Reported symptoms, and duration of these symptoms before seeking medical help (%)

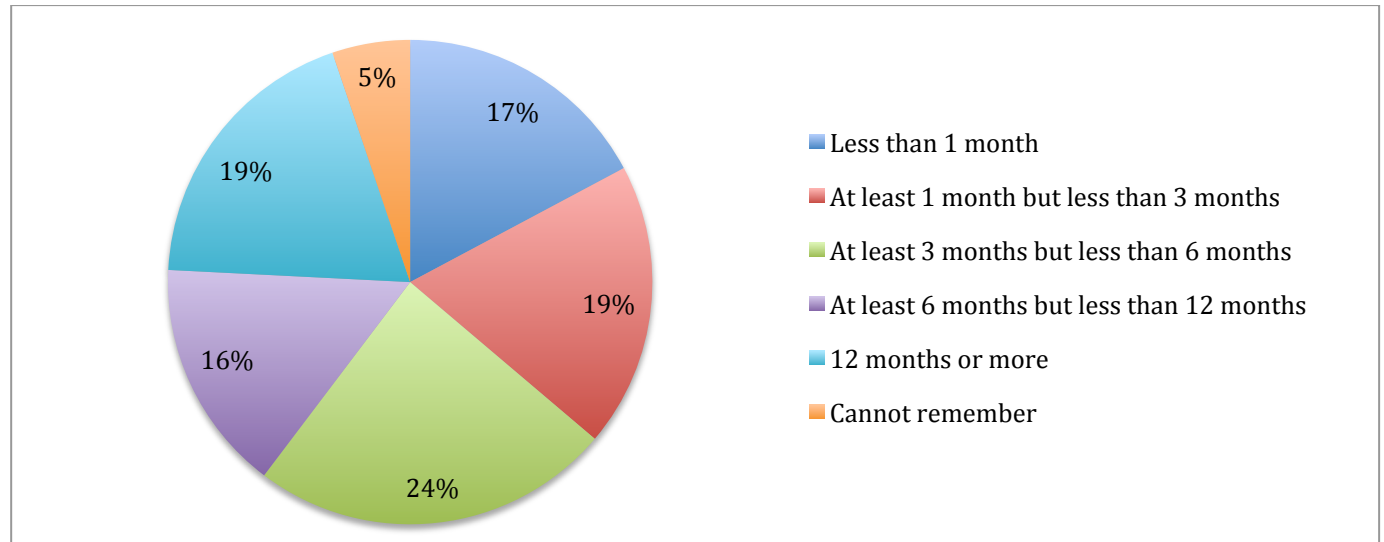
SYMPTOMS/PERCENTAGE OF RESPONDENTS²⁹	Less than 1 year	1 to 2 years	3 to 4 years	5 years or more	Total percentage of respondents experiencing symptom
Anxiety	17	15	5	5	42
Apathy	7	7	2	0	16
Bladder and bowel problems	8	7	12	14	41
Changes in the way you move (incl. the way you walk, dragging a leg, not swinging your arm, etc.)	36	27	7	2	72
Depression	12	12	3	3	30
Difficulty eating and/or swallowing	14	8	2	5	29
Eye problems	10	8	2	7	27
Falls (balance problems)	15	10	3	7	35
Fatigue	32	15	8	7	62
Freezing	7	14	2	5	28
Loss of smell or taste	29	12	3	12	56
Low blood pressure or dizziness	12	14	3	7	36
Muscle cramps	19	12	12	3	46
Pain	17	5	7	2	31
Rigidity (stiffness)	22	12	8	3	45
Skin and/or sweating problems	12	8	2	5	27
Sleep problems	20	12	5	5	42
Slowness of movement	41	20	7	3	71
Speech and communication problems (incl. small handwriting and reduced facial movements)	20	17	7	5	49
Stress	20	19	5	10	54
Thinking or memory problems	12	10	5	5	32
Tremor (shaking)	39	10	2	5	56

Other symptoms added by the respondents included: oily skin, difficulty turning in bed or standing up, breathing problems, hypertension, rapid pulse growth, numbness in the hands and feet, problems with colour recognition, headaches and rheumatic complaints.

²⁹ Respondents could select “do not apply”; and select multiple options

When asked how long it was before seeking medical help after first noticing their symptoms, one fifth of respondents waited 12 months or more (20%). 59% of respondents sought help within 3 to 12 months, while 17% sought immediate help (within 1 month) (Figure 1).

Figure 1. Timelines for seeking medical help (%)



1.4. During the first appointment

For the majority of respondents, during the first appointment with a healthcare professional, a physical examination was carried out (69%) and their medical history was discussed (67%). More than half of the respondents were referred to a specialist or another doctor/healthcare professional (57%) and told that they might have Parkinson's (55%). Nearly half of the respondents stated their symptoms were observed (48%) and prescribed medication to relieve the symptoms (47%). Just one of the respondents was told that nothing was wrong (Table 3).

Table 3. Events during the first appointment with a healthcare professional (%)

EVENTS	Response (%) ³⁰
Discussed your general medical history	67
Carried out a physical examination	69
Observed your symptom(s)	48
Referred you to a specialist, or another doctor / healthcare professional	57
Said nothing was wrong	2
Said it was too early to tell if anything was wrong	9
Said something was wrong, but not sure what	19
Prescribed medication to relieve your symptom(s)	47
Explained that you may have Parkinson's	55
Explained that you may have another disease / condition	3

³⁰ Respondents could select multiple options

A number of respondents detailed other events which happened at the first appointment, including:

- Being told they were ageing
- Being told they could try homeopathic healing although the doctor stated it wasn't recorded as helping people with Parkinson's
- Being sent for an MRI scan
- Being sent to a neurosurgeon and after X-ray, EEG, CT and MRI and three months they were told they didn't have Parkinson's. Later they were sent to a specialist neurologist who at the first appointment diagnosed them with Parkinson's
- Given they were too young at the time (43 years old) and having had only two Parkinson's symptoms it was not easy for the doctors to detect the person had Parkinson's

Respondents were asked, if they were referred to another healthcare professional, what the waiting times were. If a referral was made, mostly this was to a neurologist (either a general one or one specialised in Parkinson's disease). Only a small percentage of respondents were referred to a therapist.

The waiting times to see neurologists were less than to see a physiotherapist, with most of the respondents seeing a neurologist (either general or specialised) within three months (Table 4).

Table 4. **Waiting times to see professionals from referral (%)**³¹

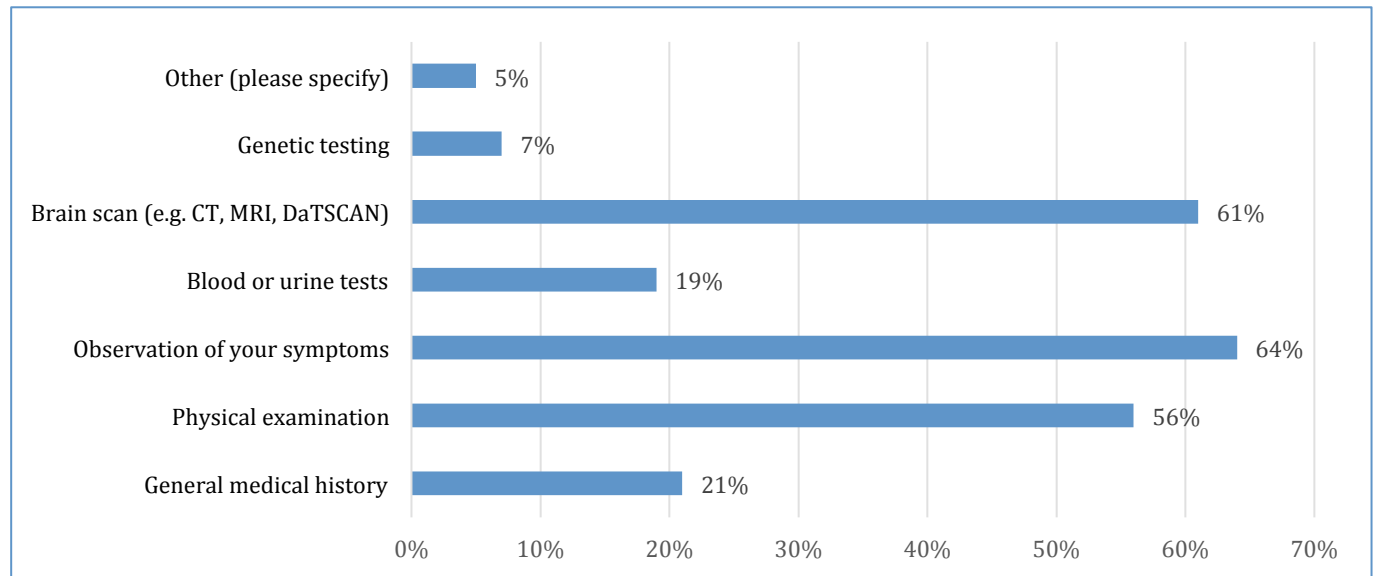
HEALTHCARE PROFESSIONAL	Within 1 month (%)	1-2 months (%)	2-3 months (%)	3-4 months (%)	4 months + (%)	% of respondents referred
General neurologist	31	9	6	2	7	54
Neurologist Specialist in Parkinson's	31	15	11	6	15	78
Geriatrician	2	4	4	0	0	10
Parkinson's disease nurse specialist	4	0	2	2	0	8
Physiotherapist	11	2	6	0	13	32
Occupational therapist	2	2	2	0	7	13
Speech and language therapist	6	0	2	0	7	15

The majority of respondents had a physical examination (82%) and observation of their symptoms (76%) to diagnose their Parkinson's disease. 70% underwent a brain scan and 67% discussed their general medical history. 50% of respondents had blood or urine tests taken (Figure 2). 15% of respondents mentioned that they also underwent other types of examinations and tests during diagnosis. These included:

- Neuropsychological tests
- Hospital medicine assessment
- A few days of hospital check-up
- Sent to an ear, nose and throat specialist
- Blood sugar, CT, neuropathy, psychology, ABPM, carotid ultrasound, and SPECT

³¹ Respondents could select multiple options

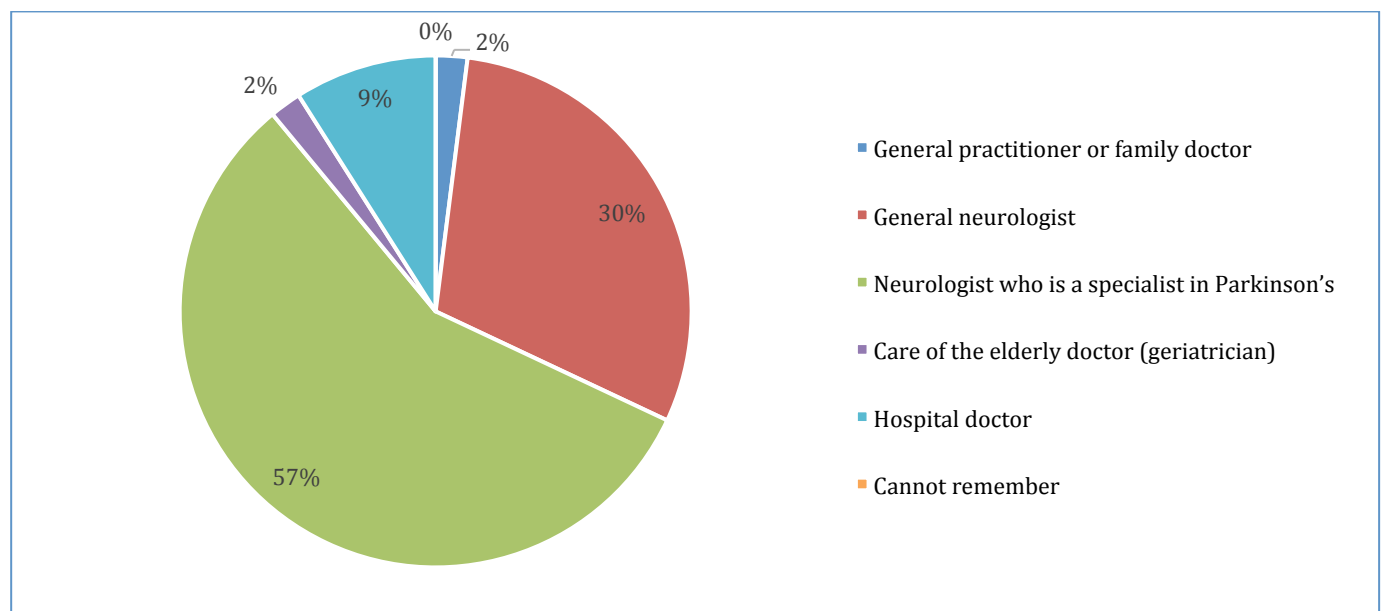
Figure 2. Examinations and tests carried out



1.5. Delivery of the diagnosis

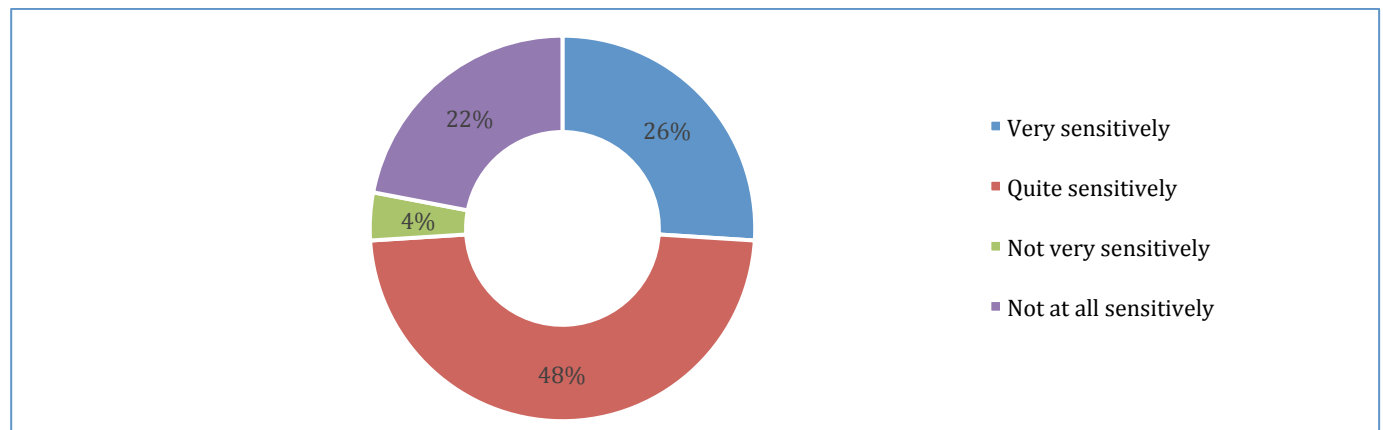
Over half of the respondents received their diagnosis of Parkinson's from a neurologist specialised in the disease (57%) and 30% by a general neurologist. 9% stated that they received the diagnosis from a hospital doctor and one respondent (2%) was given the diagnosis from a geriatrician and one (2%) from a GP (Figure 3).

Figure 3. Healthcare professional diagnosing Parkinson's (%)



In relation to the sensitivity in which the diagnosis was given, 74% of the respondents feel that they were told either very sensitively or quite sensitively (Figure 4). Despite a quarter of the respondents not feeling that the diagnosis was given sensitively, only 17% feel dissatisfied or very dissatisfied with the consultation where the initial diagnosis was given. In comparison, 15% of respondents have a neutral opinion of their consultation while 63% say they are satisfied or very satisfied

Figure 4. Sensitivity of diagnosis (%)



1.6. Information given at diagnosis

At time of diagnosis, 63% of the respondents report that they were given information verbally about the symptoms and causes of Parkinson's and more than two thirds were told about medication (67%). 45% of respondents were given information about clinical trials either verbally or with hand-outs although 4% said they did not want any information on this subject. 57% said that they were given either written or verbal information about how to maintain physical wellbeing such as healthy eating and exercise and more than a half were given advice on maintaining mental wellbeing (52%) (Table 5).

Table 5. Information given (%)³²

TOPIC AREA	Leaflet/ Handouts/ signposting to online information (%)	Explained verbally (%)	Both handouts and verbal information (%)	I did not want any information (%)	No information was provided (%)
Symptoms, diagnosis and causes of Parkinson's	4	63	9	4	17
Medication	6	67	7	4	11
Surgical treatments	4	10	2	12	59
Non-drug treatments	13	28	6	6	36
Maintaining physical wellbeing	11	38	8	6	28
Maintaining emotional wellbeing	6	40	6	9	28
Financial help available	6	11	2	8	51
Support organisations (e.g. patient associations)	4	20	7	7	50
Support for carers	4	6	0	10	57
Where to find more information on Parkinson's	8	25	19	4	30
Taking part in clinical trials	2	35	8	4	37

³² Respondents were also able to answer no information was provided or cannot remember. 2-3% of respondents answered 'cannot remember' consistently

Amongst respondents who received information, over two thirds of them found the information they were given either very or quite helpful (68%). In contrast, 13% found the information either not very helpful or not helpful.

In relation to the question enquiring whether or not respondents feel as if they had enough time to ask questions and discuss their concerns, more than one third feel that they were given enough time (36%) compared to the 19% who felt unable to ask questions at that time. A further 19% would have liked more time to ask questions while 6% responded that they did not want to ask questions at that time (Table 6).

Table 6. Time to ask questions and discuss concerns – Question responses (%)

REPONSES	Response (%)
Yes, I was given enough time	36
Yes, but I would have liked more time	19
No, I was not given any time	16
I did not want to ask questions at that time	6
I did not feel able to ask questions or discuss concerns at that time	19
Cannot remember	4

1.7. Link between quality of life, satisfaction, and availability of information

A bivariate correlation was conducted to explore the relationship between availability of information and quality of life. To calculate an 'information availability total', responses were coded '1' for leaflet, verbal, or both (i.e. 'some information provided'). These numbers were then totalled across all the categories respondents were asked to consider (i.e. medication, support for carers), with higher numbers equating to a greater availability of information.

The correlation between the quality of life (QoL) index score (Mean = .57) and the information total (Mean = 4) does not reach a satisfactory level of statistical significance ($n = 66$, $r = .07$, $p = .59$). Therefore we are unable to conclude that QoL is affected by the availability of information.

The relationship between information availability and satisfaction with care received was also explored via a correlation. A statistically significant relationship is observed ($n = 52$, $r = .30$, $p < .05$), suggesting levels of satisfaction with care are associated with the availability of information - higher levels of satisfaction with care are related to receiving more information about the disease.

The relationship between satisfaction with treatment and information was also explored. No significant relationship emerges between availability of information and satisfaction with treatment ($n = 52$, $r = .19$, $p = .18$), suggesting levels of satisfaction with treatment are not associated with availability of information.

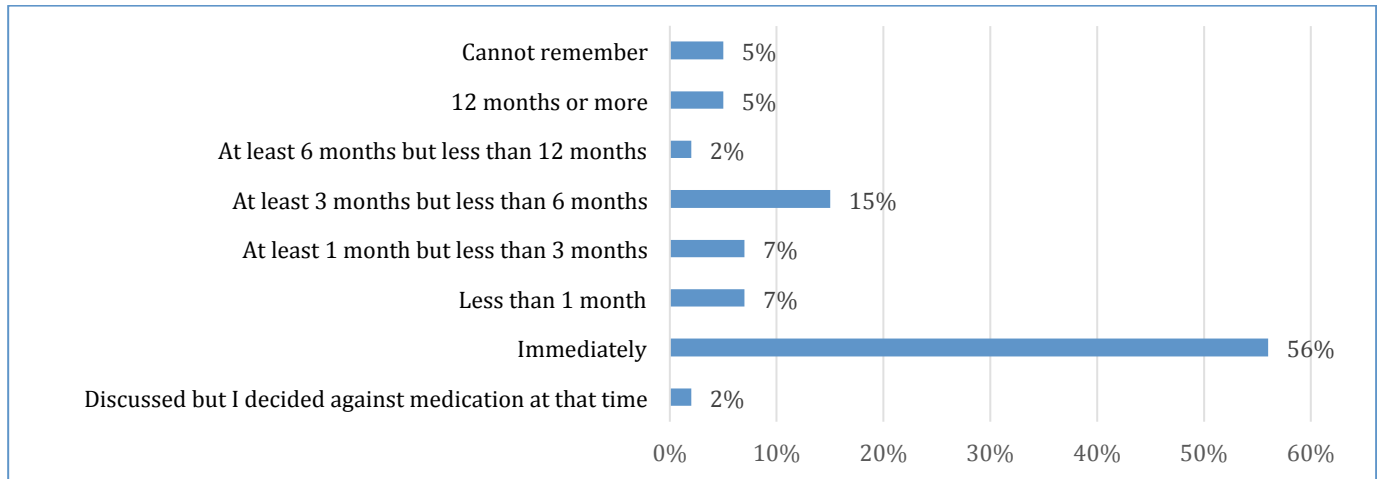
Finally, the relationship between satisfaction with the consultation where the initial diagnosis was made and the amount of information provided was also explored via a correlation. Replicating the previous correlation, results suggest a positive relationship between the two variables ($n = 54$, $r = .52$, $p < .01$) – the amount of information provided (both verbal and written) is related to how satisfied respondents are with the initial diagnosis and consultation. Respondents who receive more information also feel more satisfied with the consultation where the initial diagnosis was made.

In relation to the question enquiring whether or not respondents feel as if they had enough time to ask questions and discuss their concerns, more than one third feel that they were given enough time (36%) compared to the 19% who felt unable to ask questions at that time. A further 19% would have liked more time to ask questions while 6% responded that they did not want to ask questions at that time (Table 6).

1.8. Treatment

Over 90% of respondents started medication or treatment within the first year after diagnosis, with 68% of them starting immediately. In comparison, 6% of respondents decided not to take medication at the time of diagnosis (Figure 5).

Figure 5. Medication and treatment timings (%)

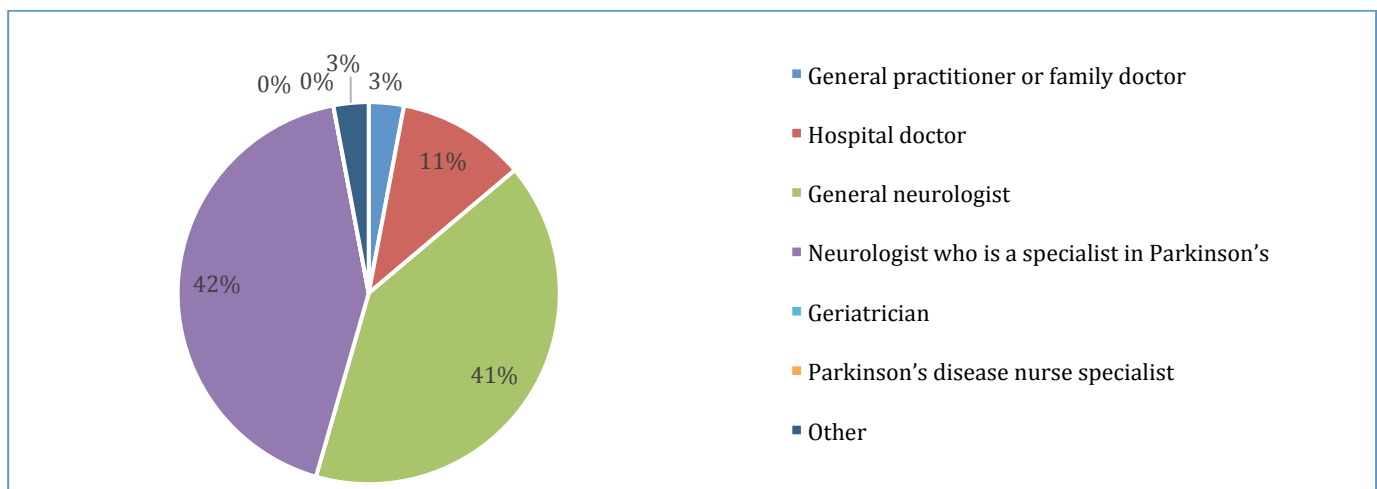


The most frequently taken medications are Madopar (67% of respondents prescribed this drug) and Rasagiline (56%) which are predominantly prescribed by either a general or specialist neurologists. However, both hospital doctor and GPs on occasions also prescribe both these medications.

Other medications which are prescribed include³³: Pramipexol (35% of respondents); Ropinirol (37%); Rotigotine (17%); Sinemet (12%); and Stalevo (40% of respondents).

The majority of the medication is prescribed by either a general neurologist (41%), a specialist neurologist (42%) or a hospital doctor (11%). Only very occasionally is medication prescribed by a GP or a geriatrician and no respondent reports being prescribed medication by a Parkinson's disease nurse specialist (Figure 6).

Figure 6. Healthcare professionals who prescribed the medication (%)



³³ Presented in alphabetical order

Nearly two thirds of respondents state that the state currently pays for their medication (62%). However, nearly one half also state that they or their families pay for some medication privately (46%) or their insurance pays (14%)³⁴. One of the respondents (2%) states that a Parkinson's organisation pay for their medication and one respondent does not know who pays.

The relationship between satisfaction with care and paying for treatment was explored. Responses about paying for treatment were assigned a group based on whether care was state funded or by private/insurance³⁵. An independent samples t-test³⁶ was conducted to investigate whether satisfaction with care differs according to whether respondents pay for the treatment or not. This analysis reveals no statistical difference. Mean levels of satisfaction do not differ between the groups. Respondents who pay for treatment (either through insurance or privately) report higher levels of satisfaction with care (n = 16, Msatisfaction = 19) to those respondents whose treatment is state funded (n = 22, Msatisfaction = 15); however the difference was not statistically different (t = 1.71, p = .10).

A second independent t-test was conducted to explore if access to health care professionals (as measured by frequency of medication review) differs according to how the health care is funded (i.e. state vs. private). Respondents who receive state funded care (n=22, Mreview = 4) report more frequent reviews of medication, compared to respondents who pay for treatment (n=16, Mreview = 3); however, the comparison between the two groups reveals a significant difference according to the two types of funding (t= 1.67, p=.10).

Using length of time to gain access to treatment after diagnosis, as a proxy for availability, a further independent t-test was conducted to establish if length of time differs between state (n=22, Mtime = 3) versus private funding (n=16, Mreview = 3). No significant differences in treatment waiting times are noted between the two groups (t= .08, p = .94).

Only 4 respondents reported being refused care due to cost and 2 due to where they lived; hence the samples are too small to conduct a valid analysis to explore links between QoL and refusal of treatment

1.9. Satisfaction

Most of the respondents are satisfied with the care they are receiving from nearly all of the healthcare professionals they were asked to comment on. 88% of respondents are satisfied with the care they are receiving from specialist neurologists while satisfaction with general neurologists is lower at 63%. Nearly three quarters of respondents are satisfied with the care they receive from their GPs (72%). The highest level of dissatisfaction is with Parkinson's disease nurse specialists (11%) although the number of respondents receiving treatment from these professionals is small.

Amongst therapists, respondents are generally satisfied with the treatment they are receiving with individual levels of satisfaction ranging from 88% for speech and language therapists, 84% for physiotherapists and 76% for occupational therapists.

In relation to treatment and overall care, respondents are most satisfied with the way professionals communicate with them about their condition and treatment options (83%). The majority are also satisfied with how often their treatment plan is reviewed (78%) and their level of involvement in decisions made about their treatment (75%). However, there is less satisfaction in relation to other care aspects, in particular the involvement of family's and

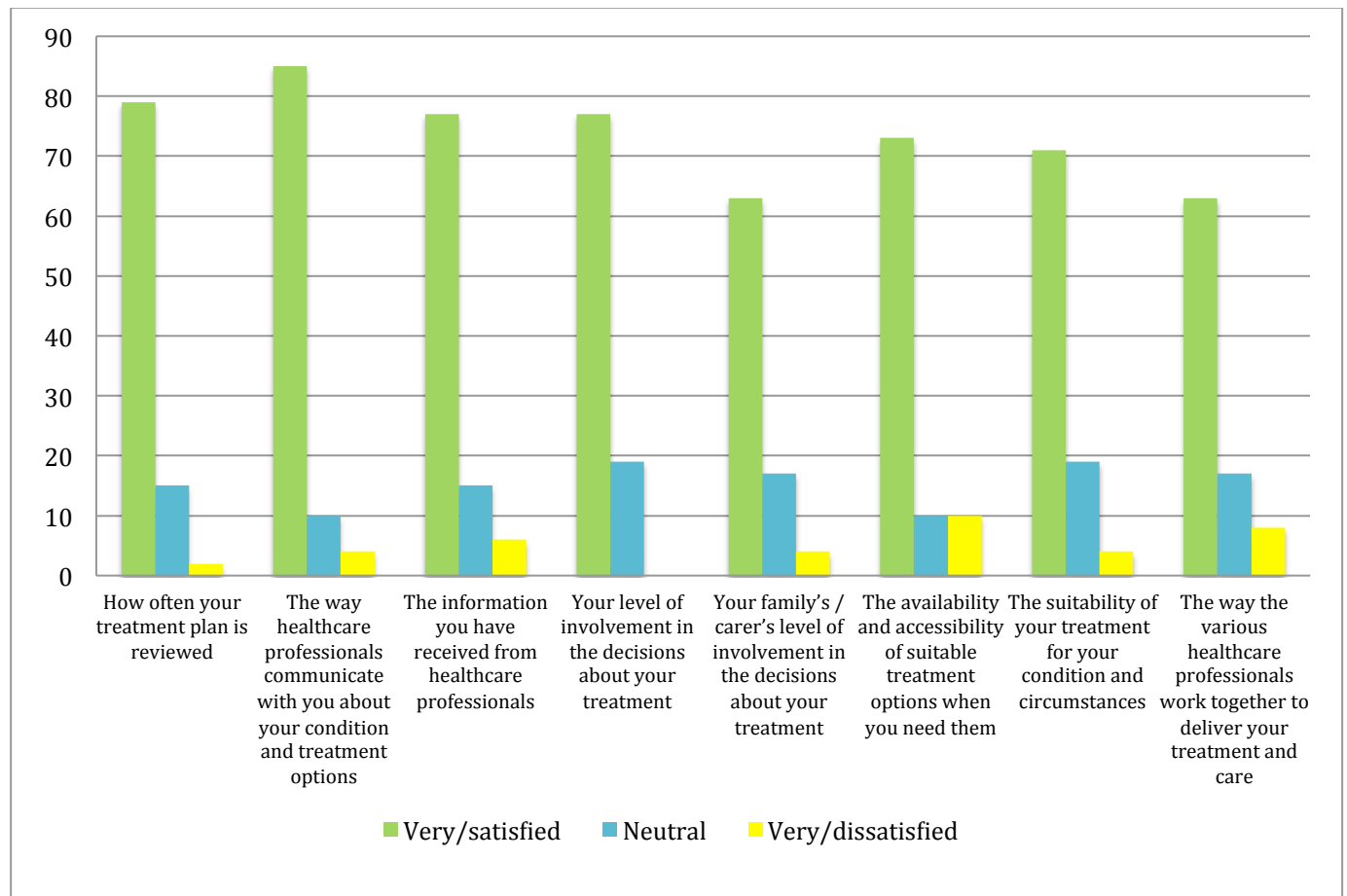
³⁴ Respondents could select multiple options.

³⁵ Insurance and private were joined together to enable a direct comparison between paying vs. non-paying care. Respondents who indicated more than one source of funding were excluded from the analysis so as to ensure valid comparisons between the groups.

³⁶ The independent-samples t-test (or independent t-test, for short) compares means values (averages) between two unrelated groups on the same continuous variable (i.e., scale scores).

carer's in the decisions made about their treatment (63% satisfied) and the way various healthcare professionals work together to deliver treatment and care (63% satisfied). (Figure 7).

Figure 7. Satisfaction with treatment and overall care (%)



The relationship between frequency of medication review and satisfaction with care was explored with a bivariate correlation. The analysis reveals a significant medium sized relationship between satisfaction with care and frequency of review, suggesting respondents who benefit from more frequent reviews, also report higher levels of satisfaction with care ($n = 52$, $r = .30$, $p < .05$).³⁷

Respondents also reported on the frequency of their medication reviews with different healthcare professionals (Table 7); because respondents may have medication reviews with different professionals, numbers in the table do not necessarily add up to 100%.

For the medication reviews, 98% of respondents report that they have their medication reviewed at least every 3 months, predominantly by either a neurologist, GP or hospital doctor. In addition, a large proportion of respondent have their medication reviewed by either a general or specialist neurologist either every 6 months (43%) or once a year (19%).

³⁷ Respondents who indicated 'do not know' and 'does not apply' were not included in this analysis

Table 7. Medication reviews (%)³⁸

HEALTHCARE PROFESSIONALS	Every 3 months (%)	Every 6 months (%)	Once a year (%)	Once every 2 years or more (%)
General practitioner or family doctor	25	8	4	0
Hospital doctor	13	10	6	0
General neurologist	21	10	4	0
Neurologist who is a specialist in Parkinson's	37	33	15	0
Geriatrician	0	0	4	0
Parkinson's disease nurse specialist	2	0	2	4

A Bivariate correlation was conducted to explore the relationship between quality of life and frequency of medication review. No significant relationship was observed ($n = 66$, $r = -.11$, $p = .40$), suggesting QoL is not associated with frequency of medication review.

In addition, a second bivariate correlation was run to assess the relationship between quality of life and satisfaction with care. Using the quality of life index and the satisfaction for care index, again no significant relationship emerges ($n = 52$, $r = -.24$, $p = .08$) suggesting QoL is not influenced by how satisfied respondents were with their care.

1.10. Advanced treatments

Only four of the 49 respondents have received surgical treatments - 2 in the form of “*Deep Brain Stimulation*” and two in the form of “*Duodopa*”. Two of the respondents had the surgery more than 15 years after being diagnosed, one stated *up to 5 years*, and the other respondent answered between 11 to 15 years. None of the four respondents have commented on whether the surgical treatment had met their expectations.

The research team were not able to look at the correlations between receiving advanced treatments and QoL/satisfaction variables as there are too few respondents who have received advanced treatments.

1.11. Findings in relation to the national guidelines

According to the professional guidelines *Parkinson's Disease and Drug Treatment*³⁹, published in 2008 by the Ministry of Health (written by College of Neurology), some of the tests to justify diagnosis of Parkinson's are MRI scan, SPECT or PET tests, Doppler, as well as applied psychological tests.

Review of the patient's treatment is at regular six month intervals. The medication treatment should start when the patient develops functional inability and the patient's quality of life is affected. Physiotherapy should be available for all patients, as well as psychological and social treatment care. Referral is required if patients want to attend physiotherapy at an outpatient clinic.

In terms of medication, different drugs are introduced depending upon the patient's symptoms and stage of the disease. Selegiline and Rasagiline are suggested for the first stage of the disease; none of these prevent motor fluctuations, and side effects are deemed acceptable. Amantadine is suggested to work effectively at the initial stages of the disease, and is likely to be effective in combination with Levodopa. Biperiden and Procyclidine are

³⁸ Respondents were also able to state that they did not know or that it did not apply for them.

³⁹ Accessed 28th January 2014: http://www.kk.pte.hu/docs/protokollok/NEUParkinson_IE.pdf

listed as drugs giving side effects such as cognitive performance deterioration, confusion, dry mouth and constipation. Bromocriptine is not seen as being effective early on with stable non-fluctuating patients. Further on in the guidelines drugs are recommended depending on whether a monotherapy or combination therapy is being pursued.

The guidelines also mention the importance of educating patients and carers about their Parkinson's disease and advising on participation in clinical trials.

Levodopa infusion and Deep Brain Stimulation surgery are available procedures for patients when their quality of life does not improve from oral medication. GP's or a specialist neurologist in Parkinson's disease refer patients for surgical treatment; Clinical centres act as investigators before the surgical treatment and aftercare.

The findings from the survey demonstrate that, in line with the guidelines, more than two-thirds of the respondents (70%) had brain scans with a further 82% undergoing a physical examination or observation of symptoms. In line with the guidelines, 70% of the respondents have had medication reviews within the first six months from a specialist neurologist in Parkinson's disease, 31% from the general neurologist and 33% from their GP.

In line with the guidelines, some respondents have also been referred to physiotherapy (13%) or occupational and speech therapy (each 7%).

In line with the guidelines, a high percentage of participants were given information on clinical trials (46%) and just over one half were told where they could find more information on the disease (52%).

APPENDIX II-E: SURVEY FINDINGS FOR IRELAND

1.1. Sample profile

In total 51 respondents completed the survey from Ireland. 57% of respondents are male and the average age of respondents was 56 years when they are diagnosed with Parkinson's, with the youngest aged 32 and oldest aged 74 years. Only 24% are currently employed. When asked to describe the area in which they live, 28% state rural, 39% town, with the remaining 33% living in cities.

1.2. Quality of life and disability scores

To explore quality of life, EuroQol's EQ-5D measure was utilised. This is a standardised instrument for measuring health status and requires respondents to answer five questions focusing on **mobility**, **self-care**, **usual activities**, **pain**, and **anxiety/depression**.

Regarding **mobility**, 33% report no problems walking, while 66% report some problems. No respondents indicate that they are confined to a bed⁴⁰.

Moving on to **self-care**, 8% report they are unable to wash or dress themselves and 28% that they have some problems with washing or dressing. However, the majority of respondents - 63% - indicate no problems with self-care.

When asked about their current ability to perform **everyday activities** such as work and leisure, just over half of the respondents (56%) experience some problems performing these activities, while 31% indicate no problems at all. Those who were unable to perform *any* everyday activities are the smallest group, accounting for 12% of the sample.

When discussing current levels of **pain and discomfort**, a high percentage of the sample - 74% - indicate that they suffer from moderate pain, while 18% indicate having no pain or discomfort. Again, those who suffer from extreme pain represent a relatively small proportion of the sample at 8%.

The final question assessing current quality of life focuses on levels of **anxiety and depression**. Equal proportions of respondents indicate they are either not anxious or depressed or moderately so (43% each). The remaining 14% of the sample report feelings of extreme anxiety or depression.

Compared with their general health over the last 12 months, only 16% of respondents state that their health is *better*. The majority of respondents feel that their health is *much the same* (57%).

When asked to rate which statement best describe how they feel about their independence, none of the respondents report to being bed bound. The most commonly recorded response is '*I am able to do all chores with some degree of slowness, difficulty and impairment, and am beginning to be aware of difficulty*' (40%) (Table 1).

⁴⁰ Results based on the number of respondents answering Question 7. This result may not tally with the number stating they are bedridden in Question 13, the results of which are shown in Table 1.

Table 1. Self-reported disability score (%)

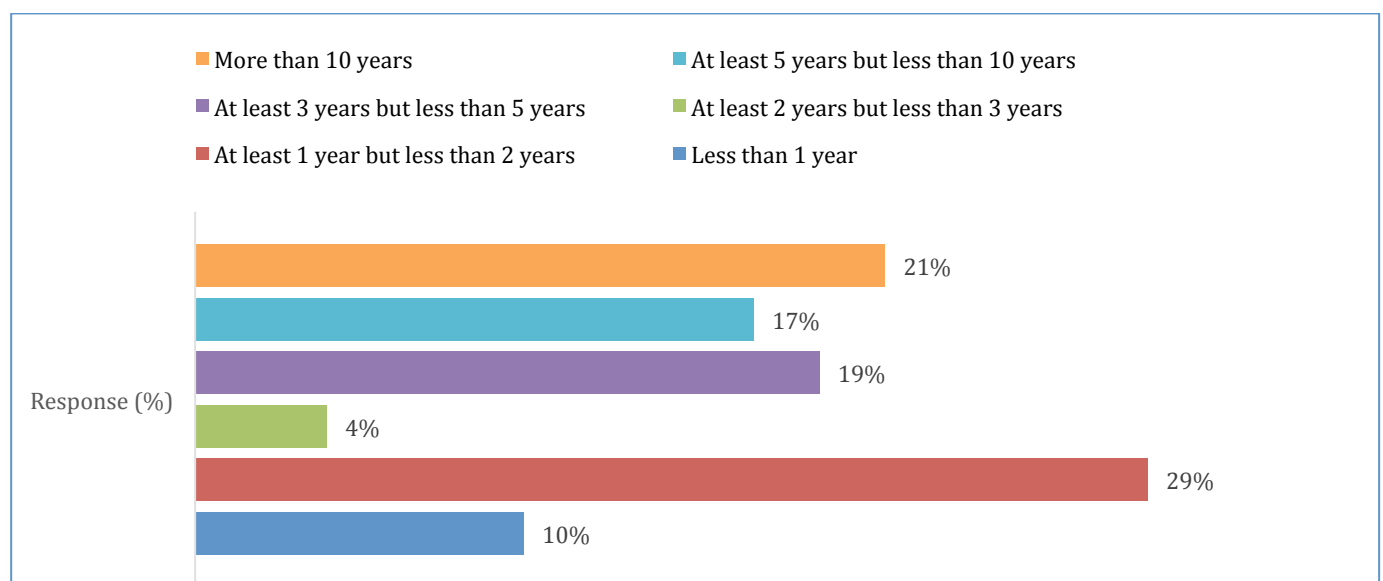
STATEMENTS	Response (%)
I am able to do all chores without slowness, difficulty or impairment	17
I am able to do all chores with some degree of slowness, difficulty and impairment, and am beginning to be aware of difficulty	40
Chores take twice as long and I am conscious of difficulty and slowness	15
Chores take three to four times as long and I spend a large part of the day doing these	0
I can do most chores, but exceedingly slowly and requiring a lot of effort	10
I need help with half the chores and have difficulty with everything	2
I can assist with all the chores, but am only able to do a few on my own	2
I can manage a few chores with some effort, but need a lot of help	4
I do nothing on my own, but can be a slight help with some chores	4
I am totally dependent and helpless	6
I am bedridden	0

1.3. Receiving a diagnosis of Parkinson's disease

1990 was the earliest date that a respondent had been diagnosed with Parkinson's and 2014 the latest (12% had been diagnosed in 2014; the median date of diagnosis was 2010). Nearly all of the respondents had been diagnosed with Parkinson's in Ireland (94%), with the exception of three of the respondents who had been diagnosed in the UK (6%).

For most of the respondents, it had been less than 5 years since diagnosis (62%). 21% of respondents were diagnosed over 10 years ago (Figure 1).

Figure 1. Length of time since diagnosis (%)



The symptoms most commonly noticed before diagnosis included rigidity (stiffness), changes in the way you move (including the way you walk, dragging a leg, not swinging your arm, etc.), tremor, and slowness of movement. Interestingly people with these symptoms were more likely to seek help within a year. However with other symptoms, such as fatigue, loss of smell or taste, and anxiety, these symptoms could often continue for over five years before help was sought (Table 2).

Table 2. Reported symptoms and duration of these symptoms before seeking medical help

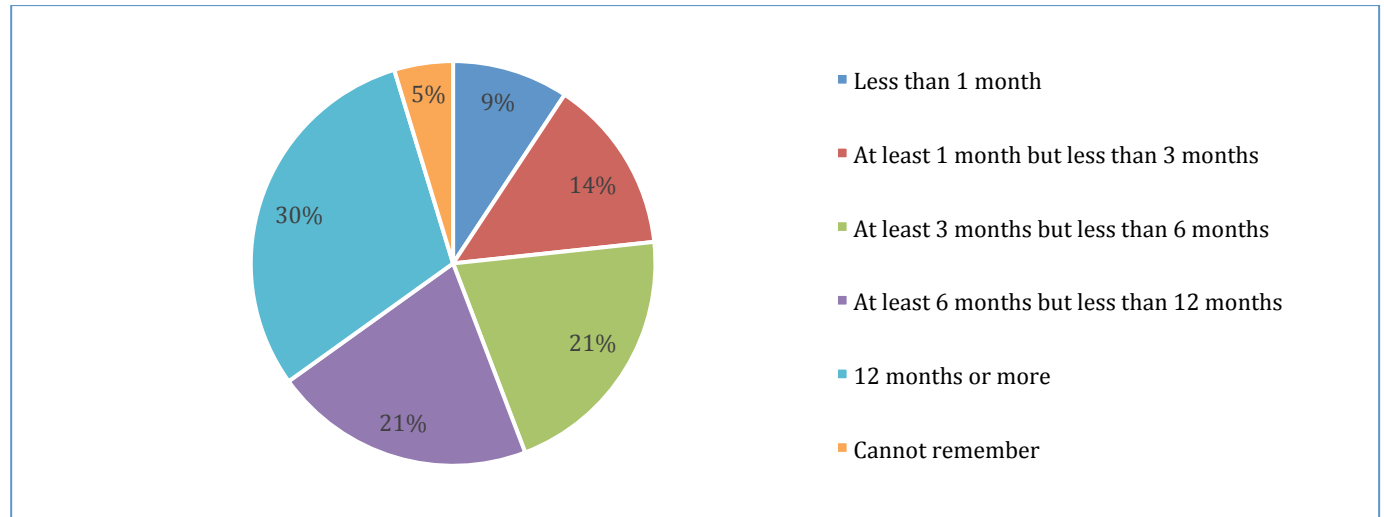
SYMPTOMS/PERCENTAGE OF RESPONDENTS ⁴¹	Less than 1 year	1 to 2 years	3 to 4 years	5 years or more	Total number of respondents experiencing symptom
Anxiety	10	4	6	15	35
Apathy	8	8	2	6	24
Bladder and bowel problems	3	2	5	2	12
Changes in the way you move (incl. the way you walk, dragging a leg, not swinging your arm, etc.)	12	12	7	2	33
Depression	2	3	3	5	13
Difficulty eating and/or swallowing	3	2	1	0	6
Eye problems	2	1	2	2	7
Falls (balance problems)	4	4	1	1	10
Fatigue	5	6	5	6	22
Freezing	5	3	2	0	10
Loss of smell or taste	6	3	2	6	17
Low blood pressure or dizziness	3	5	0	1	9
Muscle cramps	8	3	3	6	20
Pain	7	4	5	3	19
Rigidity (stiffness)	10	5	6	2	23
Skin and/or sweating problems	5	4	3	2	14
Sleep problems	8	7	4	6	25
Slowness of movement	11	8	4	1	24
Speech and communication problems (incl. small handwriting and reduced facial movements)	9	3	2	4	18
Stress	5	4	3	6	18
Thinking or memory problems	8	6	1	2	17
Tremor (shaking)	16	12	1	6	35

Other symptoms added by the respondents include: restless leg, numbness in the hands and a burning sensation in the shoulder. One respondent said that one of their first symptoms was: “a need to constantly count tablets, take appliances apart.”

⁴¹ Respondents could select “do not apply”; and select multiple options.

When asked how long it was before seeking medical help after first noticing their symptoms, nearly one-third waited 12 months or more (30%). The majority sought help within 3 to 12 months (47%) while 9% sought immediate help (within 1 month) (Figure 2).

Figure 2. Timelines for seeking medical help (%)



1.4. During the first appointment

For the overwhelming majority of respondents, during the first appointment with a healthcare professional, their medical history was discussed (72%), as well as a physical examination conducted (63%), and observation of symptoms (65%). Just over one-third were told that they might have Parkinson's (35%), although for another third of the respondents they were told that something was wrong, however the healthcare professional was unsure of the exact diagnosis (35%) (Table 3).

Table 3. Events during the first appointment with a healthcare professional (%)

EVENTS	Response (%) ⁴²
Discussed your general medical history	72
Carried out a physical examination	63
Observed your symptom(s)	65
Referred you to a specialist, or another doctor / healthcare professional	51
Said nothing was wrong	7
Said it was too early to tell if anything was wrong	9
Said something was wrong, but not sure what	35
Prescribed medication to relieve your symptom(s)	21
Explained that you may have Parkinson's	35
Explained that you may have another disease / condition	7

⁴² Respondents could select multiple options

A few respondents detailed other events which had happened at the first appointment, these included being told:

- They definitely did not have Parkinson's
- That the symptoms were caused by stress and bereavement
- They had an essential tremor
- To have massage and later cranial osteopathy
- It was just "*getting old*"

Respondents were asked, if they were referred to another healthcare professional, what the waiting times were ⁴³. If a referral was made, mostly this was to a neurologist (either general (49%) or one specialised in Parkinson's (64%). Only a small percentage of respondents were referred to a therapist (physiotherapist: 20%, occupational therapist: 10%, or speech and language therapist: 10%).

The waiting times to see neurologists were less than to see a therapist, with most of the respondents seeing a neurologist (either general or specialised) within three months. However a significant proportion of respondents still had to wait over 4 months to see a neurologist (Table 4).

Table 4. Waiting times to see professionals from referral (%) ⁴⁴

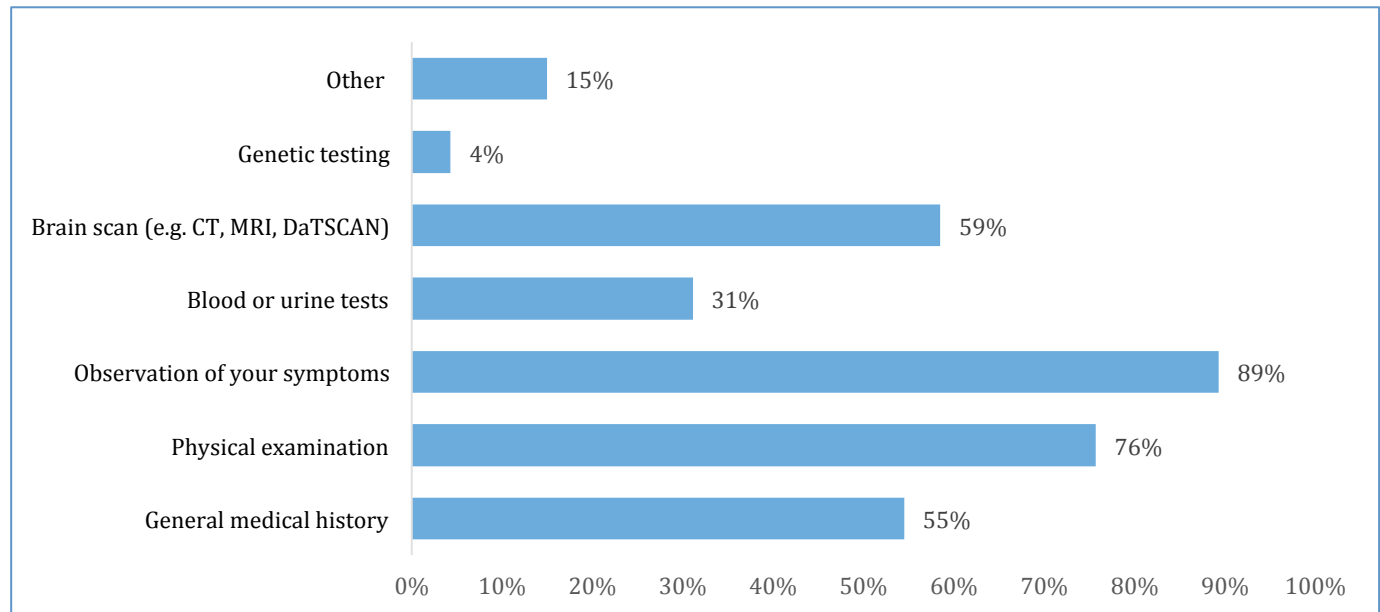
HEALTHCARE PROFESSIONAL	Within 1 month (%)	1-2 months (%)	2-3 months (%)	3-4 months (%)	4 months +
General neurologist	15	5	7	5	17
Neurologist Specialist in Parkinson's	17	7	12	7	20
Geriatrician	0	2	2	0	2
Parkinson's disease nurse specialist	2	2	2	0	7
Physiotherapist	2	0	0	2	15
Occupational therapist	0	0	0	2	7
Speech and language therapist	0	0	0	0	10

The overwhelming majority of respondents had their symptoms observed (89%) and underwent a physical examination (76%) to diagnose their Parkinson's disease. 59% of their respondents discussed their general medical history and 55% underwent a brain scan (Figure 3).

⁴³ Respondents were able to give multiple responses to the question

⁴⁴ Respondents could select all that applied or state that they could not remember

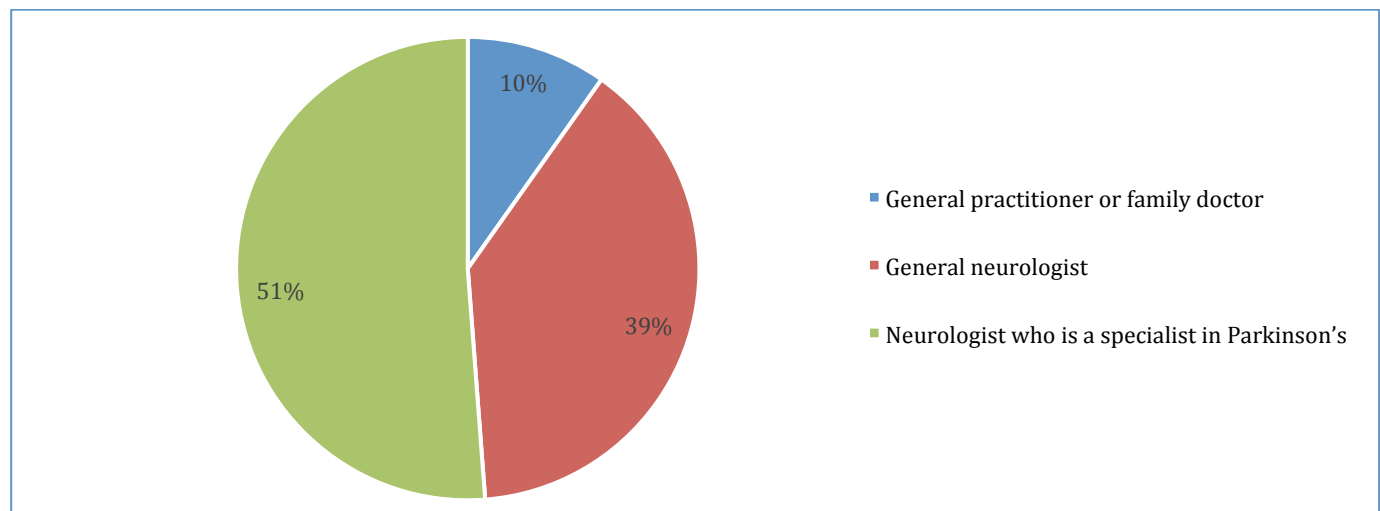
Figure 3. Examinations and tests carried out



1.5. Delivery of the diagnosis

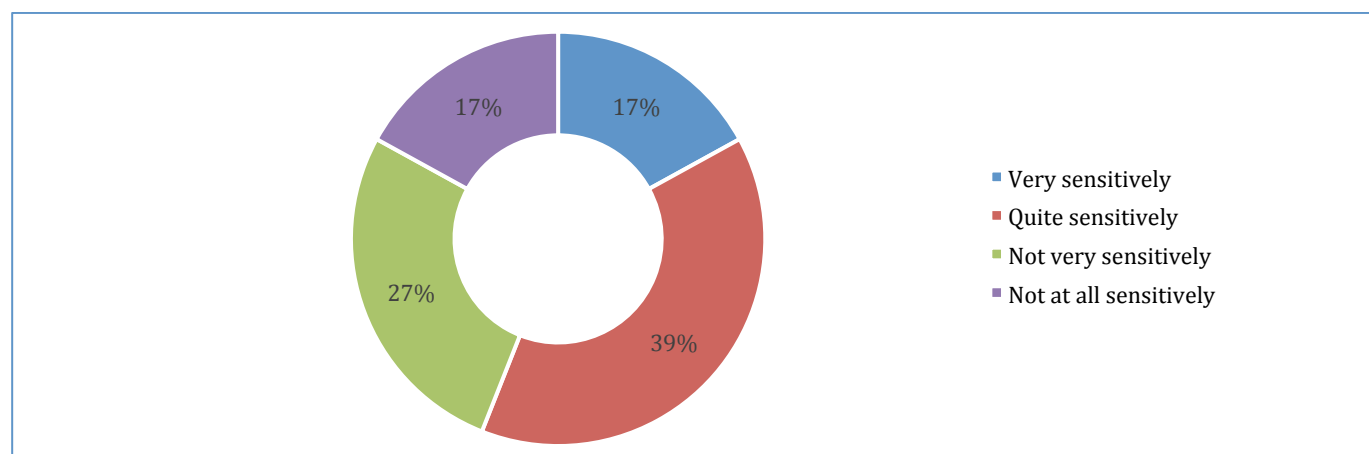
Just over half of the respondents received their diagnosis of Parkinson's from a neurologist specialised in the disease (51%) or a general neurologist (39%). Only 10% received the diagnosis from their GP (Figure 4). None of the respondents were given the diagnosis by a hospital doctor or geriatrician.

Figure 4. Healthcare professional diagnosing Parkinson's (%)



Responses were polarised in relation to the sensitivity in which the diagnosis was given. 56% feel that they were told either very sensitively or quite sensitively, while the remaining 44% believe that the diagnosis was not given sensitively (Figure 5). Despite nearly half of the respondents not feeling as if the diagnosis was given sensitively, only 24% feel dissatisfied or very dissatisfied with the consultation where the initial diagnosis was given. In comparison, 27% of respondents have a neutral opinion of their consultation, while 44% said they were satisfied or very satisfied. The remained could not remember.

Figure 5. Sensitivity of diagnosis (%)



1.6. Information given at diagnosis

At time of diagnosis, just over half of the respondents reported that they were given information verbally about the symptoms and causes of Parkinson's (54%) and the medication (62%). Only 7% were given information about clinical trials either verbally or with hand-outs; 2% of respondents said they did not want any information on this topic. 56% of respondents said that they were given either written or verbal information about how to maintain physical wellbeing (e.g. healthy eating or exercise) while 43% were given advice on maintaining mental wellbeing (Table 5).

Table 5. Information given⁴⁵

TOPIC AREA	Leaflet/ Handouts/ signposting to online information (%)	Explained verbally (%)	Both handouts and verbal information (%)	I did not want any information (%)	No information was provided
Symptoms, diagnosis and causes of Parkinson's	2	54	15	0	17
Medication	3	62	3	0	18
Surgical treatments	5	5	5	7	77
Non-drug treatments	5	17	12	5	56
Maintaining physical wellbeing	5	34	17	2	32
Maintaining emotional wellbeing	7	26	10	0	46
Financial help available	5	10	2	5	73
Support organisations (e.g. patient associations)	18	18	5	5	69
Support for carers	8	0	0	3	80
Where to find more information on Parkinson's	24	17	2	2	44
Taking part in clinical trials	0	5	2	2	78

⁴⁵ Respondents were also able to answer no information was provided or cannot remember.

Nearly half of the respondents found the information they were given either very or quite helpful (44%). However, 29% found the information not very helpful or not helpful.

Respondents are polarised in relation to the question enquiring whether or not they feel as if they had enough time to ask questions and discuss their concerns. Whilst 37% feel that they were given enough time, 37% also did not feel able to ask questions or discuss concerns at that time. 7% stated that they did not want to ask questions at that time (Table 6).

Table 6. Time to ask questions and discuss concerns – Question responses (%)

REPONSES	Response (%)
Yes, I was given enough time	37
Yes, but I would have liked more time	7
No, I was not given any time	10
I did not want to ask questions at that time	7
I did not feel able to ask questions or discuss concerns at that time	37
Cannot remember	2

1.7. Link between quality of life, satisfaction and availability of information

A bivariate correlation was conducted to explore the relationship between availability of information and quality of life. To calculate an 'information availability total', responses were coded '1' for leaflet, verbal, or both (i.e. 'some information provided'). These numbers were then totalled across all the categories respondents were asked to consider (i.e. medication, support for carers), with higher numbers equating to a greater availability of information.

The correlation between the quality of life (QoL) index score (Mean = .56) and the information total (Mean = 3) is in a positive direction; however it does not reach a satisfactory level of statistical significance ($n = 49$, $r = .25$, $p = .09$). Therefore we are unable to conclude that QoL is affected by the availability of information.

The relationship between information availability and satisfaction with care received was also explored via a correlation. No statistically significant relationship was observed ($n = 41$, $r = .06$, $p = .70$), suggesting levels of satisfaction with care are not associated with the availability of information.

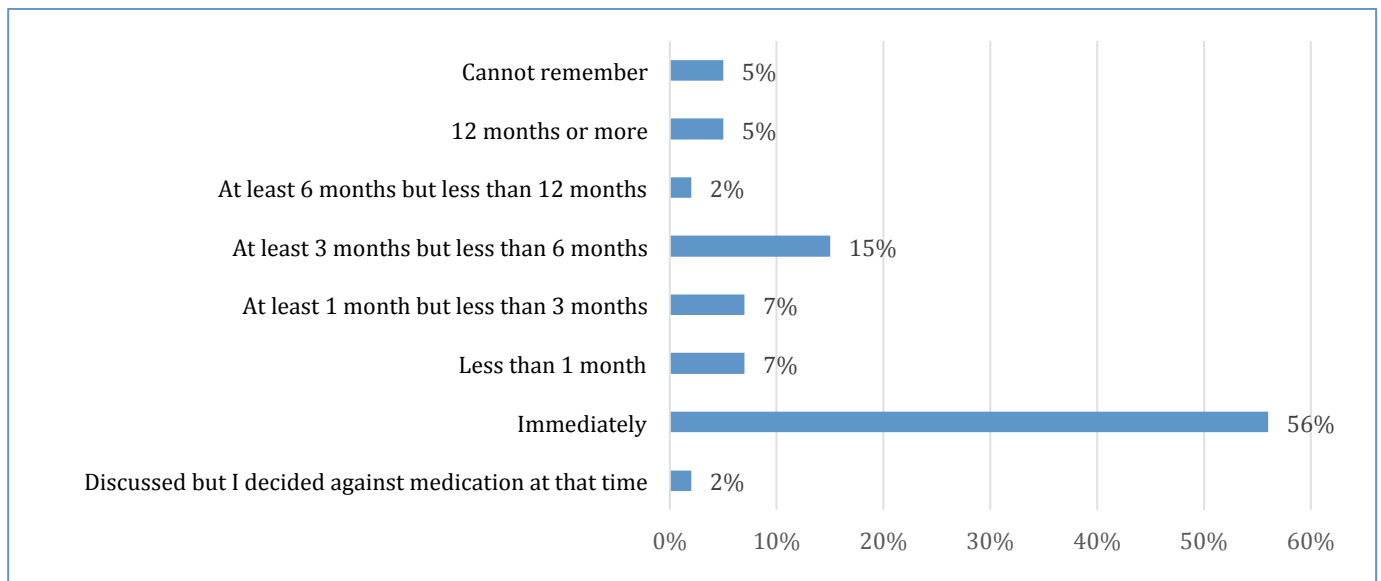
The relationship between satisfaction with treatment and information was also explored. A significant positive relationship emerges between availability of information and satisfaction with treatment ($n = 41$, $r = .35$, $p < .05$), suggesting levels of satisfaction with treatment are associated with availability of information. Respondents who report higher levels of satisfaction also receive more information (verbal and written).

Finally, the relationship between satisfaction with the consultation where the initial diagnosis was given and the amount of information provided was also explored via a correlation. Again, a positive correlation is noted suggesting a relationship between the two variables ($n = 40$, $r = .60$, $p < .01$). The amount of information provided (both verbal and written) seems to affect satisfaction levels with the initial diagnosis and consultation, with those receiving more information also reporting higher levels of satisfaction

1.8. Treatment

Just under 90% of respondents started medication or treatment within the first year after diagnosis, with over half of these starting immediately (56%) (Figure 6).

Figure 6. Medication and treatment timings (%)

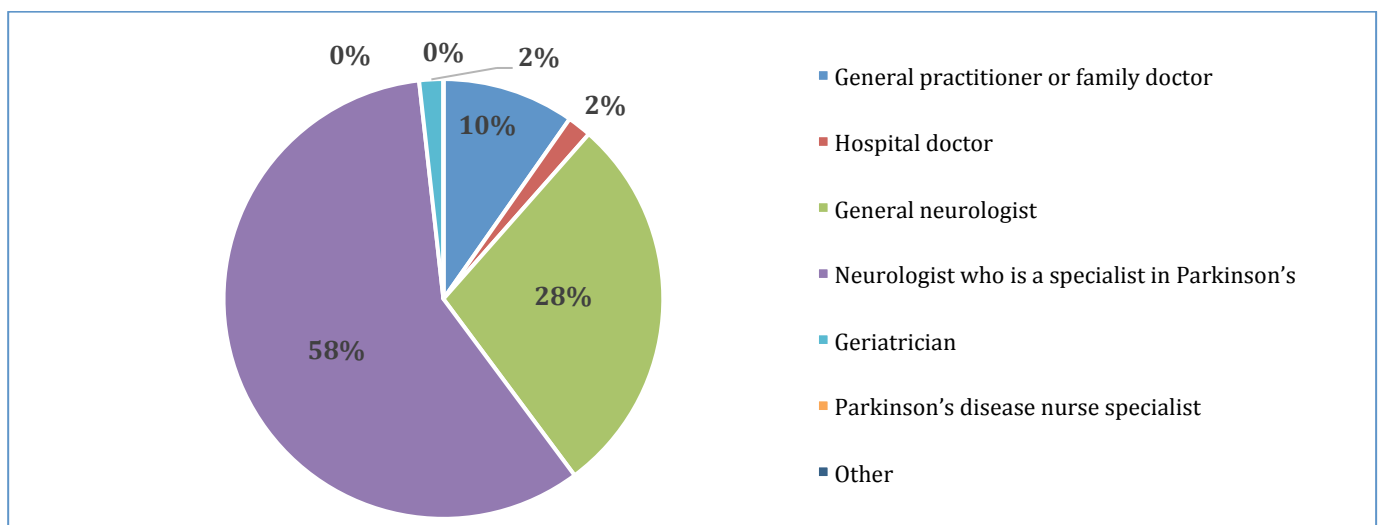


The most frequently taken medications are Sinemet (60% of respondents prescribed this medication) and Rasagiline (53%), which are predominantly prescribed by a general neurologist or a specialist neurologist. However, GPs did still on occasions prescribe both these medications (5-8% of the time).

Other medications which are prescribed include⁴⁶: Amantadine (15% of respondents); Apomorphine (5%); Entacapone (10%); Madopar (5%); Pramipexole (13%); Ropinirole (40%); Rotigotine (20%); Selegiline (18%); and Stalevo (18%).

As with Sinemet and Rasagiline, in the majority of cases, these medications are prescribed by a general neurologist or a specialist neurologist and very occasionally by a GP. Only two respondents mention a geriatrician prescribing any medication (they prescribed Pramipexole and Sinemet). No respondents report having medication prescribed by Parkinson's disease nurse specialists (Figure 7).

Figure 7. Healthcare professionals who prescribed the medication (%)



⁴⁶ Presented in alphabetical order

The overwhelming majority of respondents state that the state currently pays for their medication (90%). However, 23% also state that they pay for some medication privately (themselves/family) or their insurance pay (8%)⁴⁷. None of the respondents say that a Parkinson's organisation pay for the medication and all respondents know who pays for their medication.

As with the other countries, the intention was to explore the relationship between state vs. private funding in regard to satisfaction with care, medication review, and length of time to receive treatment. However, when splitting the groups, it became evident only 3 respondents had paid for treatment- therefore performing t-test comparisons became obsolete as this number is too small to perform a robust comparison of groups.

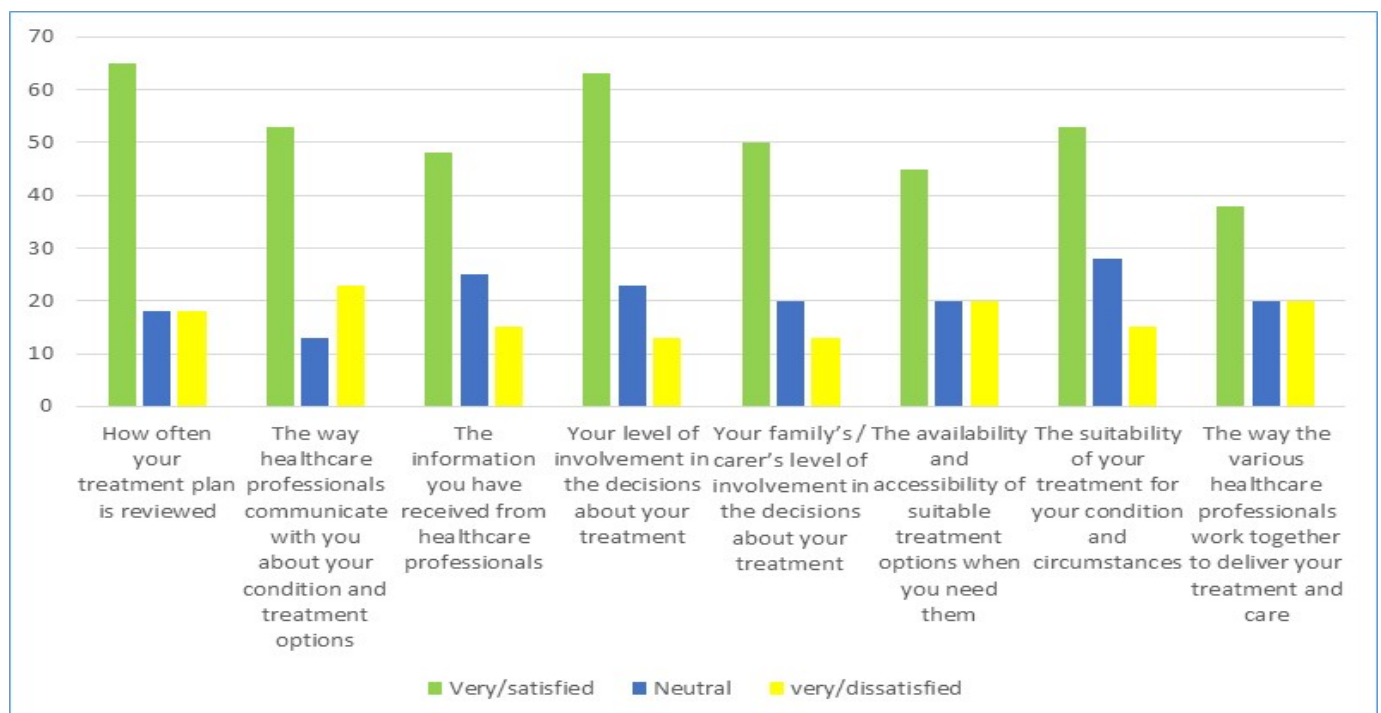
In addition, only 1 respondent reported being refused care due to cost or where they lived; hence the sample was too small to conduct a valid analysis to explore links between QoL and refusal of treatment.

1.9. Satisfaction

Most of the respondents are satisfied or very satisfied with the care they are receiving from all of the healthcare professionals they were asked to comment on (including clinical practitioners in both primary and secondary care, as well as therapists). Respondents are most likely to be dissatisfied with GPs (19% state they are dissatisfied or very dissatisfied) and speech and language therapists (27% dissatisfied or very dissatisfied). None of the respondents state that they are dissatisfied or very dissatisfied with their neurologist (who is a specialist in Parkinson's) or a geriatrician. However 20% do say they are dissatisfied in relation to the care they receive from a general neurologist.

In relation to treatment and overall care, respondents are most satisfied with how often their treatment plan are reviewed (65% satisfied) and their level of involvement in decisions about treatment (63%). However, there is less satisfaction in relation to other care aspects, in particular the way the various healthcare professionals work together to deliver the treatment and care (37% satisfied and 20% dissatisfied) (Figure 8).

Figure 8. Satisfaction with treatment and overall care (%)



⁴⁷ Respondents were asked to select all that applied and therefore the responses do not add up to 100%

The relationship between frequency of medication review and satisfaction with care was explored with a bivariate correlation. The correlation reveals no relationship between the two variables, suggesting the frequency of reviews does not impact on levels of satisfaction with care ($n = 41$, $r = .26$, $p = .10$).⁴⁸

Respondents also reported on the frequency of their medication reviews with different healthcare professionals (Table 7); because respondents may have more than one medication review a year, numbers in the table do not necessarily add up to 100%.

For the medication reviews, respondents state that a neurologist who is a specialist in Parkinson's reviews their medication either every six months (38%) or once a year (23%). Although fewer GPs review medication overall, they are more likely than any other health professional to review medication every three months. (Table 7).

Table 7. Medication reviews (%)⁴⁹

HEALTHCARE PROFESSIONALS	Every 3 months (%)	Every 6 months (%)	Once a year (%)	Once every 2 years or more (%)
General practitioner or family doctor	10	8	5	0
Hospital doctor	0	3	0	0
General neurologist	10	20	5	3
Neurologist who is a specialist in Parkinson's	0	38	23	2
Geriatrician	0	5	0	0
Parkinson's disease nurse specialist	3	5	5	0

A bivariate correlation was conducted to explore the relationship between quality of life and frequency of medication review. No significant relationship is demonstrated ($n = 49$, $r = .28$, $p = .06$) suggesting that in this sample, quality of life is not influenced by how frequent medication is reviewed.

A final bivariate correlation was run to assess the relationship between quality of life and satisfaction with care. Using the quality of life index and the satisfaction for care index, no significant relationship is demonstrated ($n = 40$, $r = -.03$, $p = .82$) suggesting quality of life is not influenced by how satisfied respondents were with their care.

1.10. Advanced treatments

Only three of the respondents have received surgical treatments. All of them say that it was "Deep Brain Stimulation" which they had received. Two of the respondents had the surgery 6 to 10 years after diagnosis, and the other respondent answered between 11 to 15 years. All three of the respondents say that the surgery has met their expectations and two of the respondents gave further explanation on this:

"Controls my tremor, reduced meds and gave me a new lease of life."

"My medication has been reduced dramatically and my tremor has been controlled. DBS has given me a new lease of life."

The research team was not able to look at the correlations between receiving advanced treatments and QoL/satisfaction variables as there are too few respondents who have received advanced treatments.

⁴⁸ Respondents who indicated 'do not know' and 'does not apply' were not included in this analysis

⁴⁹ Respondents were also able to state that they did not know or that it did not apply for them.

1.11. Findings in relation to the national guidelines

Although HSE (Ireland's public health and social care services) are currently developing a model of care and patient pathways for Parkinson's disease these have yet to be published. Therefore, it was reported (during the qualitative interviews), that the UK's NICE guidelines are followed.

In summary, the NICE guidelines, published in 2006, state that:

- People with suspected Parkinson's should be referred quickly (within 6 weeks) and untreated to a specialist with expertise in the differential diagnosis of the condition;
- The diagnosis of Parkinson's should be reviewed regularly (every 6 to 12 months);
- People with Parkinson's should have regular access to the following, which may be provided by a specialist Parkinson's nurse: monitoring and medication adjustment a continuing point of contact for support, including home visits when needed a reliable source of information about clinical and social matters of concern to people with Parkinson's and their carers;
- Access to physiotherapy, speech and language therapy and occupational therapy should be available; and
- Palliative care requirements should be considered in all phases of the condition. People with Parkinson's and their carers should be given the opportunity to discuss end-of-life issues with appropriate healthcare professionals.

Only 24% and 20% of respondents had seen either a neurologist who is a specialist in Parkinson's or general neurologists (respectively) within two months of referral. This would suggest that for many, the six-week target is not achieved. However, most respondents do say that they see their neurologist every six months for a review meeting. However, if under the care of a neurologist who is a specialist in Parkinson's, for 23% of respondents this review was conducted annually.

As there are only five reported specialist Parkinson's nurse's for Ireland, access to a nurse is limited. From the survey we cannot determine what access to physiotherapy, speech and language therapy and occupational therapy there is. However, the survey does show that referrals to these services are small in number.

APPENDIX II-F: SURVEY FINDINGS FOR ITALY

1.1. Sample profile

In total 151 respondents completed the survey from Italy. 51% of respondents are male and the average age of respondents was 58 years when they were diagnosed with Parkinson's, with the youngest aged 31 and the oldest aged 87 years. Only 25% are currently employed. When asked to describe the area in which they live, 15% state rural, 54% town, with the remaining 31% living in cities.

1.2. Quality of life and disability scores

To explore quality of life, EuroQol's EQ-5D measure was utilised. This is a standardised instrument for measuring of health status and requires respondents to answer five questions focusing on **mobility**, **self-care**, **usual activities**, **pain**, and **anxiety/depression**.

Regarding **mobility**, 23% report no problems walking, while 64% report some problems. 13% of respondents indicate that they are confined to a bed⁵⁰.

Moving on to **self-care**, 20% report they are unable to wash or dress themselves and 30% that they have some problems with washing or dressing. The majority of respondents (50%) indicate no problems with self-care.

When asked about current ability to perform **everyday activities** such as work and leisure, 61% of respondents experience some problems performing these activities, while 22% indicate no problems at all. Those who are unable to perform any everyday activities are the smallest group, accounting for 17% of the sample.

When discussing current levels of **pain and discomfort**, the majority of the sample- 63%- indicate that they suffer from moderate pain, while 13% indicate having no pain or discomfort. Those who suffer from extreme pain represent 24% of the sample.

The final question assessing current quality of life focuses on levels of **anxiety and depression**. Over half of respondents (58%) indicate moderate levels of anxiety or depression, while 22% report no feelings of anxiety or depression. The smallest proportion of the sample (20%), report feelings of extreme anxiety or depression.

Compared with their general health over the last 12 months, only 8% state that their health is *better*. The majority of respondents feel that their health is *worse* (58%). 34% of respondents feel that their health is *much the same*.

When asked to rate which statement best describes how they feel about their independence, none of the respondents report to being bed bound; although 10% of them state that they are *"totally dependent and helpless"*. The most commonly recorded response is *'I am able to do all chores with some degree of slowness, difficulty and impairment, and am beginning to be aware of difficulty'* (33%) (Table 1).

⁵⁰ Results based on the number of respondents answering Question 7. This result may not tally with the number stating they are bedridden in Question 13, the results of which are shown in Table 1.

Table 1. Self-reported disability score

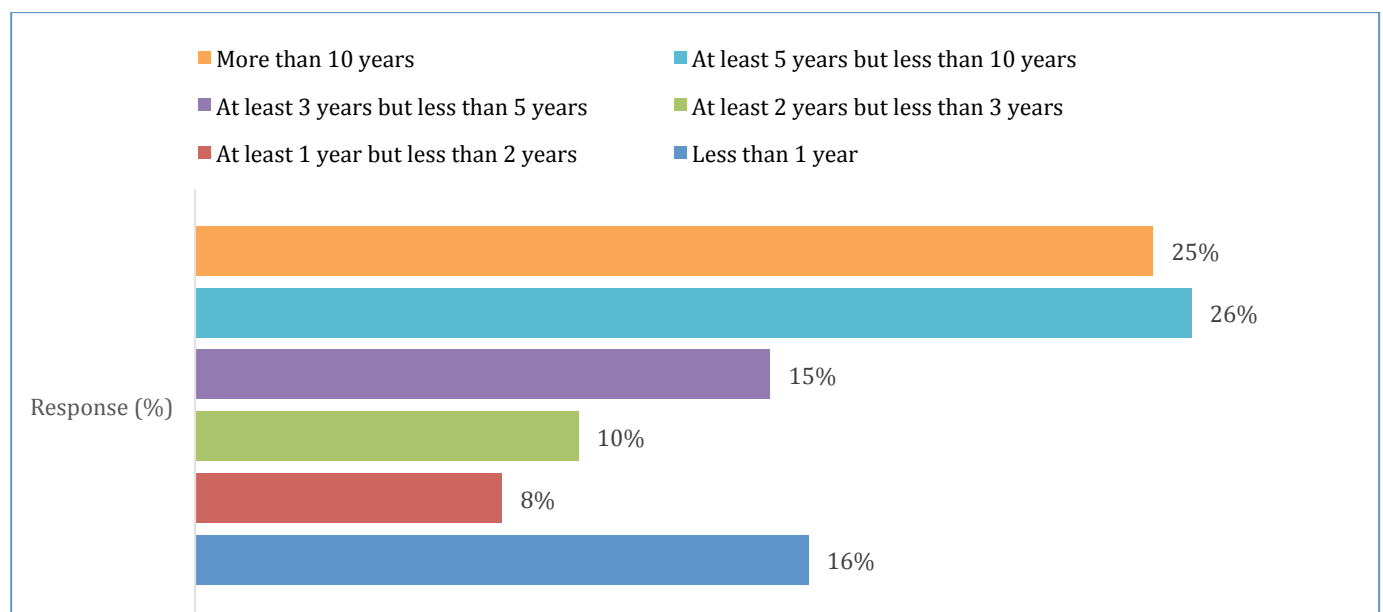
STATEMENTS	Response (%)
I am able to do all chores without slowness, difficulty or impairment	8
I am able to do all chores with some degree of slowness, difficulty and impairment, and am beginning to be aware of difficulty	33
Chores take twice as long and I am conscious of difficulty and slowness	19
Chores take three to four times as long and I spend a large part of the day doing these	1
I can do most chores, but exceedingly slowly and requiring a lot of effort	11
I need help with half the chores and have difficulty with everything	1
I can assist with all the chores, but am only able to do a few on my own	5
I can manage a few chores with some effort, but need a lot of help	7
I do nothing on my own, but can be a slight help with some chores	5
I am totally dependent and helpless	10
I am bedridden	0

1.3. Receiving a diagnosis of Parkinson's disease

1987 was the earliest date that a respondent had been diagnosed with Parkinson's and 2014 the latest (5% had been diagnosed in 2014; the median date of diagnosis was 2007). 97% of respondents had been diagnosed with Parkinson's in Italy, although five had been diagnosed in either France, Slovenia or Romania.

For 50% of respondents, it has been less than 5 years since diagnosis. 25% of respondents were diagnosed over 10 years ago (Figure 1).

Figure 1. Length of time since diagnosis (%)



The symptoms most commonly noticed before diagnosis included changes in the way you move (including the way you walk, dragging a leg, not swinging your arm, etc.), slowness of movement, fatigue, and tremor. People with these symptoms were more likely to seek help within a year. However with other symptoms, such as depression, bladder and bowel problems and sleep problems, these symptoms could often continue for up to five years before help was sought (Table 2).

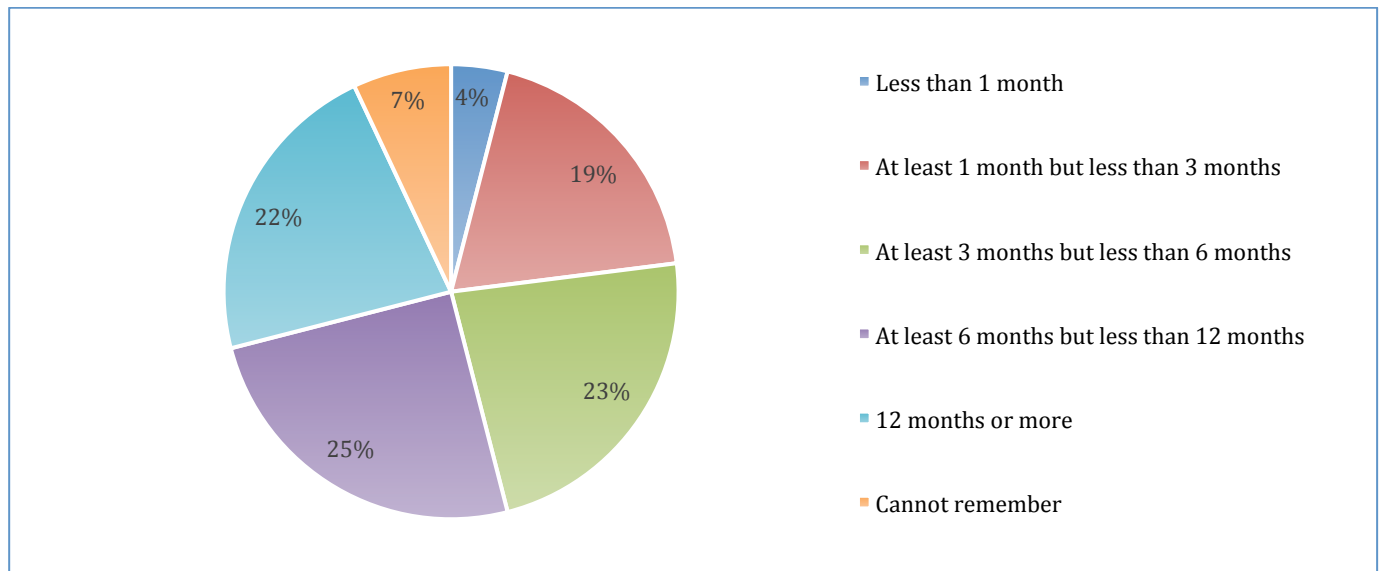
Table 2. Reported symptoms, and duration of these symptoms before seeking medical help (%)

SYMPTOMS/PERCENTAGE OF RESPONDENTS¹	Less than 1 year	1 to 2 years	3 to 4 years	5 years or more	Total number of respondents experiencing symptoms
Anxiety	13	5	11	13	42
Apathy	9	13	6	6	35
Bladder and bowel problems	9	10	5	14	38
Changes in the way you move (incl. the way you walk, dragging a leg, not swinging your arm, etc.)	30	32	8	9	79
Depression	12	7	10	12	42
Difficulty eating and/or swallowing	12	8	2	3	24
Eye problems	12	10	2	6	29
Falls (balance problems)	16	9	4	5	34
Fatigue	24	20	10	11	65
Freezing	16	7	3	4	30
Loss of smell or taste	12	7	9	13	42
Low blood pressure or dizziness	14	13	6	4	37
Muscle cramps	19	19	8	9	54
Pain	19	12	6	6	43
Rigidity (stiffness)	25	15	10	6	56
Skin and/or sweating problems	6	12	5	8	32
Sleep problems	19	14	11	17	61
Slowness of movement	27	20	11	9	66
Speech and communication problems (incl. small handwriting and reduced facial movements)	29	20	5	6	61
Stress	13	13	12	12	50
Thinking or memory problems	17	11	4	8	39
Tremor (shaking)	33	14	8	6	61

Other symptoms added by the respondents include difficulties driving and problems with cleaning teeth.

When asked how long it was before seeking medical help after first noticing your symptoms, nearly a quarter of respondents waited 12 months or more (22%). Two thirds of respondents sought help within three to 12 months (67%), while 4% sought immediate help (within 1 month) (Figure 2).

Figure 2. Timelines for seeking medical help (%)



1.4. During the first appointment

During the first appointment with a healthcare professional, just under one half of respondents underwent a physical examination (47%) or discussed their medical history (45%). 58% of respondents reported undergoing an observation of their symptoms. 41% of respondents were told that they might have Parkinson's, although another 21% of respondents were told that something was wrong; however the healthcare professional was unsure of the exact diagnosis. Less than one half of respondents (43%) were referred to another doctor or healthcare professional following their first appointment (Table 3).

Table 3. Events during the first appointment with a healthcare professional (%)

EVENTS	Response (%) ¹
Discussed your general medical history	45
Carried out a physical examination	47
Observed your symptom(s)	58
Referred you to a specialist, or another doctor / healthcare professional	43
Said nothing was wrong	8
Said it was too early to tell if anything was wrong	5
Said something was wrong, but not sure what	21
Prescribed medication to relieve your symptom(s)	15
Explained that you may have Parkinson's	41
Explained that you may have another disease / condition	9

17% of respondents detailed other events which had happened at the first appointment, including being told:

- There was nothing wrong
- They might have Multiple Sclerosis
- They might have depression

Respondents were asked, if they were referred to another healthcare professional, what the waiting times were. If a referral was made, this was mostly to a neurologist (either general or one specialised in Parkinson's disease). Few respondents were referred to any other healthcare professional with the exception of physiotherapists (20% of respondents referred).

Most of the respondents saw a neurologist (either general or specialised) within three months of referral with a significant proportion of these appointments taking place within one month. (Table 4).

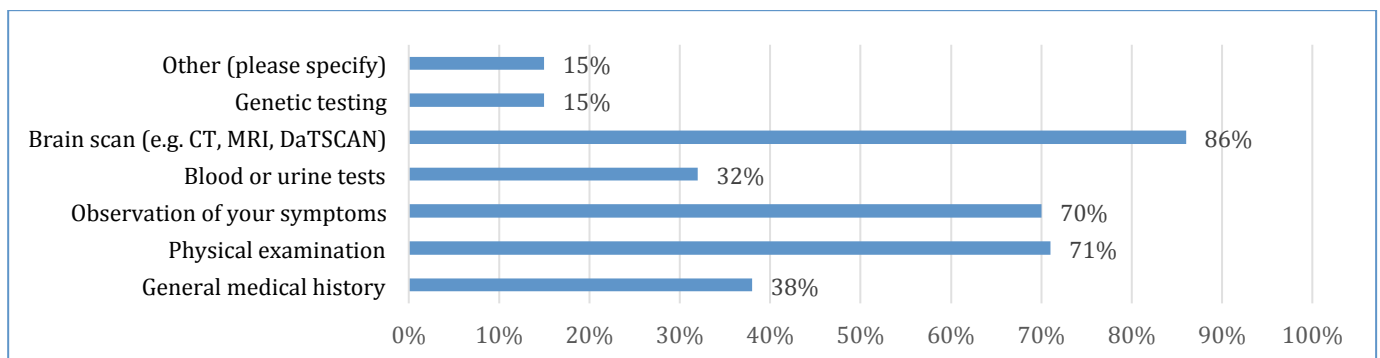
Table 4. Waiting times to see professionals from referral (%)¹

HEALTHCARE PROFESSIONAL	Within 1 month (%)	1-2 months (%)	2-3 months (%)	3-4 months (%)	4 months +	% of respondents referred
General neurologist	32	10	3	3	8	61
Neurologist Specialist in Parkinson's	29	12	6	6	19	74
Geriatrician	2	1	0	0	1	5
Parkinson's disease nurse specialist	2	1	0	0	1	5
Physiotherapist	9	3	0	2	6	20
Occupational therapist	2	1	0	0	2	6
Speech and language therapist	3	2	0	0	5	11

To diagnose their Parkinson's disease nearly three quarters of respondents state that they had their symptoms observed (70%) or underwent a physical examination (71%). The vast majority of respondents had a brain scan (86%) (Figure 3). 15% of respondents also mention that they also underwent other types of examinations and tests during diagnosis, including:

- PET (Positron emission tomography) Scan
- Scintigraphy

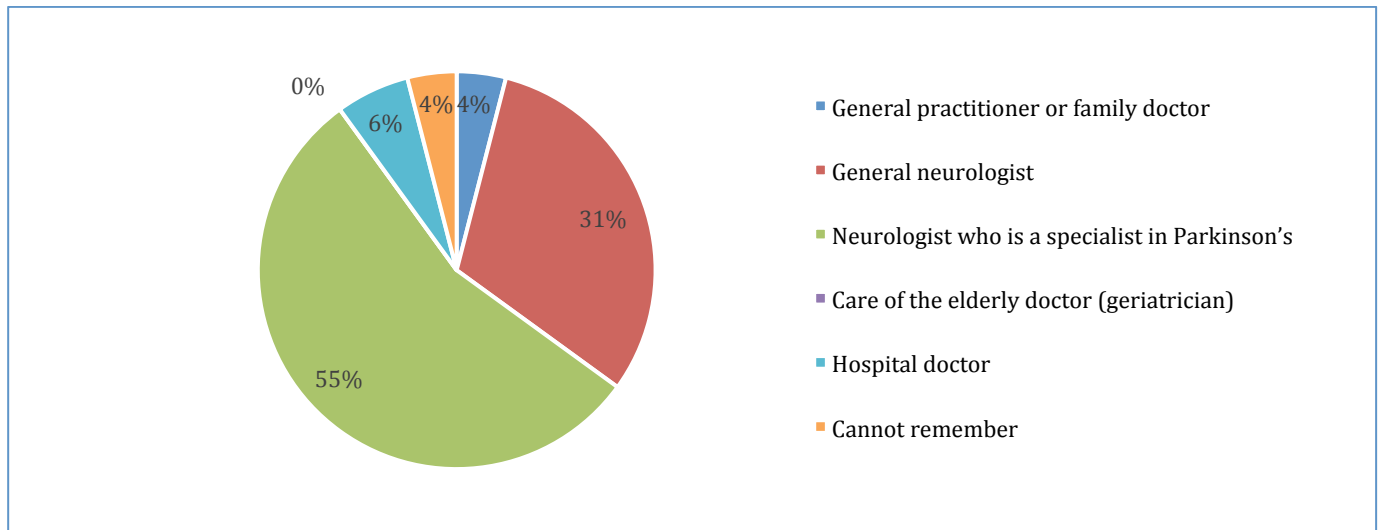
Figure 3. Examinations and tests carried out



1.5. Delivery of the diagnosis

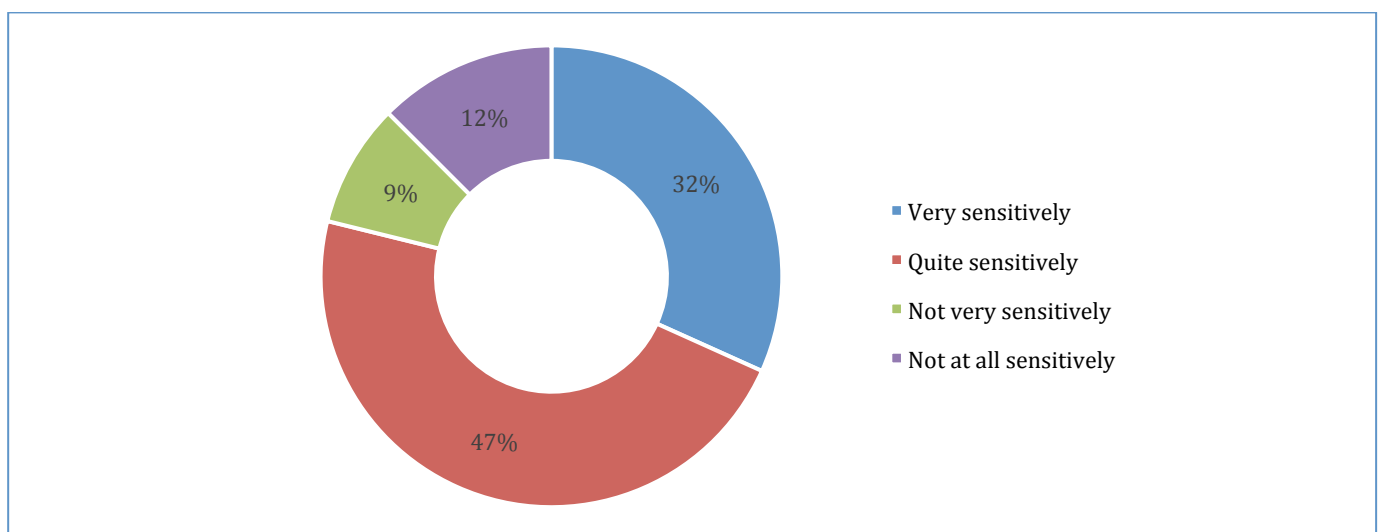
Over a half of respondents received their diagnosis of Parkinson's from a neurologist specialised in the disease (55%), while a further third were diagnosed by a general neurologist (31%). 6% of respondents received the diagnosis from a hospital doctor and another 4% from their GP or family doctor. No respondent was given their diagnosis by a geriatrician (Figure 4).

Figure 4. Healthcare professional diagnosing Parkinson's (%)



Responses were overwhelmingly positive in relation to the sensitivity in which the diagnosis was given (Figure 5). 79% of respondents feel that they were told either very sensitively or quite sensitively, while the other 21% believe that the diagnosis was not given sensitively. Similarly, only 18% of respondents feel dissatisfied or very dissatisfied with the consultation where the initial diagnosis was given. In comparison, 72% of respondents say they are satisfied or very satisfied with this consultation and the remaining 10% have a neutral opinion.

Figure 5. Sensitivity of diagnosis (%)



1.6. Information given at diagnosis

At time of diagnosis, just under a half of the respondents report that they were given information verbally about the symptoms and causes of Parkinson's (46%) while a half were also told about medication (51%). 29% of respondents were given information about clinical trials either verbally, with handouts or through signposting to online information, while 9% report that they did not want any information on this subject. 60% of respondents state that they were given written or verbal information about how to maintain physical wellbeing (e.g. healthy eating or exercise) and 50% of them received advice on maintaining mental wellbeing (Table 5).

Table 5. Information given (%)¹

TOPIC AREA	Leaflet/ handouts/ signposting to online information (%)	Explained verbally (%)	Both handouts and verbal information (%)	I did not want any information (%)	No information was provided
Symptoms, diagnosis and causes of Parkinson's	15	46	7	16	4
Medication	16	51	13	13	4
Surgical treatments	5	6	7	6	2
Non-drug treatments	14	22	5	8	9
Maintaining physical wellbeing	19	29	11	12	9
Maintaining emotional wellbeing	14	26	10	13	14
Financial help available	2	6	9	14	18
Support organisations (e.g. patient associations)	6	11	7	9	16
Support for carers	3	7	8	11	19
Where to find more information on Parkinson's	10	18	7	9	17
Taking part in clinical trials	7	15	7	9	16

Amongst respondents who received information, 75% found the information they were given either very or quite helpful. In contrast, 25% found the information either not very helpful or not helpful.

In relation to the question enquiring whether or not respondents felt as if they had enough time to ask questions and discuss their concerns, 44% of respondents feel that they were given enough time compared to just 8% who were not given time to ask questions. A further 22% of respondents would have appreciated more time to ask questions. 17% of respondents felt unable to ask questions at the time of diagnosis while 7% did not want to ask questions at that time (Table 6).

Table 6. Time to ask questions and discuss concerns – Question responses (%)

REPONSES	Response (%)
Yes, I was given enough time	44
Yes, but I would have liked more time	22
No, I was not given any time	8
I did not want to ask questions at that time	7
I did not feel able to ask questions or discuss concerns at that time	17
Cannot remember	3

1.7. Link between quality of life, satisfaction, and availability of information

A bivariate correlation was conducted to explore the relationship between availability of information and quality of life. To calculate an 'information availability total', responses were coded '1' for leaflet, verbal, or both (i.e. 'some information provided'). These numbers were then totalled across all the categories respondents were asked to consider (i.e. medication, support for carers), with higher numbers equating to a greater availability of information.

The correlation between the quality of life (QoL) index score (Mean = .44) and the information total (Mean = 3) is in a positive direction; however it does not reach a satisfactory level of statistical significance ($n = 142^1$, $r = .11$, $p = .18$). Therefore we are unable to conclude that QoL is affected by the availability of information.

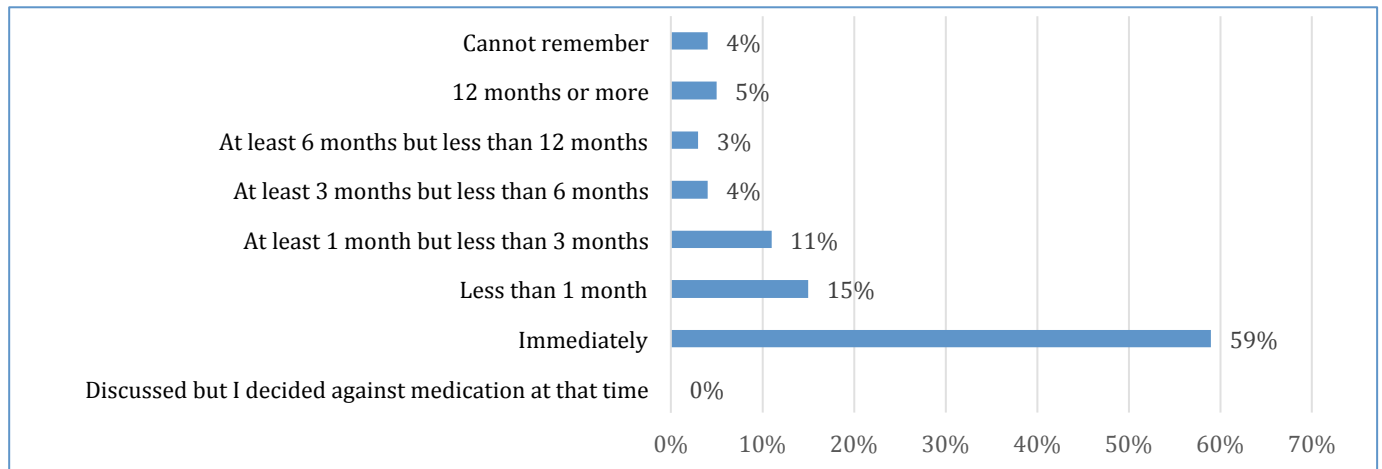
The relationship between information availability and satisfaction with care received was also explored via a correlation. No statistically significant relationship was observed ($n = 98$, $r = .01$, $p = .52$), suggesting levels of satisfaction with care were not associated with the availability of information. The relationship between satisfaction with treatment and information was also explored. Again, no relationship emerges between availability of information and satisfaction with treatment ($n = 95$, $r = -.17$, $p = .11$), suggesting levels of satisfaction with treatment are not associated with availability of information.

Finally, the relationship between satisfaction with the consultation where the initial diagnosis was given and the amount of information provided was also explored via a correlation. In contrast to the previous correlations, results suggest a significant negative relationship between the two variables ($n = 108$, $r = -.41$, $p < .01$). – the amount of information provided (both verbal and written) seems to affect how satisfied PwP are with the initial diagnosis and consultation. Specifically, the more information provided, the less satisfied respondents are with the consultation.

1.8. Treatment

Over 92% of respondents started medication or treatment within the first year after diagnosis, with 59% of them starting immediately. No respondents indicated that they opted not to take medication at the time of diagnosis (Figure 6).

Figure 6. Medication and treatment timings (%)

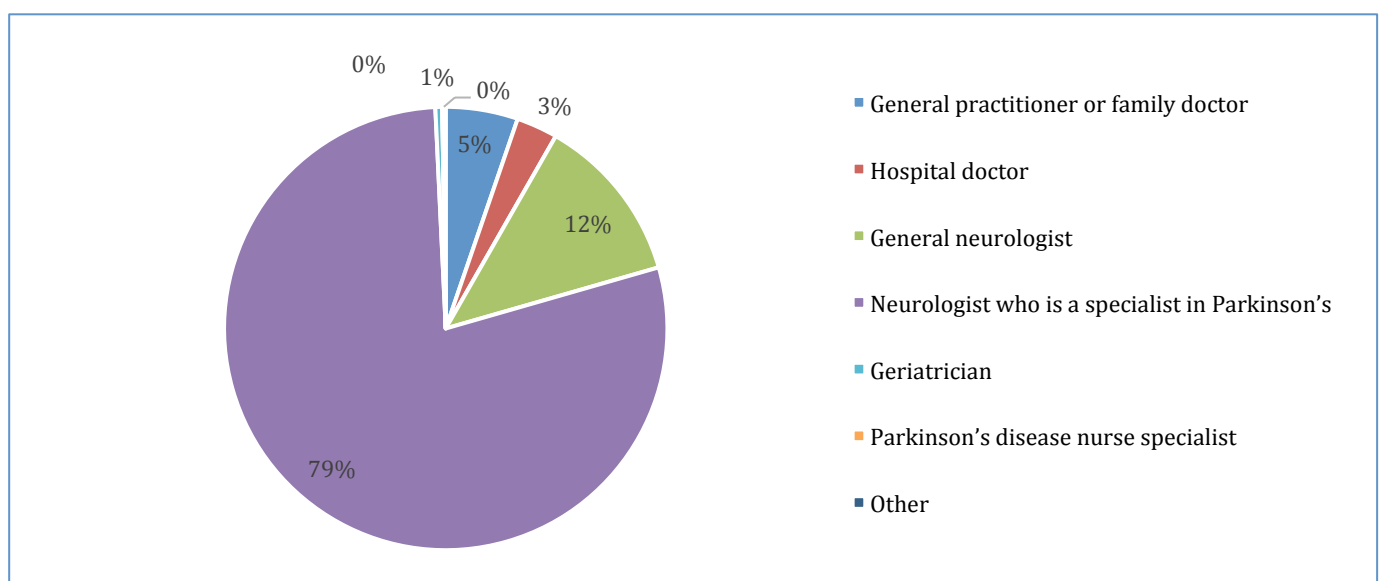


The most frequently taken medications are: Rasagaline (54% of respondents prescribed this drug); Pramipexole (51%); Sinemet (50%); Madopar (49%); and Ropinirole (48%). These drugs are almost exclusively prescribed by a specialist neurologist.

Other medications which are prescribed include¹: Entacapone (12% of respondents); Rotigotine (32%); Stalevo (33%); and Tolcapone (15%).

As with Rasagaline, Pramipexole, Sinemet, Madopar and Ropinirole, for the vast majority of the time, these medications are prescribed by a specialist neurologist. Indeed specialist neurologists are responsible for nearly four fifths of all prescriptions (79%), with a further 12% prescribed by a general neurologist. No respondents report receiving a prescription from a Parkinson's disease nurse specialist or geriatrician (Figure 7).

Figure 7. Healthcare professionals who prescribed the medication (%)



85% of respondents state that the state funds their medication while just under one third mention that they or their families pay for medication privately (29%). A further 3% of respondents report that their insurance pays for medication¹. No respondent reports that a Parkinson's organisation pays for the medication and 4% do not know who pays.

The relationship between satisfaction with care and paying for treatment was explored. Responses about paying for treatment were assigned a group based on whether care was state funded or by private/insurance¹. An independent samples t-test¹ was conducted to investigate whether satisfaction with care differed according to whether respondents paid for the treatment or not. This analysis reveals no statistical difference. Mean levels of satisfaction do not differ between the groups. Respondents who pay for treatment (either through insurance or privately) report higher levels of satisfaction with care ($n = 13$, $M_{\text{satisfaction}} = 13$) compared to those respondents whose treatment is state funded ($n = 67$, $M_{\text{satisfaction}} = 8$), but the difference does not reach an acceptable level of statistical significance ($t = 1.65$, $p = .10$).¹

A second independent t-test was conducted to explore if access to health care professionals (as measured by frequency of medication review) differs according to how the health care is funded (i.e. state vs. private). Respondents who receive state funded care ($n=67$, $M_{\text{review}} = 3$) report less frequent reviews of medication, compared to respondents who pay for treatment ($n=13$, $M_{\text{review}} = 4$); however, the comparison between the two groups reveals no significant difference according to the two types of funding ($t = 1.01$, $p = .32$).

Using length of time to gain access to treatment after diagnosis, as a proxy for availability, a further independent t-test was conducted to establish if length of time differed between state ($n=67$, $M_{\text{time}} = 3$) versus private funding ($n=13$, $M_{\text{time}} = 3$). Again, no differences in treatment waiting times are noted between the two groups ($t = 1.00$, $p = .32$).

Only 17 respondents reported being refused care due to cost and 13 due to where they lived; hence the samples are too small to conduct a valid analysis to explore links between QoL and refusal of treatment.

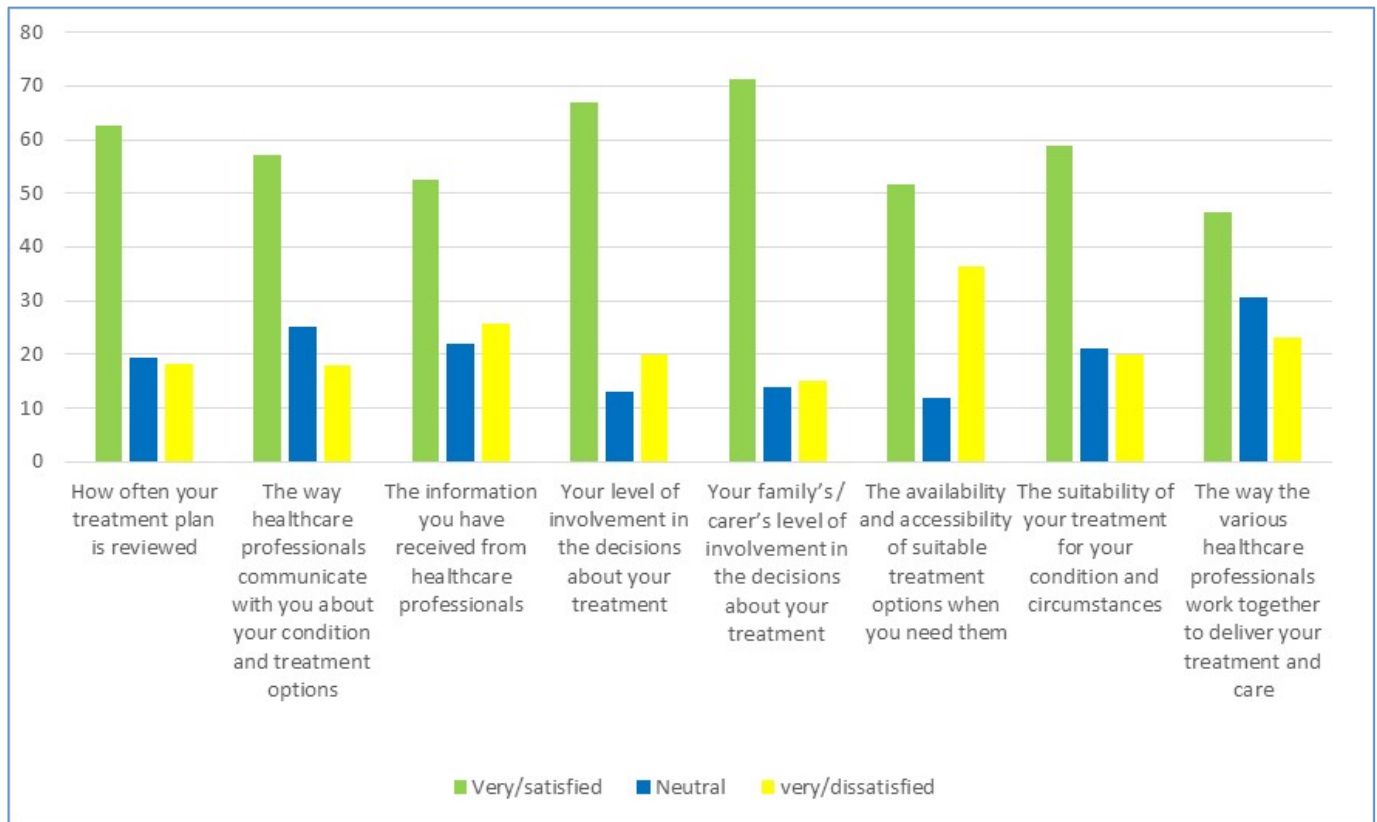
1.9. Satisfaction

Across nearly all healthcare professions, the highest levels of satisfaction are with specialist neurologists (78% satisfied) physiotherapists (69%) and GPs (61%). Less than half of respondents are satisfied with the care they are receiving from general neurologists (47% satisfied), Parkinson's disease nurse specialists (47%) and occupational therapists (30%).

Levels of dissatisfaction are highest with occupational therapists (50% dissatisfied), geriatricians (46%) and Parkinson's disease nurse specialists (40%). However the actual number of respondents using these professionals is small in comparison to the number using specialist neurologists where only 14% of respondents are dissatisfied.

Levels of satisfaction by respondents with different aspects of their care varied markedly between categories. Respondents are most satisfied with their family's/carer's level of involvement in decisions about their care (71%) and least satisfied about how different healthcare professionals work together to deliver treatment and care (46%). The highest level of dissatisfaction is recorded in the availability and accessibility of suitable treatment options where 36% of respondents state that they are dissatisfied (Figure 8).

Figure 8. Satisfaction with treatment and overall care (%)



The relationship between frequency of medication review and satisfaction with care was explored with a bivariate correlation. Responses provided for 'how often is your medication reviewed and by who' were coded so that most frequent reviews ('every 3 months') were assigned the highest number '4', through to '1' for 'once every 2 years'. The correlation reveals a significant small sized relationship between satisfaction with care and frequency of review. Hence, this result suggests that respondents who benefit from more frequent reviews also report higher levels of satisfaction with their care ($n = 98$, $r = .28$, $p < .01$).¹

Respondents also reported on the frequency of their medication reviews with different healthcare professionals (Table 7); because respondents may have more than one medication review a year, numbers in the table do not necessarily add up to 100%.

For the medication reviews, most respondents state that a neurologist who is a specialist in Parkinson's reviews their medication either every six months (45%) or once a year (24%). Apart from GPs, few other healthcare professionals carry out reviews of respondent's medication. Just under half of respondents (44%) report that they have their medication reviewed at least every 3 months by a healthcare professional, predominantly by a specialist neurologist or GP (Table 7).

Table 7. Medication reviews (%)¹

Healthcare professionals	Every 3 months (%)	Every 6 months (%)	Once a year (%)	Once every 2 years or more (%)
General practitioner or family doctor	16	7	4	0
Hospital doctor	2	6	3	0
General neurologist	4	6	6	0
Neurologist who is a specialist in Parkinson's	19	45	24	1
Geriatrician	1	2	1	0
Parkinson's disease nurse specialist	2	4	1	0

A Bivariate correlation was conducted to explore the relationship between quality of life and frequency of medication review. No significant relationship was observed ($n = 142$, $r = .05$, $p = .56$), suggesting QoL is not associated with frequency of medication review.

In addition, a second bivariate correlation was run to assess the relationship between quality of life and satisfaction with care. Using the quality of life index and the satisfaction for care index, again no significant relationship emerges ($n = 98$, $r = -.12$, $p = .23$) suggesting QoL is not influenced by how satisfied respondents are with their care.

1.10. Advanced treatments

Eight respondents report receiving surgical treatment in the form of "Deep Brain Stimulation". Two of the respondents had the surgery within 5 years of diagnosis, while five answered between 6 to 10 years after diagnosis. The remaining respondent reported having the treatment over 11 years after diagnosis. Respondents who comment on the effectiveness of the surgery are generally negative. One respondent says: "After a promising start...there was a worsening of my condition" while another concludes: "The disadvantages outweigh the benefits."

The research team were not able to look at the correlations between receiving advanced treatments and QoL/satisfaction variables as there are too few respondents who have received advanced treatments.

1.11. Findings in relation to the national guidelines

National guidelines for the diagnosis and treatment of PD were developed by the National Institute of Health in 2010 and revised again in August 2013. These guidelines recommend that:

- Neurologists should be aware of the lack of specificity of the clinical diagnosis of PD in the early stages of the disease and to take into account this uncertainty in informing and planning the management of the patient;
- Patients should be offered regular follow-up appointments to improve the management of PD;
- The most effective therapy for treatment of symptoms is L-Dopa although prolonged use of L-Dopa can result in various complications such as dyskinesia,
- Therefore for Parkinson's patients with an early onset, consideration should be given to treating with Dopamine-based drugs such as Pramipexole, Ropinirole and Rotigotine;
- The benefits of Deep Brain Stimulation are recognised for patients with advanced Parkinson's disease;
- Exercise is recommended to improve physical performance and quality of life; in particular the guidelines recognise the benefits of Tai Chi and dance;
- Speech and language therapy may assist in treatment of patients' communication disorders and problems with swallowing;

- Occupational therapy can help patients overcome problems with daily living and improve quality of life.

Although it was not possible to find out the recommended referral time to see a neurologist, the study shows that over 80% of respondents saw a neurologist within two months of referral (81%). This would suggest that for the majority of patients, the six-week target that is common in other European countries is also being achieved in Italy.

In addition to this, the most commonly prescribed drugs were the L-dopa ones, such as Rasagiline (Azilect®) (54%), followed by Pramipexole (MIRAPEXIN®/SIFROL®) (51%) and Madopar® (49%).

The guidelines also recommend that patients be offered regular follow up sessions to review and manage their care. The results of the survey show that 88% of respondents have their medication reviewed at least every year by a specialist neurologist while reviews also take place with general neurologists and GPs.

Despite the guidelines emphasising the important role of therapists in managing the care of patients with Parkinson's disease, the actual number of respondents being referred to these services is small. Only 20% of respondents mention being referred to a physiotherapist and just 5% to an occupational therapist.

APPENDIX II-G: SURVEY FINDINGS FOR THE NETHERLANDS

1.1. Sample profile

In total 175 respondents completed the survey from the Netherlands. 65% of respondents are male and the average age of respondents was 57 years when they were diagnosed with Parkinson's, with the youngest aged 27 and the oldest aged 85 years. Only 16% are currently employed. When asked to describe the area in which they live, 8% state rural, 47% town, with the remaining 44% living in cities.

1.2. Quality of life and disability scores

To explore quality of life, EuroQol's EQ-5D measure was utilised. This is a standardised instrument for measuring health status and requires respondents to answer five questions focusing on **mobility**, **self-care**, **usual activities**, **pain**, and **anxiety/depression**.

Regarding **mobility**, 21% report no problems walking, while 78% report some problems. 1% of respondents indicate that they are confined to a bed⁵¹.

Moving on to **self-care**, 3% report they are unable to wash or dress themselves and 28% that they have some problems with washing or dressing. However, the majority of respondents - 70% - indicate no problems with self-care.

When asked about their current ability to perform **everyday activities** such as work and leisure, 69% of the respondents experience some problems performing these activities, while 24% indicate no problems at all. Those who were unable to perform *any* everyday activities are the smallest group, accounting for 8% of the sample.

When discussing current levels of **pain and discomfort**, a high percentage of the sample - 74% - indicate that they suffer from moderate pain, while 24% indicate having no pain or discomfort. Again, those who suffer from extreme pain represent a relatively small proportion of the sample at 2%.

The final question assessing current quality of life focuses on levels of **anxiety and depression**. 65% of respondents indicate they are either not anxious or depressed, while 34% are moderately so. The remaining 1% of the sample report feelings of extreme anxiety or depression.

Compared with their general health over the last 12 months, only 6% of respondents state that their health is *better*. The majority of respondents feel that their health is *much the same* (61%).

When asked to rate which statement best describes how they feel about their independence, none of the respondents report to being bed bound. The most commonly recorded response is '*I am able to do all chores with some degree of slowness, difficulty and impairment, and am beginning to be aware of difficulty*' (46%) (Table 1).

⁵¹ Results based on the number of respondents answering Question 7. This result may not tally with the number stating they are bedridden in Question 13, the results of which are shown in Table 1.

Table 1. Self-reported disability score (%)

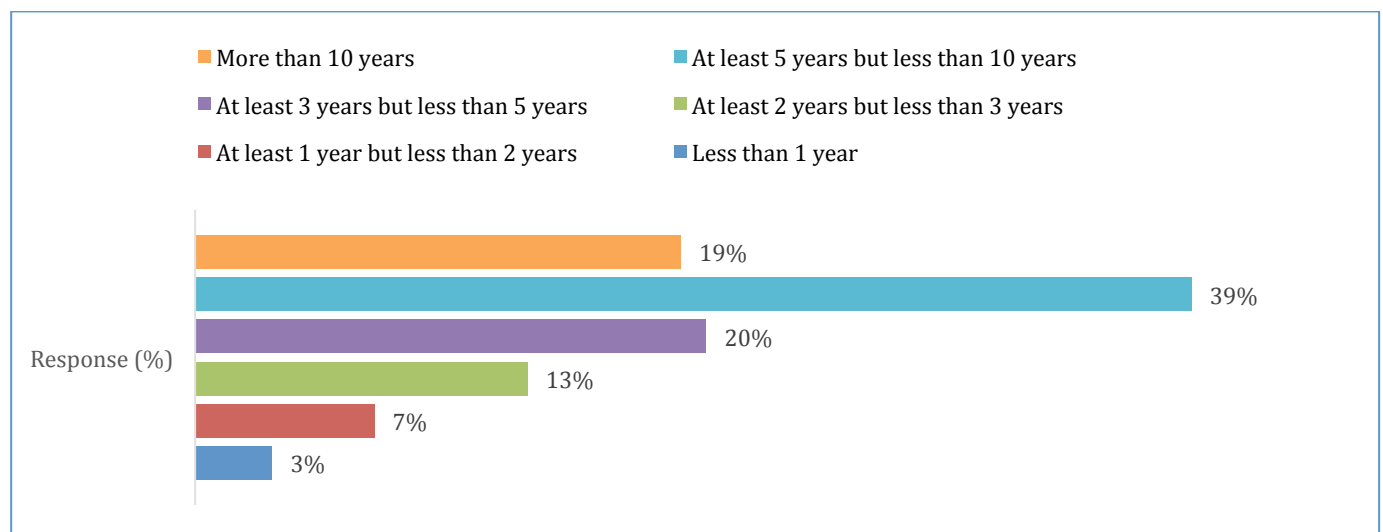
STATEMENTS	Response (%)
I am able to do all chores without slowness, difficulty or impairment	7
I am able to do all chores with some degree of slowness, difficulty and impairment, and am beginning to be aware of difficulty	46
Chores take twice as long and I am conscious of difficulty and slowness	10
Chores take three to four times as long and I spend a large part of the day doing these	3
I can do most chores, but exceedingly slowly and requiring a lot of effort	11
I need help with half the chores and have difficulty with everything	1
I can assist with all the chores, but am only able to do a few on my own	5
I can manage a few chores with some effort, but need a lot of help	10
I do nothing on my own, but can be a slight help with some chores	6
I am totally dependent and helpless	1
I am bedridden	1

1.3. Getting a diagnosis of Parkinson's disease

1980 was the earliest date that a respondent had been diagnosed with Parkinson's and 2014 the latest (4% had been diagnosed in 2014; the median date of diagnosis was 2008). 97% of respondents had been diagnosed with Parkinson's in the Netherlands, with the exception of four respondents (3%) who had been diagnosed in either France, Belgium or Slovenia.

For 43% of respondents, it has been less than 5 years since diagnosis. Nearly 20% of respondents were diagnosed over 10 years ago (Figure 1).

Figure 1. Length of time since diagnosis (%)



The symptoms most commonly noticed before diagnosis included changes in the way you move (including the way you walk, dragging a leg, not swinging your arm, etc.), fatigue, rigidity and slowness of movement. Interestingly people with these symptoms were more likely to seek help within a year. However with other symptoms, such as loss of smell or taste and stress, these symptoms could often continue for over three years before help was sought (Table 2).

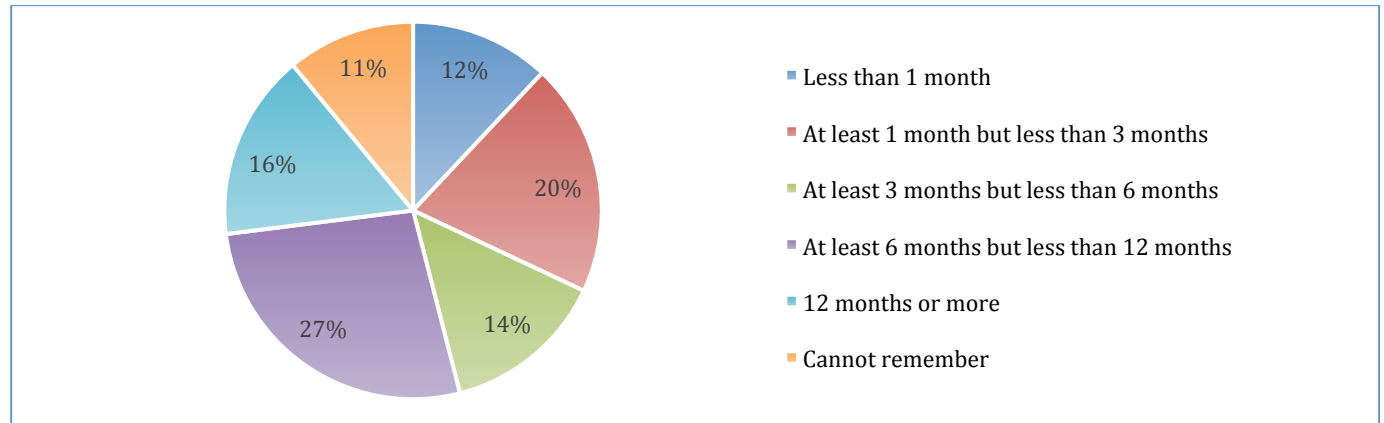
Table 2. Reported symptoms, and duration of these symptoms before seeking medical help (%)

SYMPTOMS/PERCENTAGE OF RESPONDENTS ¹	Less than 1 year	1 to 2 years	3 to 4 years	5 years or more	Total number of respondents experiencing symptoms
Anxiety	9	5	2	4	21
Apathy	7	4	4	3	18
Bladder and bowel problems	6	9	9	9	34
Changes in the way you move (incl. the way you walk, dragging a leg, not swinging your arm, etc.)	24	30	12	13	79
Depression	5	11	5	5	27
Difficulty eating and/or swallowing	11	5	1	3	21
Eye problems	10	7	6	5	29
Falls (balance problems)	13	11	5	3	32
Fatigue	17	18	9	18	62
Freezing	13	9	2	1	26
Loss of smell or taste	9	11	12	14	46
Low blood pressure or dizziness	7	8	5	7	27
Muscle cramps	16	17	7	8	48
Pain	13	7	5	11	37
Rigidity (stiffness)	21	19	11	12	64
Skin and/or sweating problems	7	9	5	7	28
Sleep problems	12	13	9	12	46
Slowness of movement	26	22	11	8	67
Speech and communication problems (incl. small handwriting and reduced facial movements)	26	16	8	7	57
Stress	6	12	10	8	36
Thinking or memory problems	15	13	10	7	45
Tremor (shaking)	31	11	7	6	21

Other symptoms added by the respondents include: choking and accumulated saliva, increased clumsiness and difficulties playing sports such as swimming and skiing. One respondent said that one of their first symptoms was: *"Finding it difficult to shake hands."*

When asked how long it was before seeking medical help after first noticing your symptoms, just over one-third waited 12 months or more (34%). Just under half of respondents sought help within three to 12 months (48%) while 12% sought immediate help (within 1 month) (Figure 2).

Figure 2. Timelines for seeking medical help (%)



1.4. During the first appointment

During the first appointment with a healthcare professional, over 60% of respondents underwent an observation of their symptoms (61%), while around one half underwent a physical examination (55%) and 40% discussed their general medical history. One half of respondents were told that they might have Parkinson's (50%), although nearly one fifth of respondents were told that something was wrong; however the healthcare professional was unsure of the exact diagnosis (18%). Over three quarters of respondents (78%) were referred to another doctor or healthcare professional following their first appointment (Table 3).

Table 3. Events during the first appointment with a healthcare professional (%)

EVENTS	Response (%) ¹
Discussed your general medical history	40
Carried out a physical examination	55
Observed your symptom(s)	61
Referred you to a specialist, or another doctor / healthcare professional	78
Said nothing was wrong	10
Said it was too early to tell if anything was wrong	9
Said something was wrong, but not sure what	18
Prescribed medication to relieve your symptom(s)	14
Explained that you may have Parkinson's	50
Explained that you may have another disease / condition	12

A number of respondents detailed other events which had happened at the first appointment; these included:

- Being told they defiantly did not have Parkinson's
- That the symptoms were caused by anxiety
- Being told that they were too young to have Parkinson's

Respondents were asked, if they were referred to another healthcare professional, what the waiting times were. If a referral was made, this was mostly to a neurologist (either general or one specialised in Parkinson's disease). However a significant number of respondents were also referred to a Parkinson's disease nurse specialist or a physiotherapist.

Most of the respondents saw a neurologist (either general or specialised) within three months of referral with a significant proportion of these appointments taking place within one month. (Table 4). A significant proportion of respondents also gained access to a physiotherapist within 2 months of referral.

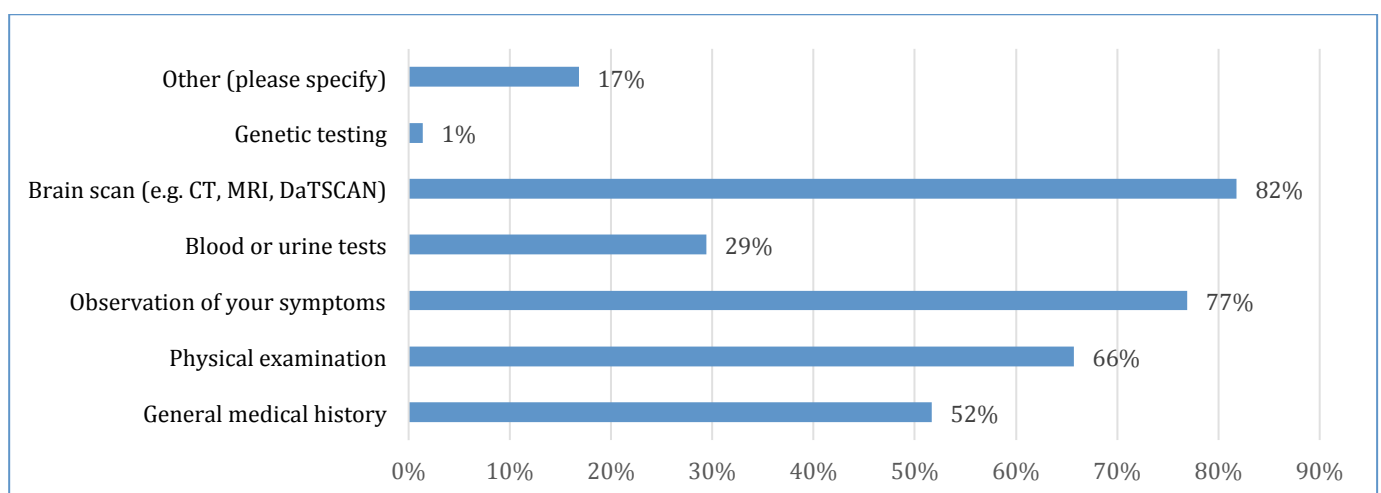
Table 4. Waiting times to see professionals from referral¹

HEALTHCARE PROFESSIONAL	Within 1 month (%)	1-2 months (%)	2-3 months (%)	3-4 months (%)	4 months + (%)	% of respondents referred
General neurologist	36	17	6	1	5	73
Neurologist Specialist in Parkinson's	29	13	5	1	17	73
Geriatrician	1	0	1	1	0	4
Parkinson's disease nurse specialist	8	10	6	3	15	46
Physiotherapist	20	8	8	3	17	62
Occupational therapist	3	2	7	1	9	29
Speech and language therapist	4	3	4	2	13	34

The overwhelming majority of respondents had a brain scan to diagnose their Parkinson's disease (82%). Two thirds (66%) state that they underwent a physical examination and just over three quarters (77%) had their symptoms observed (Figure 3). 17% of respondents mention that they also underwent other types of examinations and tests during diagnosis. These included:

- Lumber puncture
- PET (Positron emission tomography) Scan

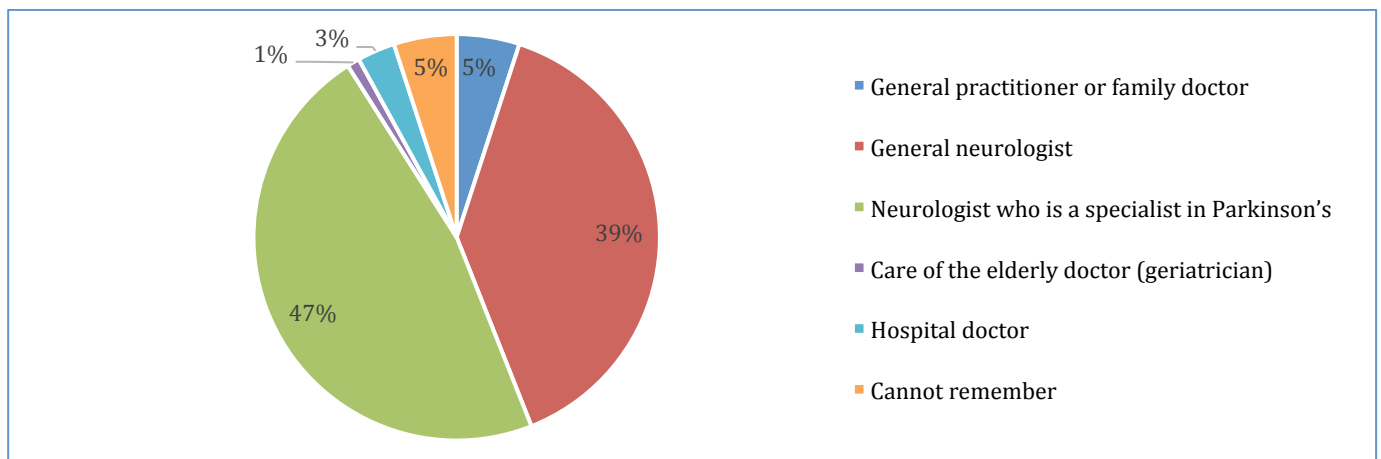
Figure 3. Examinations and tests carried out



1.5. Delivery of the diagnosis

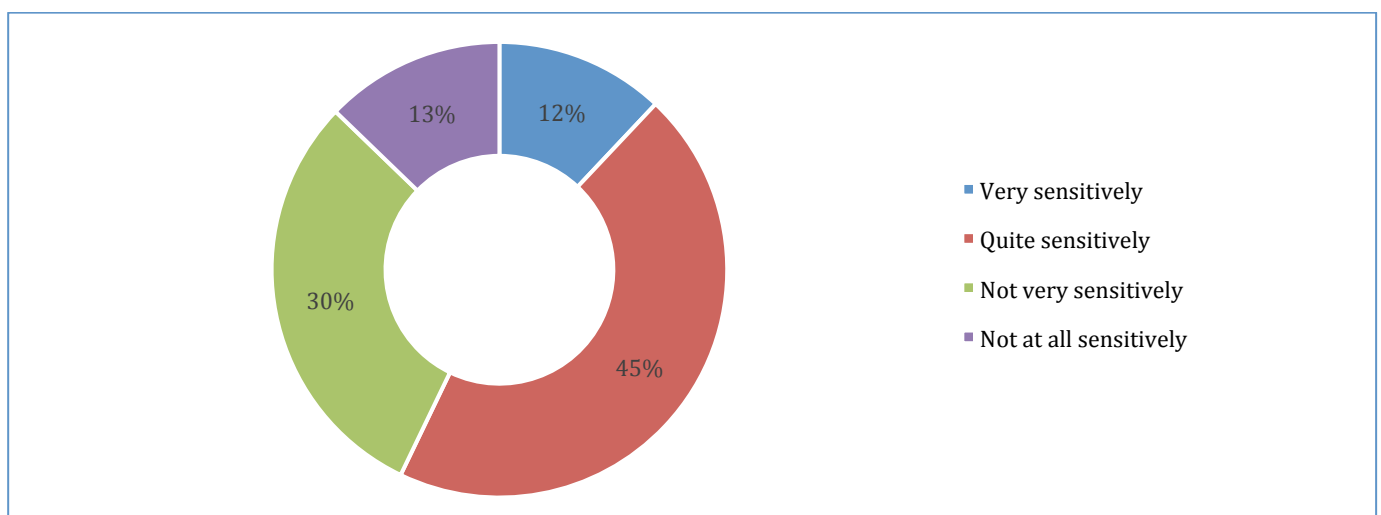
Nearly 50% of respondents received their diagnosis of Parkinson's from a neurologist specialised in the disease (47%), while a further 39% were diagnosed by a general neurologist. Only 4% received the diagnosis from either a geriatrician or a hospital doctor and a further 5% of the respondents were given the diagnosis by their GP (Figure 4).

Figure 4. Healthcare professional diagnosing Parkinson's (%)



Responses were split in relation to the sensitivity in which the diagnosis was given (Figure 5). 57% of respondents feel that they were told either very sensitively or quite sensitively, while the remaining 43% believe that the diagnosis was not given sensitively. However, only 15% feel dissatisfied or very dissatisfied with the consultation where the initial diagnosis was given. In comparison, 27% of respondents have a neutral opinion of their consultation, while 56% say they are satisfied or very satisfied.

Figure 5. Sensitivity of diagnosis (%)



1.6. Information given at diagnosis

At time of diagnosis, just under a half of the respondents report that they were given information verbally about the symptoms and causes of Parkinson's (44%) while one half were told about medication (50%). Only 19% were given information about clinical trials either verbally, with handouts or through signposting to online information; 2% of respondents said they did not want any information on this subject. 43% of respondents state that they were

given either written or verbal information about how to maintain physical wellbeing (e.g. healthy eating or exercise) while 31% were given advice on maintaining mental wellbeing. (Table 5).

Table 5. Information given¹

TOPIC AREA	Leaflet/ handouts/ signposting to online information (%)	Explained verbally (%)	Both handouts and verbal information (%)	I did not want any information (%)	No information was provided
Symptoms, diagnosis and causes of Parkinson's	11	44	28	1	11
Medication	11	50	20	1	14
Surgical treatments	7	8	3	1	55
Non-drug treatments	8	38	13	1	26
Maintaining physical wellbeing	7	27	9	0	39
Maintaining emotional wellbeing	5	22	4	1	46
Financial help available	5	2	1	0	61
Support organisations (e.g. patient associations)	16	24	8	2	35
Support for carers	4	14	7	2	48
Where to find more information on Parkinson's	21	25	11	2	30
Taking part in clinical trials	5	12	2	2	53

Amongst respondents who received information, nearly three quarters of them (72%) found the information they were given either very or quite helpful. In contrast, only 8% found the information either not very helpful or not helpful.

In relation to the question enquiring whether or not respondents feel as if they had enough time to ask questions and discuss their concerns, 56% feel that they were given enough time compared to the 11% who felt unable to ask questions at that time. A further 14% of respondents state that they would have liked further time to ask questions while 7% respond that they did not want to ask questions at that time (Table 6).

Table 6. Time to ask questions and discuss concerns – Question responses (%)

REPONSES	Response (%)
Yes, I was given enough time	56
Yes, but I would have liked more time	14
No, I was not given any time	9
I did not want to ask questions at that time	7
I did not feel able to ask questions or discuss concerns at that time	11
Cannot remember	3

1.7. Link between quality of life, satisfaction, and availability of information

A bivariate correlation was conducted to explore the relationship between availability of information and quality of life. To calculate an 'information availability total', responses were coded '1' for leaflet, verbal, or both (i.e. 'some information provided'). These numbers were then totalled across all the categories respondents were asked to consider (i.e., medication, support for carers), with higher numbers equating to a greater availability of information.

The correlation between the quality of life (QoL) index score (Mean = .63) and the information total (Mean = 4) was in a positive direction; however it does not reach a satisfactory level of statistical significance ($n = 174$, $r = .03$, $p = .67$). Therefore we are unable to conclude that QoL is affected by the availability of information.

The relationship between information availability and satisfaction with care received was also explored via a correlation. A significant positive relationship is observed ($n = 129$, $r = .38$, $p < .01$), suggesting levels of satisfaction with care are associated with the availability of information. Respondents, who report receiving more information, also indicate higher levels of satisfaction with care.

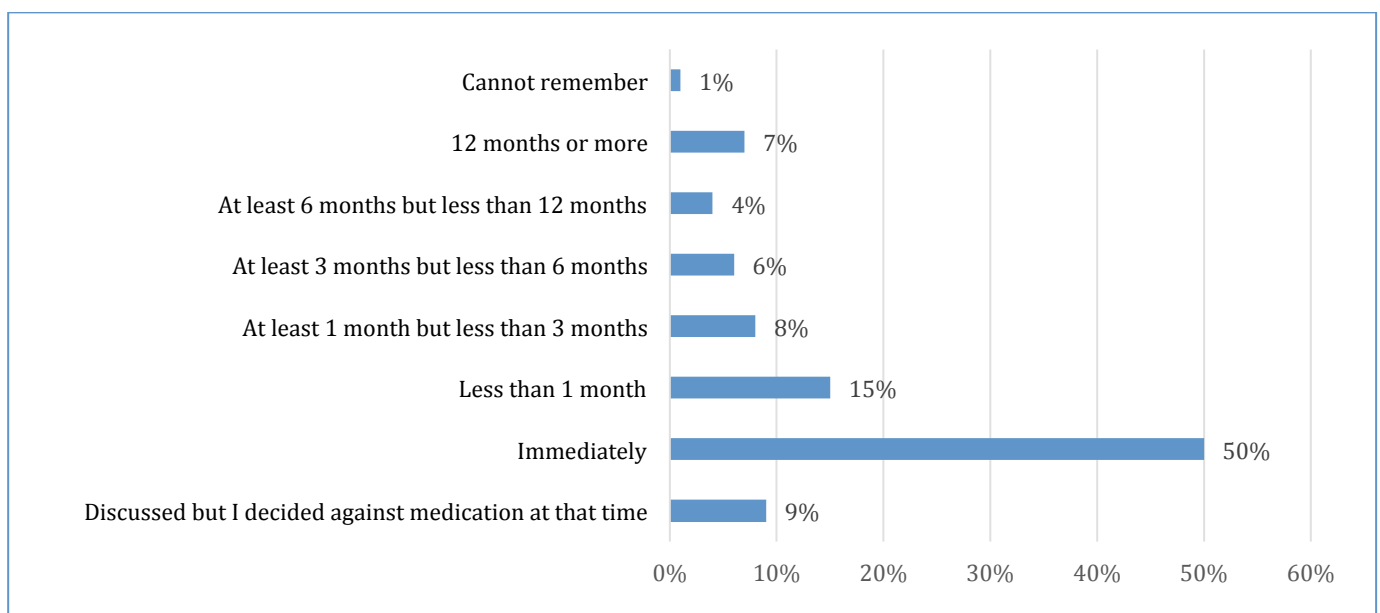
The relationship between satisfaction with treatment and information was also explored. Again, a positive relationship emerged between availability of information and satisfaction with treatment ($n = 128$, $r = .18$, $p < .05$), suggesting levels of satisfaction with treatment are associated with availability of information. Respondents, who report receiving more information, also indicate higher levels of satisfaction with treatment.

Finally, the relationship between satisfaction with the consultation where the initial diagnosis was given and the amount of information provided was also explored via a correlation. Results suggest a significant positive relationship between the two variables ($n = 142$, $r = .37$, $p < .01$) – the amount of information provided (both verbal and written) seems to affect how satisfied PwP are with the initial diagnosis and consultation. Specifically, the more information provided, the more satisfied respondents are with the consultation.

1.8. Treatment

Over 80% of respondents started medication or treatment within the first year after diagnosis, with around 50% of them starting immediately. However, nearly 10% of respondents decided not to take medication at the time of diagnosis (Figure 6).

Figure 6. Medication and treatment timings (%)

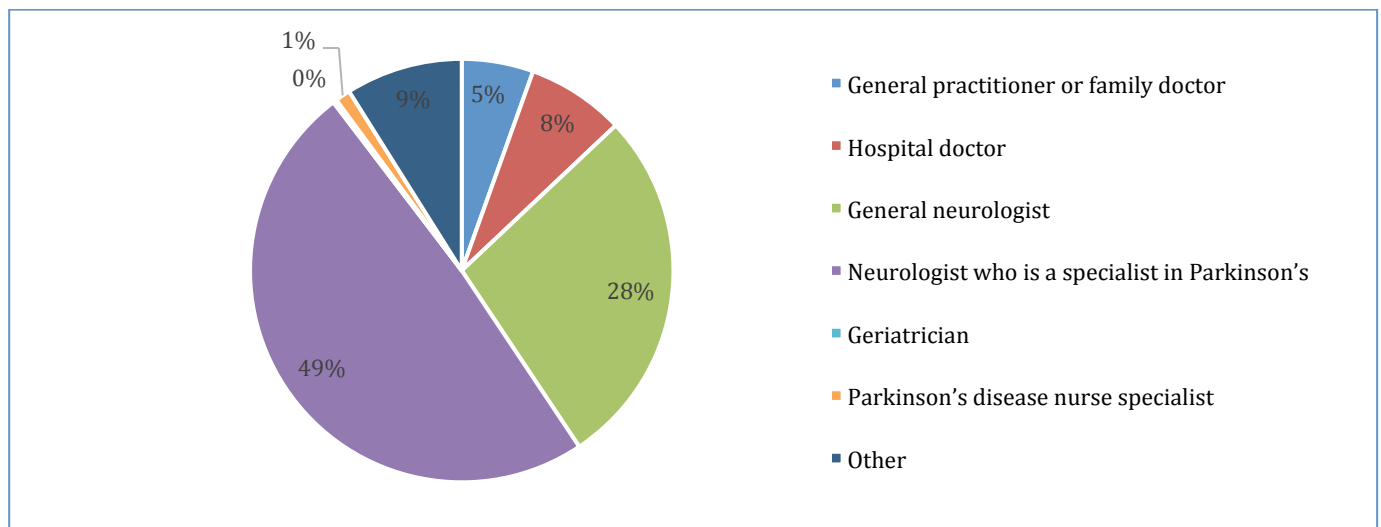


The most frequently taken medications are Sinemet (63% of respondents prescribed this drug), Madopar (38%) and Pramipexole (31%); these drugs are predominantly prescribed by a general neurologist or a specialist neurologist. However, a very small number of respondents report that these drugs are prescribed by their GP (1% of respondents), hospital doctor (2%) or Parkinson's disease nurse specialist (1% of respondents).

Other medications that are prescribed include¹: Amantadine (16% of respondents); Duodopa (13%); Rasagiline (13%); Ropinirole (26%); Rotigotine (11%); and Stalevo (11%).

As with Sinemet, Madopar and Praxipexole, for the majority of the time, these medications are almost exclusively prescribed by a general neurologist or a specialist neurologist. Only 1% of respondents mention a GP prescribing any medication, while there was just a single prescription from a Geriatrician (Figure 7).

Figure 7. Healthcare professionals who prescribed the medication (%)



The overwhelming majority of respondents state that their health insurance currently pay for their medication (95%). However, 16% also state that they pay for some medication privately (themselves/family) or the state pay (2%)¹. None of the respondents report that a Parkinson's organisation pay for their medication and around 2% of all respondents do not know who pays for their medication.

As only one respondent had exclusively received care funded by the state we were unable to explore potential relationships between paying for care, satisfaction with care, treatment, and length of time to receive care.

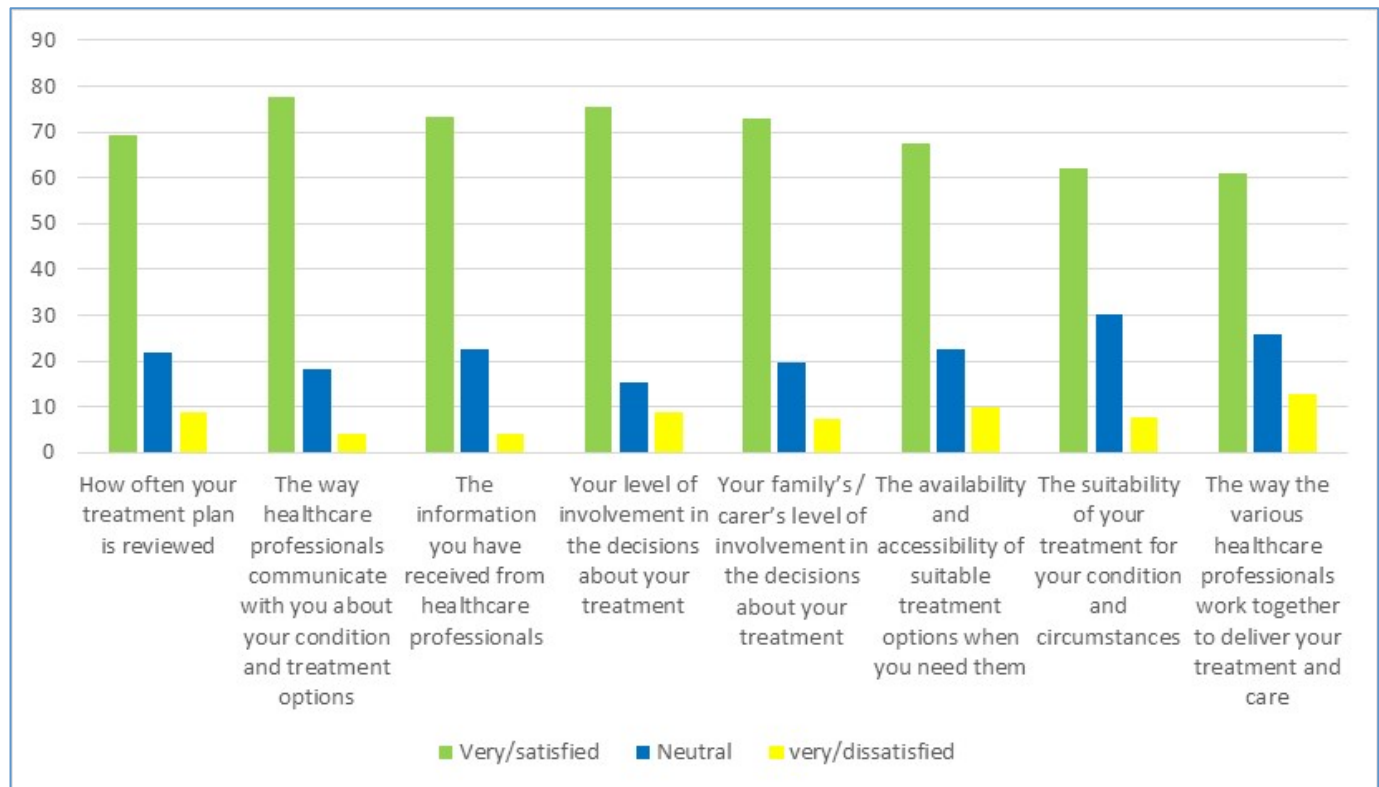
1.9. Satisfaction

Amongst respondents, levels of satisfaction with the care they receive is high. The lowest level of satisfaction is with general neurologists (67% satisfied or very satisfied) while the highest level of satisfaction is with geriatricians (100%). However the actual number of respondents under the care of a geriatrician is very small. Levels of satisfaction with neurologists specialising in Parkinson's disease are higher than for general neurologists (84%) while 85% of respondents are satisfied with the care they receive from Parkinson's disease nurse specialists. Amongst therapists levels of satisfaction are also extremely high: speech therapists (90%), occupational therapists (86%) and physiotherapists (94%).

Respondents are predominantly satisfied with most aspects of their treatment and overall care, with the highest level of satisfaction being recorded in the way professionals communicate with patients (76% satisfied).

Respondents are least satisfied in relation to the way the various healthcare professionals work together to deliver the treatment and care (13% dissatisfied) (Figure 8).

Figure 8. Satisfaction with treatment and overall care (%)



The relationship between frequency of medication review and satisfaction with care was explored with a bivariate correlation. Responses provided for 'how often is your medication reviewed and by who' were coded so that most frequent reviews ('every 3 months') were assigned the highest number '4', through to '1' for 'once every 2 years'. The correlation reveals a significant medium sized relationship between satisfaction with care and frequency of review. Hence this result suggests, respondents who benefit from more frequent reviews, also report higher levels of satisfaction with care ($n = 129$, $r = .35$, $p < .01$).¹

Respondents also reported on the frequency of their medication reviews with different healthcare professionals (Table x); because respondents may have more than one medication review a year, numbers in the table do not necessarily add up to 100%.

For the medication reviews, respondents state that a neurologist who is a specialist in Parkinson's reviews their medication either every six months (40%) or once a year (13%). A significant number of respondents also state that their medication is reviewed by a Parkinson's disease nurse specialist either every 6 months (19%) or once a year (8%). 27% of respondents report that they have their medication reviewed at least every 3 months by a healthcare professional (Table 7).

Table 7. Medication reviews (%)¹

HEALTHCARE PROFESSIONALS	Every 3 months (%)	Every 6 months (%)	Once a year (%)	Once every 2 years or more (%)
General practitioner or family doctor	1	1	2	2
Hospital doctor	1	3	1	2
General neurologist	6	14	4	4
Neurologist who is a specialist in Parkinson's	13	40	12	5
Geriatrician	1	0	1	0
Parkinson's disease nurse specialist	5	19	8	2

A Bivariate correlation was conducted to explore the relationship between quality of life and frequency of medication review. No significant relationship is observed ($n = 174$, $r = -.13$, $p = .09$), suggesting QoL is not associated with frequency of medication review.

In addition, a second bivariate correlation was run to assess the relationship between quality of life and satisfaction with care. Using the quality of life index and the satisfaction for care index, a significant negative relationship emerges ($n = 129$, $r = -.22$, $p < .05$) suggesting QoL is influenced by how satisfied respondents are with their care. The direction of the correlation implies respondents with the higher QoL are also less satisfied with the quality of their care.

1.10. Advanced treatments

Nine respondents report receiving surgical treatment in the form of “*Deep Brain Stimulation*”. Two of the respondents had the surgery within 5 years of diagnosis, five had it between 6 to 10 years of diagnosis and the remaining two answered between 11 to 15 years after diagnosis. Most respondents say that the surgery has met their expectations. Two respondents commented:

“Very satisfied with the result.”

“Deep Brain Stimulation definitely does the job.”

The research team were not able to look at the correlations between receiving advanced treatments and QoL/satisfaction variables as there are too few respondents who have received advanced treatments.

1.11. Findings in relation to the national guidelines

The Dutch College of General Practitioners published guidelines on the diagnosis of Parkinson's disease in 2011. These state that:

- People with suspected Parkinson's disease should be referred to a neurologist for diagnosis and treatment within 6 weeks;
- When Parkinson's disease is diagnosed, a collaborative treatment plan should be developed between the GP, neurologist and Parkinson's disease nurse specialist;
- GPs should monitor patients at least once a year, in particular checking for any side effects arising from the medication;
- GPs should also monitor patients for new symptoms of the disease such as depression, sleep disorders, falls and problems with swallowing and saliva. If necessary, patients should be referred to specialists such as occupational therapists;

- GPs should lead on detecting psychosocial problems such as relationship issues and supporting carers; and
- It is the GP's responsibility to intensify and coordinate the care of the patient in the final stage or palliative phase of the condition.

Detailed treatment guidelines for patients with Parkinson's disease have also been developed for occupational therapists, physiotherapists and speech therapists. These guidelines stress:

- Patients should be referred shortly after diagnosis and not when problems have got worse;
- The importance of all different healthcare professionals treating a patient communicating with each other; and
- The necessity of involving care givers in the treatments.

In total, 95% of respondents report that they have seen either a neurologist who is a specialist in Parkinson's or general neurologists within two months of referral. This would suggest that for most patients, the six-week target is being achieved. In contrast, only 4% report having their medication reviewed by their GP at the recommended interval of at least once a year, although 89% of respondents meet with their neurologist at least annually. In addition, a third of respondents have their medication reviewed at least annually by a Parkinson's disease nurse specialist (32%).

From the survey we cannot determine what access to physiotherapy, speech and language therapy and occupational therapy there is; however, the survey does show that referrals across these services vary. For example, although over one half of respondents report being referred to a physiotherapist (56%), only around a quarter saw a speech and language therapist or occupational therapist (26% and 22%, respectively). The survey also shows that where respondents are referred to these professionals, a large proportion of them are seen within two months of referral.

The Dutch guidelines emphasise the importance of collaborative care between the different healthcare specialists when treating patients. The results of this survey indicate that only around 60% of respondents are satisfied by this aspect of their treatment – this is the lowest level of satisfaction amongst all the categories of treatment surveyed.

APPENDIX II-H: SURVEY FINDINGS FOR SLOVENIA

1.1. Sample profile

In total 90 respondents completed the survey from Slovenia. 63% of respondents are male and the average age of respondents was 58 years when they were diagnosed with Parkinson's, with the youngest aged 29 and the oldest aged 90 years. Only 7% are currently employed. When asked to describe the area in which they live, 51% state rural, 48% town, with the remaining 1% living in a city.

1.2. Quality of life and disability scores

To explore quality of life the EQ-5D measure was utilised. This is a standardised instrument for measuring of health status and requires respondents to answer five questions focusing on **mobility**, **self-care**, **usual activities**, **pain**, and **anxiety/depression**.

Regarding **mobility**, 9% report no problems walking and 91% report some problems. No respondents indicate they are confined to a bed.⁵²

Moving on to **self-care**, no one reports that they are unable to wash or dress themselves. The majority of respondents (66%) indicate some problems with self-care, while 34% have no problems.

When asked about their **current ability** to perform everyday activities such as work and leisure, 68% of respondents experience some problems performing these activities, while 17% indicate no problems at all. Those who were unable to perform any everyday activities are the smallest group, accounting for 16% of the sample.

When discussing current levels of **pain and discomfort**, the majority of the sample- 69%- indicate that they suffer from moderate pain, while 11% indicate having no pain or discomfort. Those who suffered from extreme pain represent 20% of the sample.

The final question assessing current quality of life focuses on levels of **anxiety and depression**. Over half of respondents (56%) indicate moderate levels of anxiety or depression, while 41% report no feelings of anxiety or depression. The smallest proportion of the sample (3%), report feelings of extreme anxiety or depression.

Compared with their general health over the last 12 months, 21% of respondents state that their health is *better* while 29% believe it is *much the same*. The majority of respondents feel that their health is *worse* (50%).

When asked to rate which statement best describes how they feel about their independence, none of the respondents report to being bed bound. The most commonly recorded response is '*I am able to do all chores with some degree of slowness, difficulty and impairment, and am beginning to be aware of difficulty*' (29%) followed by '*Chores take twice as long and I am conscious of difficulty and slowness*' (16%) and '*I can do most chores, but exceedingly slowly and requiring a lot of effort*' (16%) (Table 1).

⁵² Results based on the number of respondents answering Question 7. This result may not tally with the number stating they are bedridden in Question 13, the results of which are shown in Table 1.

Table 1. Self-reported disability score (%)

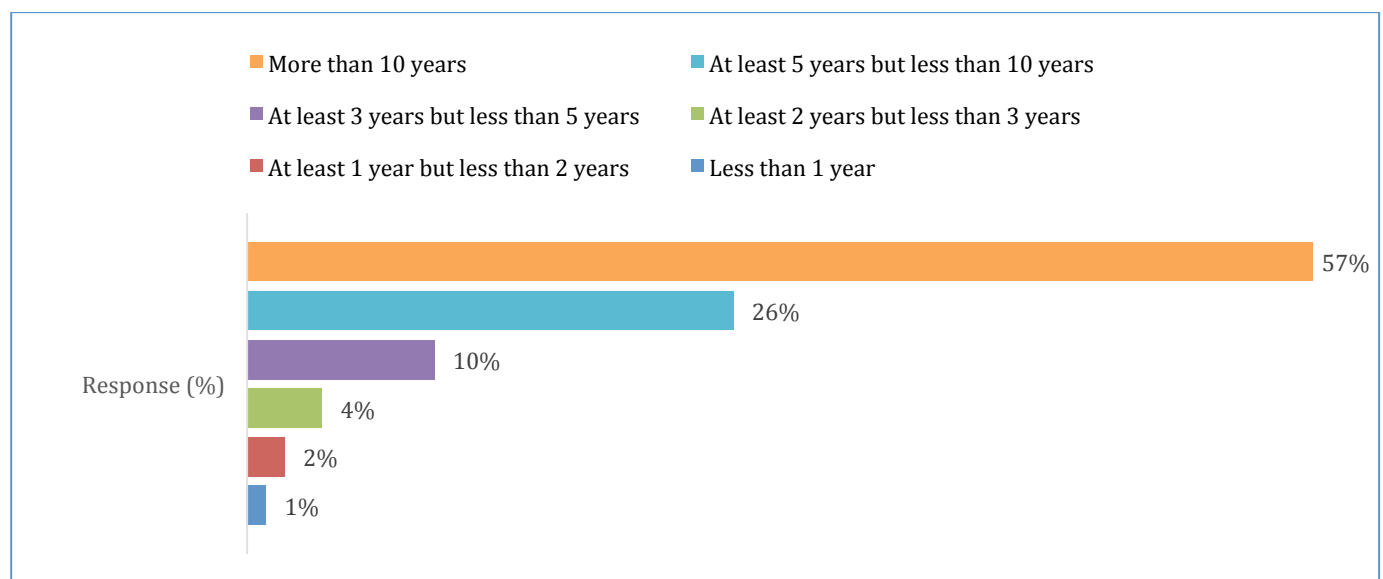
STATEMENTS	Response (%)
I am able to do all chores without slowness, difficulty or impairment	2
I am able to do all chores with some degree of slowness, difficulty and impairment, and am beginning to be aware of difficulty	29
Chores take twice as long and I am conscious of difficulty and slowness	16
Chores take three to four times as long and I spend a large part of the day doing these	7
I can do most chores, but exceedingly slowly and requiring a lot of effort	16
I need help with half the chores and have difficulty with everything	7
I can assist with all the chores, but am only able to do a few on my own	5
I can manage a few chores with some effort, but need a lot of help	12
I do nothing on my own, but can be a slight help with some chores	3
I am totally dependent and helpless	3
I am bedridden	0

1.3. Receiving a diagnosis of Parkinson's disease

1985 was the earliest date that a respondent had been diagnosed with Parkinson's and 2013 the latest (the median date of diagnosis was 2004). Nearly all of the respondents had been diagnosed with Parkinson's in Slovenia (97%), with the exception of three of the respondents who had been diagnosed in Denmark, Sweden and Romania.

For most of the respondents, it has been more than 10 years since diagnosis (57%). Only 17% of respondents received their diagnosis within the last 5 years (Figure 1).

Figure 1. Length of time since diagnosis (%)



The symptoms most commonly noticed before diagnosis included speech and communication problems (including small handwriting and reduced facial movements), thinking or memory problems, changes in the way they move (including the way they walk, dragging a leg, not swinging their arm, etc.) and fatigue. People with these symptoms were more likely to seek help within a year, and interestingly, with tremors or slowness of movement within 1 to 2 years. However with other symptoms, such as bladder and bowel problems, eye problems, loss of smell or taste, or sleep problems, these symptoms could often continue for over five years before help was sought (Table 2).

Table 2. Reported symptoms, and duration of these symptoms before seeking medical help (%)

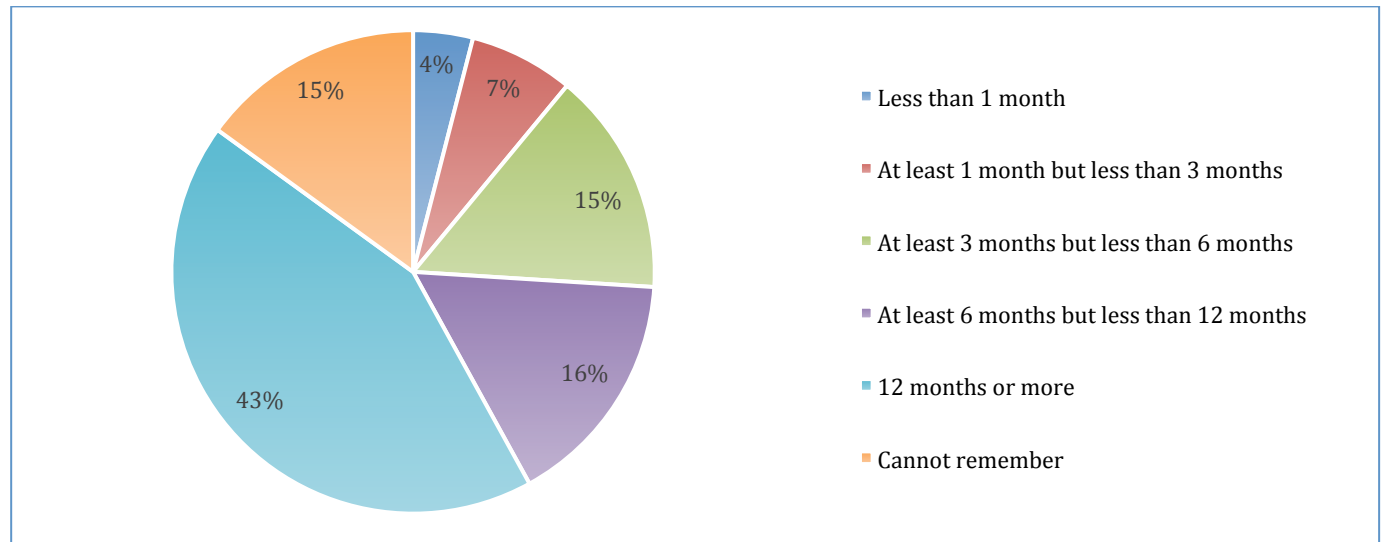
SYMPTOMS/PERCENTAGE OF RESPONDENTS ⁵³	Less than 1 year	1 to 2 years	3 to 4 years	5 years or more	Total percentage of respondents experiencing symptom
Anxiety	7	6	6	8	27
Apathy	2	10	1	5	18
Bladder and bowel problems	8	6	11	16	41
Changes in the way you move (incl. the way you walk, dragging a leg, not swinging your arm, etc.)	21	24	11	15	71
Depression	6	4	10	13	33
Difficulty eating and/or swallowing	6	5	2	5	18
Eye problems	4	5	1	17	27
Falls (balance problems)	8	10	6	12	36
Fatigue	15	11	15	20	61
Freezing	6	9	0	7	22
Loss of smell or taste	14	7	2	23	46
Low blood pressure or dizziness	12	5	7	10	34
Muscle cramps	13	12	7	9	41
Pain	10	11	8	13	42
Rigidity (stiffness)	7	10	5	11	33
Skin and/or sweating problems	9	10	9	10	38
Sleep problems	12	11	10	17	50
Slowness of movement	12	17	6	17	52
Speech and communication problems (incl. small handwriting and reduced facial movements)	17	12	8	7	44
Stress	11	5	5	11	32
Thinking or memory problems	16	5	2	7	30
Tremor (shaking)	16	23	6	9	54

Other symptoms added by the respondents included: high blood pressure, difficulty doing buttons and difficulty with walking.

⁵³ Respondents could select “do not apply”; and select multiple options

When asked how long it was before seeking medical help after first noticing their symptoms, the majority waited 12 months or more (43%) while nearly one third sought help within 3 to 12 months (31%). Only 4% of respondents report seeking immediate help (within 1 month). A significant proportion of respondents were unable to remember their timescales for seeking help (15%) (Figure 2).

Figure 2. Timelines for seeking medical help (%)



1.4. During the first appointment

A majority of respondents, during the first appointment with a healthcare professional, were referred to a specialist or another doctor (53%). Over one third of respondents underwent a physical examination (37%) and almost one third were told that they might have Parkinson's (33%). For one quarter of respondents, health professionals discussed their general medical history (24%), and for another quarter their symptoms were observed (26%) (Table 3).

Table 3. Events during the first appointment with a healthcare professional (%)

EVENTS	Response (%) ⁵⁴
Discussed your general medical history	24
Carried out a physical examination	37
Observed your symptom(s)	26
Referred you to a specialist, or another doctor / healthcare professional	53
Said nothing was wrong	9
Said it was too early to tell if anything was wrong	6
Said something was wrong, but not sure what	17
Prescribed medication to relieve your symptom(s)	18
Explained that you may have Parkinson's	33
Explained that you may have another disease / condition	8

⁵⁴ Respondents could select multiple options

A few respondents detailed other events which happened at the first appointment, including being told that:

- They were falling down because they were drinking too much
- They should see a psychiatrist
- They had chronic arthritis

Respondents were asked, if they were referred to another healthcare professional, what the waiting times were. If a referral was made, this was mostly to a neurologist (either general or one specialised in Parkinson's). However a much smaller number of respondents state that they were sent to a nurse specialised in Parkinson's disease or a therapist.

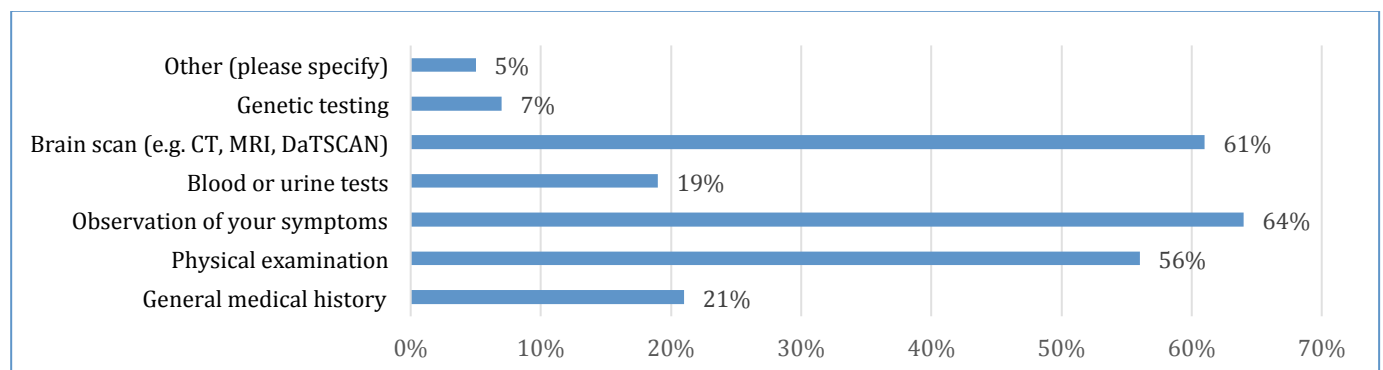
Just over one half of respondents report seeing a neurologist within 2 months of referral (54%); in comparison a significant proportion of respondents did not manage to see a neurologist until over 4 months after referral (Table 4).

Table 4. Waiting times to see professionals from referral (%)⁵⁵

HEALTHCARE PROFESSIONAL	Within 1 month (%)	1-2 months (%)	2-3 months (%)	3-4 months (%)	4 months + (%)	% of respondents referred
General neurologist	4	13	6	4	12	39
Neurologist Specialist in Parkinson's	16	5	7	18	14	60
Geriatrician	1	0	0	1	0	2
Parkinson's disease nurse specialist	7	2	1	2	4	16
Physiotherapist	5	0	0	1	4	10
Occupational therapist	2	1	1	1	0	5
Speech and language therapist	2	0	1	1	0	4

The majority of respondents underwent an observation of their symptoms (64%) or a brain scan to diagnose their Parkinson's (61%). 56% state that they had physical examination. (Figure 3). A number of respondents also mention that they underwent other tests as part of their diagnosis; however no further details about these treatments have been provided.

Figure 3. Examinations and tests carried out

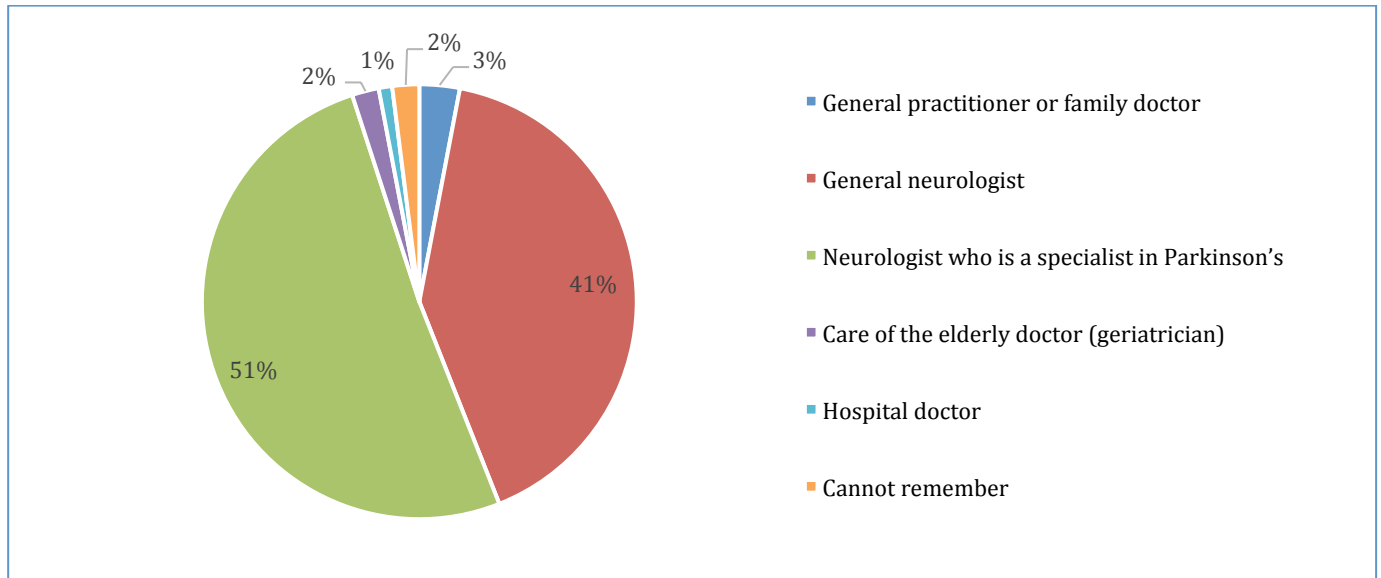


⁵⁵ Respondents could select multiple options or state that they could not remember

1.5. 8.5 Delivery of the diagnosis

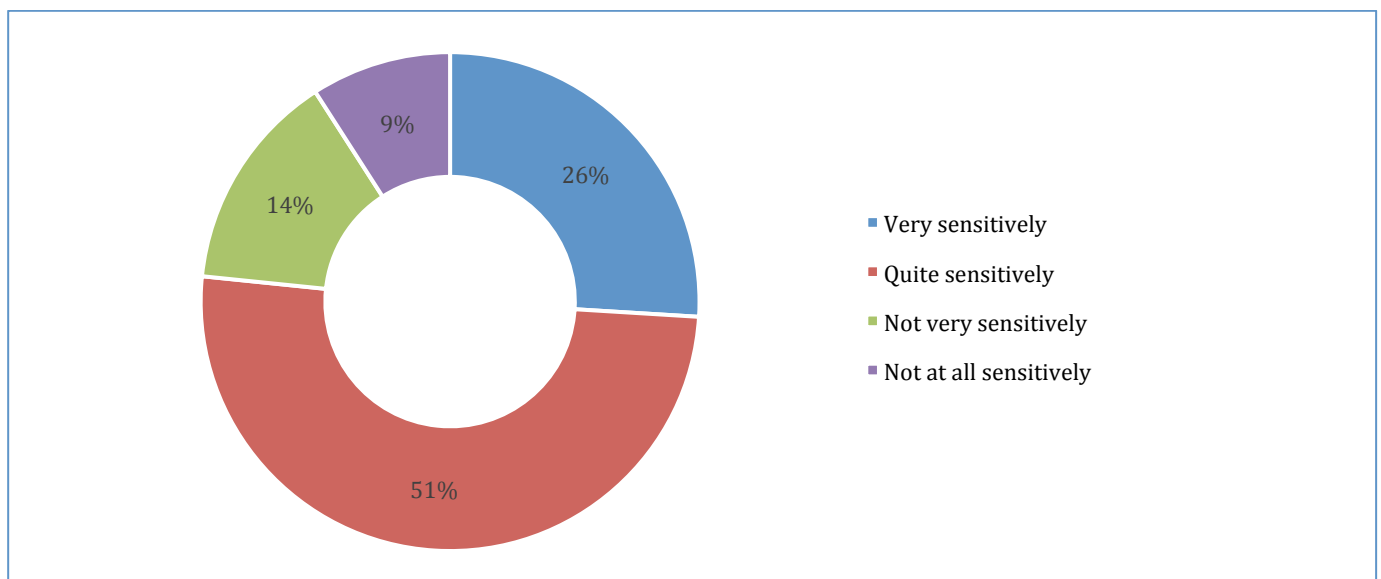
Just over half of the respondents received their diagnosis of Parkinson's from a neurologist specialised in the disease (51%) while a further 41% were diagnosed by a general neurologist. Only small numbers of respondents received the diagnosis from their GP, a geriatrician or a hospital doctor (Figure 4).

Figure 4. Healthcare professional diagnosing Parkinson's (%)



In relation to the sensitivity in which the diagnosis was given, over three quarters of the respondents (77%) feel that they were told either very sensitively or quite sensitively while the remaining 23% believe that the diagnosis had not been given sensitively (Figure 5). Similarly, only 17% feel dissatisfied or very dissatisfied with the consultation where the initial diagnosis was given; while 64% feel satisfied or very satisfied.

Figure 5. Sensitivity of diagnosis (%)



1.6. Information given at diagnosis

At time of diagnosis, just over half of the respondents report that they were given information verbally about the symptoms and causes of Parkinson's (54%) while just under one half received an explanation of the medication for Parkinson's (45%). Just under one quarter of respondents were given information about clinical trials either verbally, with hand-outs or through signposting to online information (24%); no respondents refused information on this topic. 44% said that they were given either written or verbal information about how to maintain physical wellbeing and 30% received advice on the importance of maintaining mental wellbeing (Table 5).

Table 5. Information given (%)⁵⁶

TOPIC AREA	Leaflet/ handouts/ signposting to online information (%)	Explained verbally (%)	Both handouts and verbal information (%)	I did not want any information (%)	No information was provided (%)
Symptoms, diagnosis and causes of Parkinson's	4	54	10	1	7
Medication	4	45	19	0	5
Surgical treatments	4	12	4	1	12
Non-drug treatments	5	22	5	0	11
Maintaining physical wellbeing	5	33	6	1	9
Maintaining emotional wellbeing	4	17	9	1	11
Financial help available	2	10	5	0	22
Support organisations (e.g. patient associations)	11	21	10	0	12
Support for carers	4	13	5	0	15
Where to find more information on Parkinson's	26	18	11	0	7
Taking part in clinical trials	9	9	6	0	15

Amongst respondents who received information, nearly three quarters found the information they were given either very or quite helpful (73%). In contrast, only 10% found the information either not very helpful or not helpful.

In relation to the question enquiring whether or not respondents had enough time to ask questions and discuss their concerns 24% felt they were given enough time, while 25% would have liked to have been given more. Whilst 18% stated they did not want to ask questions at the time, 13% felt they were not able to discuss concerns at the time. 8% responded they were not given any time (Table 6).

⁵⁶ Respondents were also able to answer no information was provided or cannot remember.

Table 6. Time to ask questions and discuss concerns – Question responses (%)

REPONSES	Response (%)
Yes, I was given enough time	24
Yes, but I would have liked more time	25
No, I was not given any time	8
I did not want to ask questions at that time	18
I did not feel able to ask questions or discuss concerns at that time	13
Cannot remember	12

1.7. Link between quality of life, satisfaction, and availability of information

A bivariate correlation was conducted to explore the relationship between availability of information and quality of life. To calculate an 'information availability total', responses were coded '1' for leaflet, verbal, or both (i.e. 'some information provided'). These numbers were then totalled across all the categories respondents were asked to consider (i.e., medication, support for carers), with higher numbers equating to a greater availability of information.

The correlation between the quality of life (QoL) index score (Mean = .50) and the information total (Mean = 4) does not reach a satisfactory level of statistical significance ($n = 89$, $r = -.00$, $p = .98$). Therefore we are unable to conclude that QoL is affected by the availability of information.

The relationship between information availability and satisfaction with care received was also explored via a correlation. A statistically significant relationship is observed ($n = 81$, $r = .36$, $p < .01$), suggesting levels of satisfaction with care are associated with the availability of information - higher levels of satisfaction with care is related to receiving more information about the disease.

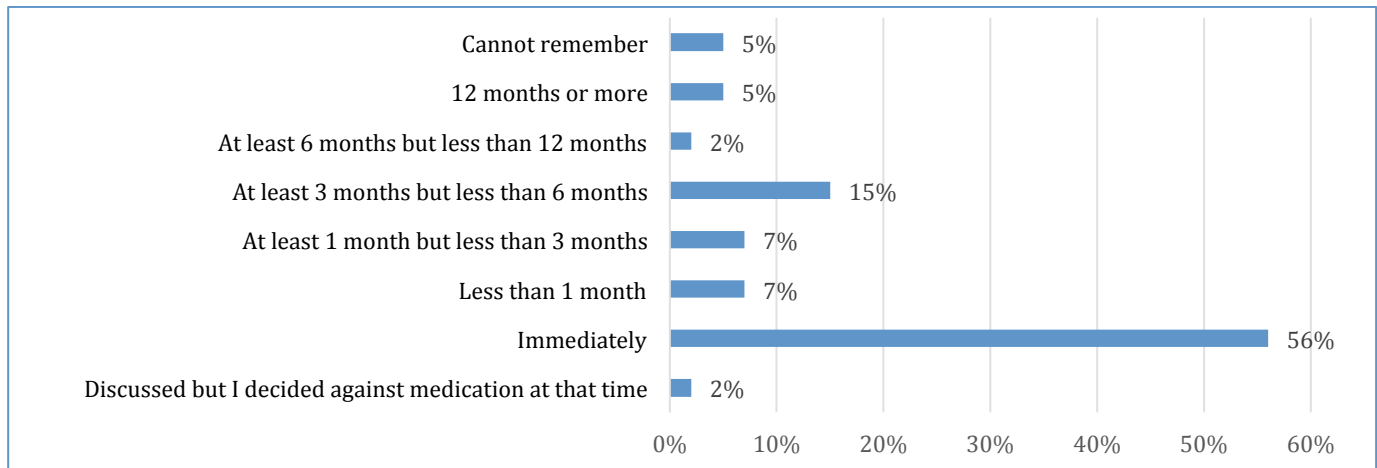
The relationship between satisfaction with treatment and information was also explored. Again, a significant relationship emerges between availability of information and satisfaction with treatment ($n = 78$, $r = .46$, $p < .01$), suggesting that higher levels of satisfaction with treatment are related to receiving more information about the disease.

Finally, the relationship between satisfaction with the consultation where the initial diagnosis was made and the amount of information provided was also explored via a correlation. Replicating the previous correlations, results suggest a positive relationship between the two variables ($n = 88$, $r = .28$, $p = .01$) – the amount of information provided (both verbal and written) is related to how satisfied respondents are with the initial diagnosis and consultation. Respondents who receive more information also feel more satisfied with the consultation where the initial diagnosis was made.

1.8. Treatment

Around 90% of respondents started medication or treatment within the first year after diagnosis, with two thirds of them starting immediately (66%). In comparison, only 1% of respondents decided not to take medication at the time of diagnosis (Figure 6).

Figure 6. Medication and treatment timings (%)

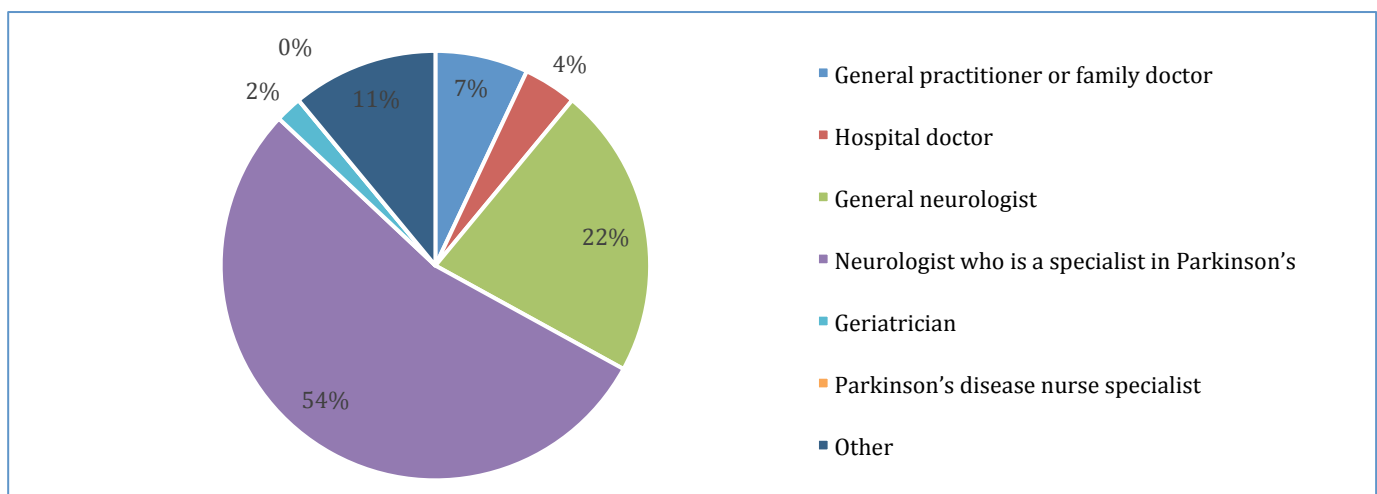


The most frequently taken medications are Madopar (61% of respondents), followed by Stalevo (57%) and Duodopa (54%), which are all predominantly prescribed by general and specialist neurologists. However, hospital doctors occasionally prescribe both Madopar and Duodopa.

Other medications that are prescribed include⁵⁷: Amantadine (30% of respondents); Entacapone (21%); Praximxole (38%); Rasagiline (27%); Rotigotine (12%); Sinemet (17%); and Tolcapone (11%).

Overall just over three quarters of medication is prescribed by either a specialist or general neurologist (76%). Most of the remainder is either prescribed by a geriatrician (11%) or GP (7%). No respondent reports being prescribed medication by a Parkinson's disease nurse specialist (Figure 7).

Figure 7. Healthcare professionals who prescribed the medication (%)



⁵⁷ Presented in alphabetical order

Two thirds of respondents state that their insurance currently pays for their medication (66%), while just over another one third get state funding (35%). 5% of respondents state that they or their family pay for some medication privately. One person has medication paid for by the Parkinson's organisation (1%), and 7% do not know who pays for their medication.⁵⁸

The relationship between satisfaction with care and paying for treatment was explored. Responses about paying for treatment were assigned a group based on whether care was state funded or by private/insurance⁵⁹. An independent samples t-test⁶⁰ was conducted to investigate whether satisfaction with care differs according to whether respondents pay for the treatment or not. This analysis reveals no statistical difference. Mean levels of satisfaction do not differ between the groups. Respondents who pay for treatment (either through insurance or privately) report similar levels of satisfaction with care ($n = 48$, $M_{\text{satisfaction}} = 16$) to those respondents whose treatment is state funded ($n = 21$, $M_{\text{satisfaction}} = 18$) ($t = .91$, $p = .37$).⁶¹

A second independent t-test was conducted to explore if access to health care professionals (as measured by frequency of medication review) differs according to how the health care is funded (i.e. state vs. private). Respondents who receive state funded care ($n=21$, $M_{\text{review}} = 4$) report more frequent reviews of medication, compared to respondents who pay for treatment ($n=48$, $M_{\text{review}} = 3$). Furthermore, the comparison between the two groups reveals a significant difference according to the two types of funding ($t = 2.79$, $p < .01$).

Using length of time to gain access to treatment after diagnosis, as a proxy for availability, a further independent t-test was conducted to establish if length of time differs between state ($n=21$, $M_{\text{time}} = 3$) versus private funding ($n=48$, $M_{\text{review}} = 2$). No significant differences in treatment waiting times is noted between the two groups ($t = 1.71$, $p = .09$).

Only 19 respondents report being refused care due to cost and 11 due to where they lived; hence the samples are too small to conduct a valid analysis to explore links between QoL and refusal of treatment.

1.9. Satisfaction

Amongst respondents, levels of satisfaction with the care they receive is generally high. Over 90% of respondents are satisfied or very satisfied with the care they receive from specialist neurologists while satisfaction with general neurologist is slightly lower at 78%. Three quarters of respondents are satisfied or very satisfied with the care they receive from both GPs (73%) and hospital doctors (75%).

Amongst therapists, levels of satisfaction are also very high ranging from 84% for physiotherapist to 70% for occupational therapists.

Across all the healthcare professions, respondents only express low levels of actual dissatisfaction across three professions – GPs (7% dissatisfied), general neurologist (2%) and specialist neurologists (1%).

In relation to treatment and overall care, respondents are most satisfied with the information they receive from health care professionals (65%), the way healthcare professionals were communicate with them about their condition and treatment options (63%), and the level of their family's/carer's involvement in decisions about

⁵⁸ Respondents could select multiple options

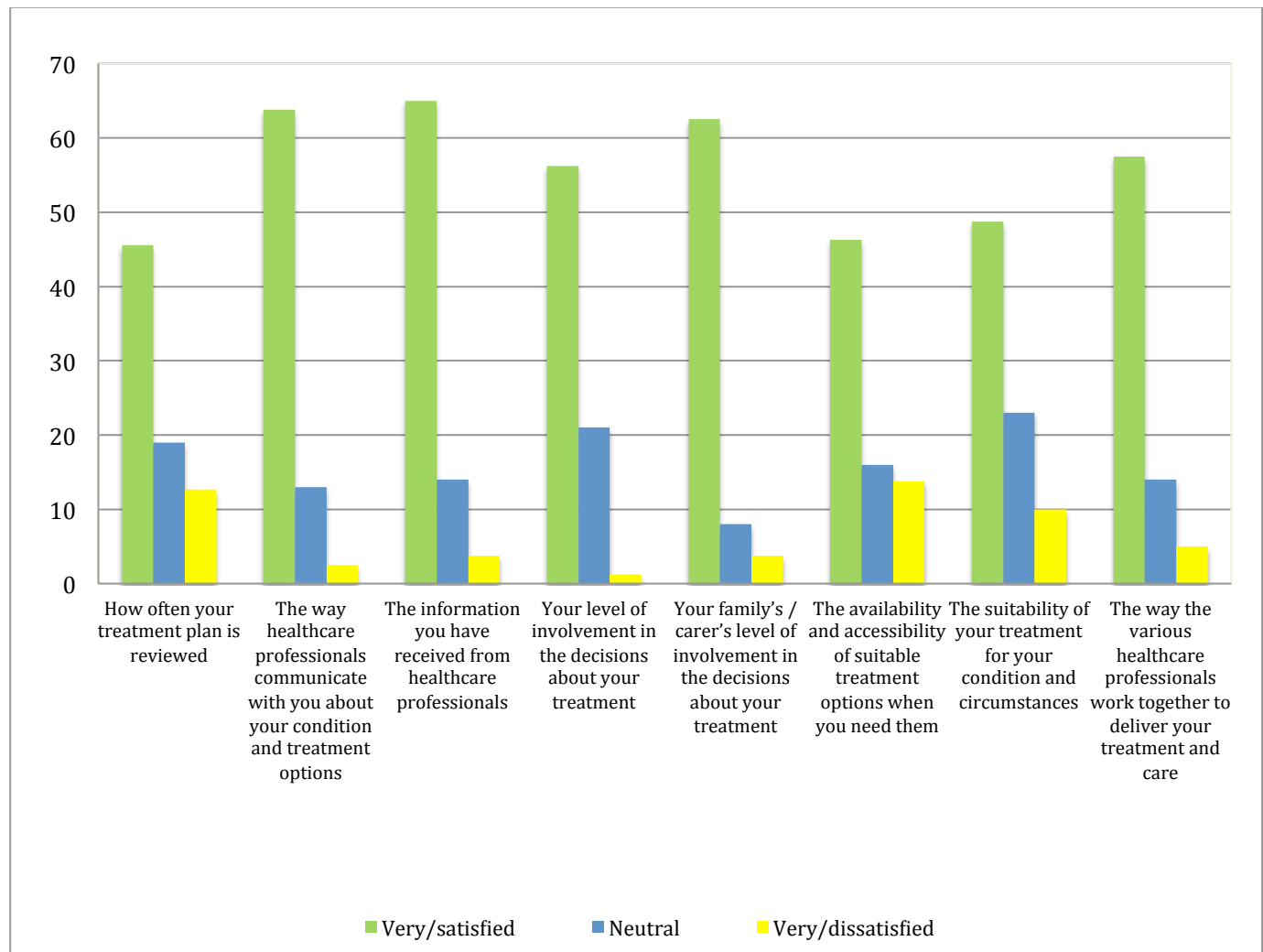
⁵⁹ Insurance and private were joined together to enable a direct comparison between paying vs. non-paying care. Respondents who indicated more than one source of funding were excluded from the analysis so as to ensure valid comparisons between the groups.

⁶⁰ The independent-samples t-test (or independent t-test, for short) compares means values (averages) between two unrelated groups on the same continuous variable (i.e., scale scores).

⁶¹ Uneven groups are problematic when conducting t-tests; hence the current analysis should ideally be replicated with more balanced groups in each condition.

treatment (62%). However, there was less satisfaction in relation to how often their treatment plan was reviewed (45% satisfied) and the availability and accessibility of suitable treatment options (48%) (Figure 8).

Figure 8. Satisfaction with treatment and overall care (%)



The relationship between frequency of medication review and satisfaction with care was explored with a bivariate correlation. The analysis reveals a significant medium sized relationship between satisfaction with care and frequency of review, suggesting respondents who benefit from more frequent reviews, also report higher levels of satisfaction with care ($n = 81$, $r = .35$, $p < .01$).⁶²

Respondents also reported on the frequency of their medication reviews with different healthcare professionals (Table 7); because respondents may have more than one medication review a year, numbers in the table do not necessarily add up to 100%.

For the medication reviews, respondents state that a neurologist who is a specialist in Parkinson's reviews their medication every 6 months (11%) or once a year (43%). 11% of respondents report that these professionals only review their medication around every 2 years. Smaller numbers of respondents report that they have their medication reviewed by general neurologists or GPs. Less than a quarter of respondents report having their medication reviewed at least every 3 months by a healthcare professional (Table 7).

⁶² Respondents who indicated 'do not know' and 'does not apply' were not included in this analysis

A Bivariate correlation was conducted to explore the relationship between quality of life and frequency of medication review. No significant relationship is observed ($n = 89$, $r = .05$, $p = .65$), suggesting QoL is not associated with frequency of medication review.

Table 7. Medication reviews (%)⁶³

HEALTHCARE PROFESSIONALS	Every 3 months (%)	Every 6 months (%)	Once a year (%)	Once every 2 years or more (%)
General practitioner or family doctor	6	2	5	5
Hospital doctor	1	5	1	0
General neurologist	4	5	9	1
Neurologist who is a specialist in Parkinson's	11	11	43	11
Geriatrician	1	0	1	0
Parkinson's disease nurse specialist	1	3	9	0

In addition, a second bivariate correlation was run to assess the relationship between quality of life and satisfaction with care. Using the quality of life index and the satisfaction for care index, again no significant relationship emerges ($n = 80$, $r = -.17$, $p = .14$) suggesting QoL is not influenced by how satisfied respondents were with their care.

1.10. Advanced treatments

Twenty one of the 79 respondents report receiving surgical treatments. Four of these treatments comprised “Deep Brain Stimulation”, 13 received Duodopa and the remaining four were unspecified. Treatment had occurred across a wide spectrum of time. Three of the respondents had the surgery up to 5 years after diagnosis, six had surgical treatment 6 to 10 years after diagnosis, eight of the respondents received the treatment 11 to 15 years after diagnosis and they remaining four respondents were treated more than 15 years after diagnosis.

Few of the respondents commented on the effectiveness of their medication. However one respondent says that the medication prescribed after his surgical treatment did not work well for them, while another criticises the waiting time for the treatment.

The research team were not able to look at the correlations between receiving advanced treatments and QoL/satisfaction variables as there are too few respondents who have received advanced treatments.

1.11. Findings in relation to the national guidelines

In summary the Slovenian Clinical Route for patients with Parkinson's disease⁶⁴ guidelines state that:

- If Parkinson's disease is suspected, GP's should refer the patient to a neurological clinic where a neurologist assesses whether the patient has the disease. In the case of patients less than 40 years, of age, or if they are currently employed but unable to perform their duties, they are referred for review in 4 weeks. Otherwise, a second review with the neurological clinic occurs within six months;

⁶³ Respondents could have reviews from more than one healthcare professional and were also able to state that they did not know or that it did not apply for them.

⁶⁴ Accessed 27th January 2015: http://www.kobz.si/si/Klinicne_poti/klinicna_pot_PB.pdf

- During the appointment, the patient's medical history should be examined, symptoms observed and a physical examination performed;
- If additional clinical information is required, further tests should be carried out (e.g. MRI, SPECT-DAT, CT);
- If treatment is considered, the first follow up appointment is in three months to check the effectiveness of the treatment and any side effects. In cases where the patient's treatment is non-responsive, patients should undergo daily medication tests in hospital (Levodopa test, Apomorphine, and additional imaging diagnostics);
- Patients are referred for further follow up appointments every six to nine months;
- For medication treatment – drugs such as a Dopamine agonists are recommended, as well as Levodopa, Stalevo and Amantadine;
- Non-medical measures are recommended in the form of talks with patients and their relatives about the disease, directing them to nurses, providing information on treatment options and introducing the Parkinson's organisation *Aspen*;
- Surgical treatment Deep Brain Stimulation is optional.

The findings from the survey demonstrate that, in line with the guidelines, 24% of the respondents had their medical history discussed during the first appointment with a health care professional, 37% underwent a physical examination and 53% were referred to another specialist. For further tests, 64% state that their symptoms were observed, 61% had a brain scan and 57% underwent a physical examination.

- In line with the guidelines, the most frequent medication is Madopar (61% of respondents), Stalevo (57%), and Amantadine (30%).
- In line with the guidelines, 43% of the respondents report being given details of support organisations and 21% received information for carers.

APPENDIX II-I: SURVEY FINDINGS FOR SPAIN

1.1. Sample profile

In total 65 respondents completed the survey from Spain. 51% of respondents are female and the average age of respondents was 56 years when they were diagnosed with Parkinson's, with the youngest aged 28 and oldest aged 82 years. Only 17% are currently employed. When asked to describe the area in which they live, 6% state rural, 19% town, with the majority living in cities (75%).

1.2. Quality of life (QoL) and disability scores

Regarding **mobility**, 29% report no problems walking, while 64% report some problems. 7% of respondents indicate that they are confined to a bed⁶⁵.

Moving on to **self-care**, 10% report they are unable to wash or dress themselves and 41% that they have some problems with washing or dressing. However, the majority of respondents - 48% - indicate no problems with self-care.

When asked about their current ability to perform **everyday activities** such as work and leisure, over half of the respondents (69%) experience some problems performing these activities, while 19% indicate no problems at all. Those who were unable to perform *any* everyday activities are the smallest group, accounting for 12% of the sample.

When discussing current levels of **pain and discomfort**, a high percentage of the sample - 67% - indicate that they suffer from moderate pain, while 16% indicate having no pain or discomfort. Again, those who suffer from extreme pain represent a relatively small proportion of the sample at 17%.

The final question assessing current quality of life focuses on levels of **anxiety and depression**. Nearly a third of respondents indicate they are either not anxious or depressed (29), while 66% indicate moderately so. The remaining 5% of the sample report feelings of extreme anxiety or depression.

Compared with their general health over the last 12 months, only 9% state that their health is *better*. More than half of the respondents feel that their health is *much the same* (56%).

When asked to rate which statement best describes how they feel about their independence, none of the respondents report to being bed bound. The most commonly recorded response is '*I am able to do all chores with some degree of slowness, difficulty and impairment, and am beginning to be aware of difficulty*' (40%) (Table 1).

⁶⁵ Results based on the number of respondents answering Question 7. This result may not tally with the number stating they are bedridden in Question 13, the results of which are shown in Table 1.

Table 1. Self-reported disability score (%)

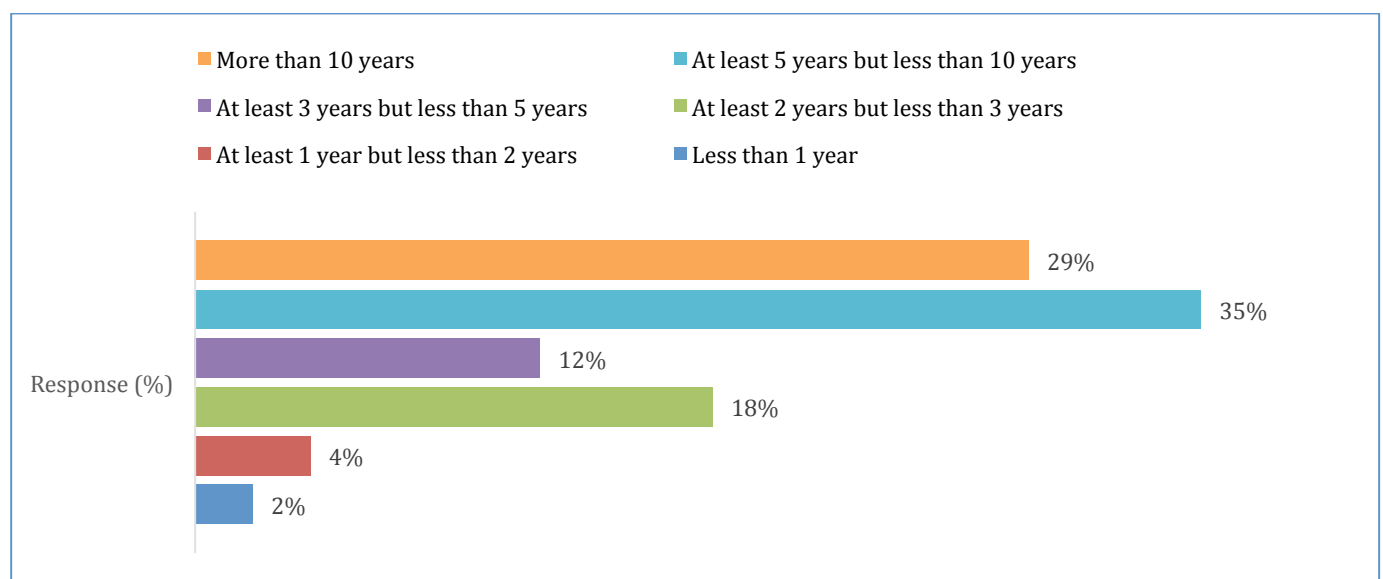
STATEMENTS	Response (%)
I am able to do all chores without slowness, difficulty or impairment	5
I am able to do all chores with some degree of slowness, difficulty and impairment, and am beginning to be aware of difficulty	40
Chores take twice as long and I am conscious of difficulty and slowness	20
Chores take three to four times as long and I spend a large part of the day doing these	4
I can do most chores, but exceedingly slowly and requiring a lot of effort	13
I need help with half the chores and have difficulty with everything	2
I can assist with all the chores, but am only able to do a few on my own	5
I can manage a few chores with some effort, but need a lot of help	0
I do nothing on my own, but can be a slight help with some chores	2
I am totally dependent and helpless	9
I am bedridden	0

1.3. Receiving the diagnosis of Parkinson's disease

1984 was the earliest date that a respondent had been diagnosed with Parkinson's and 2014 the latest (two respondents had been diagnosed in 2014; the median date of diagnosis was 2008). Nearly all of the respondents had been diagnosed with Parkinson's disease in Spain, with the exception of one respondent who had been diagnosed in Brazil.

For most of the respondents, it has been at least 5 years but less than 10 years since diagnosis (35%). 29% of respondents were diagnosed over 10 years ago (Figure 1).

Figure 1. Length of time since diagnosis (%)



The symptoms most commonly noticed before diagnosis included changes in the way you move (including the way you walk, dragging a leg, not swinging your arm, etc.), rigidity (stiffness), speech and communication problems (incl. small handwriting and reduced facial movements), tremor, fatigue and freezing. Interestingly, people with these symptoms were more likely to seek help within a year. However with other symptoms, such as falls (balance problems), loss of smell or taste, anxiety, slowness of movement, thinking or memory problems, bladder and bowel problems, pain, and muscle cramps, these symptoms could often continue for over five years before help was sought (Table 2).

Table 2. Reported symptoms, and duration of these symptoms before seeking medical help (%)

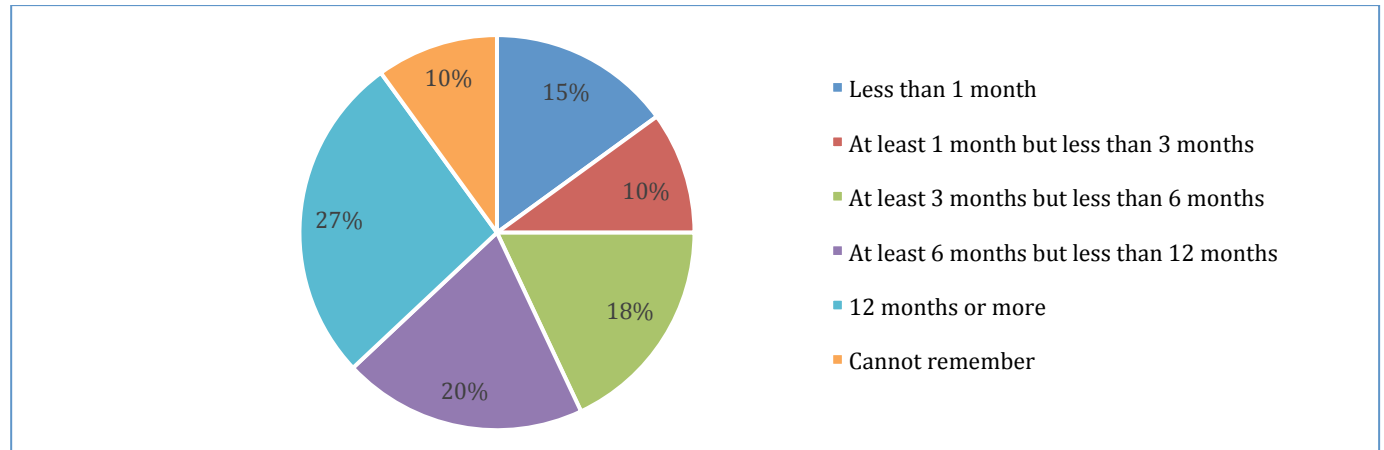
SYMPTOMS/PERCENTAGE OF RESPONDENTS ⁶⁶	Less than 1 year	1 to 2 years	3 to 4 years	5 years or more	Total number of respondents experiencing symptom
Anxiety	13	13	3	3	32
Apathy	18	0	5	5	28
Bladder and bowel problems	8	10	15	10	43
Changes in the way you move (incl. the way you walk, dragging a leg, not swinging your arm, etc.)	28	28	15	8	79
Depression	5	18	13	5	41
Difficulty eating and/or swallowing	10	10	5	3	28
Eye problems	5	13	3	5	26
Falls (balance problems)	15	10	10	3	38
Fatigue	20	10	10	0	40
Freezing	18	15	23	0	56
Loss of smell or taste	13	13	13	0	39
Low blood pressure or dizziness	13	10	5	3	31
Muscle cramps	15	15	5	8	43
Pain	15	8	10	8	41
Rigidity (stiffness)	25	15	13	10	63
Skin and/or sweating problems	8	5	8	0	21
Sleep problems	13	10	20	15	58
Slowness of movement	13	23	10	5	51
Speech and communication problems (incl. small handwriting and reduced facial movements)	20	15	8	5	48
Stress	13	15	5	3	36
Thinking or memory problems	10	15	8	3	36
Tremor (shaking)	23	10	5	13	51

Other symptoms added by the respondents included: dyskinesia, slowness, and an “*over-active bladder*”.

⁶⁶ Respondents could select “do not apply”, and select multiple options

When asked how long it was before seeking medical help after first noticing their symptoms, more than a quarter of the respondents state that they waited 12 months or more (27%). 38% sought help within the first 3 to 12 month, while 15% sought immediate help (Figure 2).

Figure 2. Timelines for seeking medical help (%)



1.4. During the first appointment

More than a half of the respondents, during the first appointment with a healthcare professional, were referred to a specialist or another health professional (53%). Nearly half of the respondents state that a physical examination was conducted (48%) and the same percentage report that their symptoms were observed. One-fifth were told that they might have Parkinson's (20%) and for another 18% of the respondents medication was prescribed. 15% of the respondents were told by the healthcare professional that something was wrong but that the exact diagnosis was unclear (Table 3).

Table 3. Events during the first appointment with a healthcare professional (%)

EVENTS	Response (%) ⁶⁷
Discussed your general medical history	15
Carried out a physical examination	48
Observed your symptom(s)	48
Referred you to a specialist, or another doctor / healthcare professional	53
Said nothing was wrong	3
Said it was too early to tell if anything was wrong	10
Said something was wrong, but not sure what	15
Prescribed medication to relieve your symptom(s)	18
Explained that you may have Parkinson's	20
Explained that you may have another disease / condition	5

A number of respondents detailed other events which happened at the first appointment, including:

⁶⁷ Respondents could select multiple options

- Being told they were “*overworked*”
- Advised to watch TV if the tremor was “*annoying them*”
- Diagnosed as having clinical unipolar depression
- Informed they were “*just getting old*”

Respondents were asked, if they were referred to another healthcare professional, what the waiting times were. If a referral was made, this was predominantly to a neurologist either general or one specialised in Parkinson's. Only a small percentage of respondents were referred to a therapist.

The waiting times to see neurologists were less than to see a therapist, with most of the respondents seeing a neurologist (either general or specialised) within three months (Table 4).

Table 4. Waiting times to see professionals from referral (%)⁶⁸

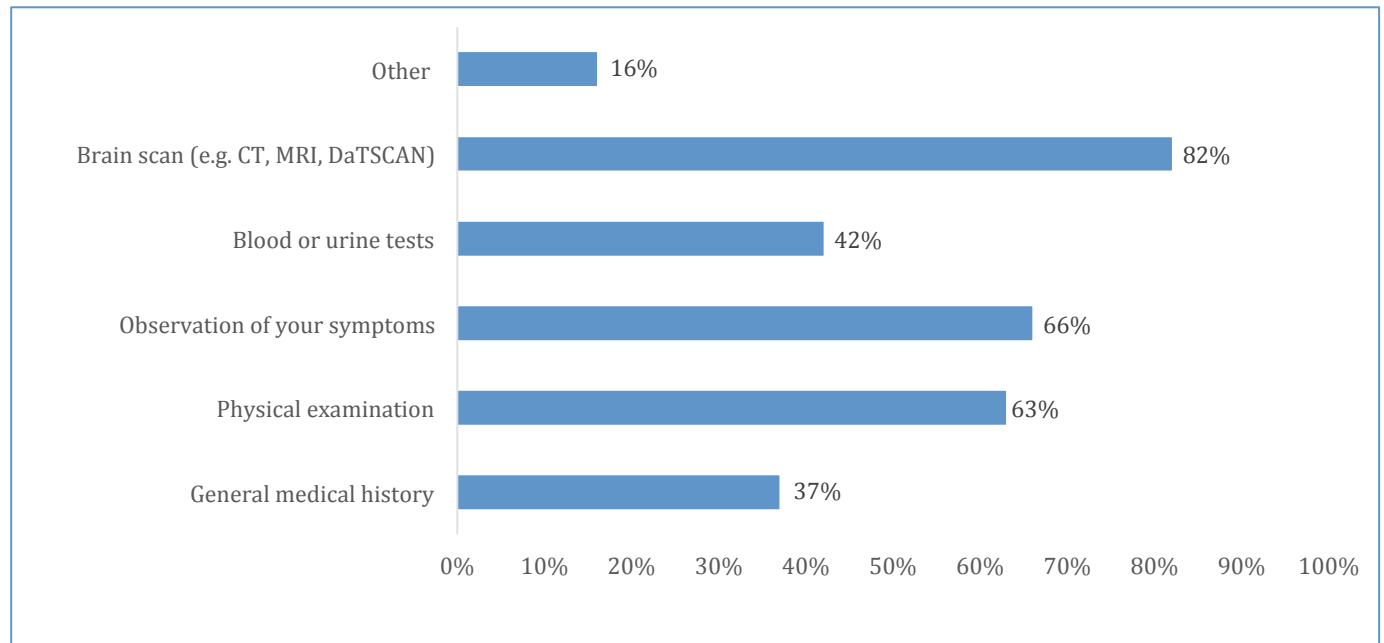
HEALTHCARE PROFESSIONAL	Within 1 month (%)	1-2 months (%)	2-3 months (%)	3-4 months (%)	4 months +	% of respondents referred
General neurologist	34	5	8	5	26	78
Neurologist Specialist in Parkinson's	11	3	3	3	29	49
Geriatrician	0	0	0	0	0	0
Parkinson's disease nurse specialist	0	0	0	0	5	5
Physiotherapist	0	3	0	3	11	17
Occupational therapist	0	0	0	3	3	6
Speech and language therapist	0	0	0	3	8	11

The overwhelming majority of respondents had a brain scan to diagnose their Parkinson's (82%). Around two thirds stated that their symptoms were observed (66%) or they underwent a physical examination (63%) (Figure 3). 16% of respondents mentioned that they also underwent other types of examinations and tests during diagnosis. These included:

- Electromyogram
- SPECT

⁶⁸ Respondents could select multiple options or state that they could not remember

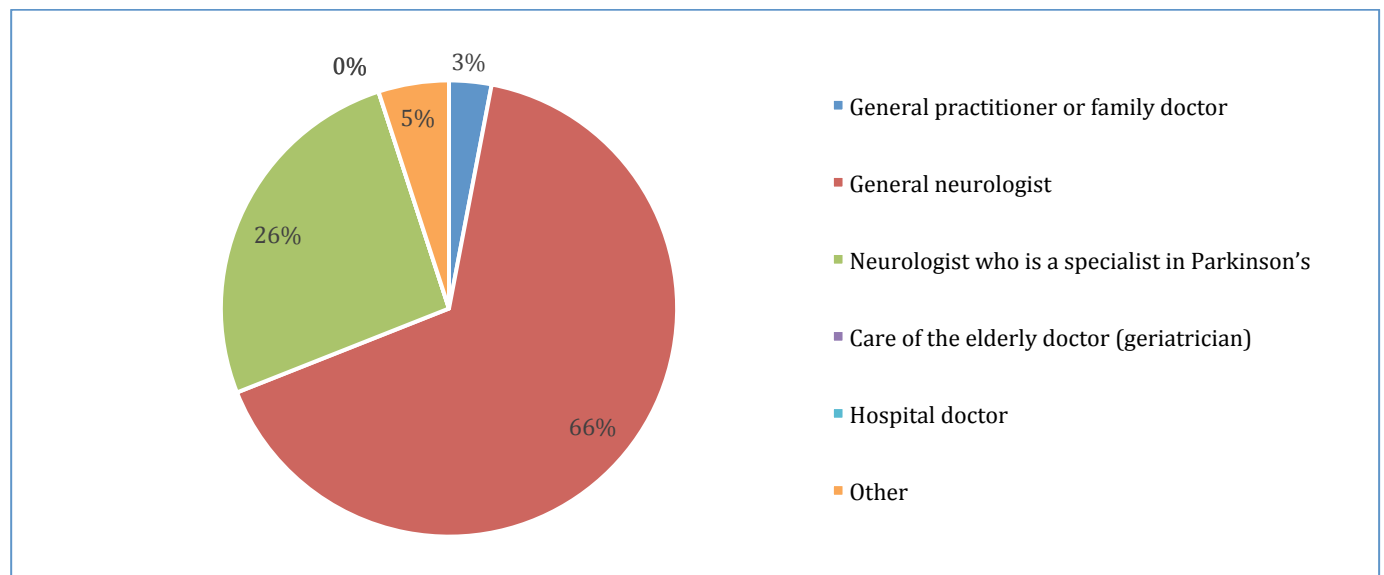
Figure 3. Examinations and tests carried out (%)



1.5. Delivery of the diagnosis

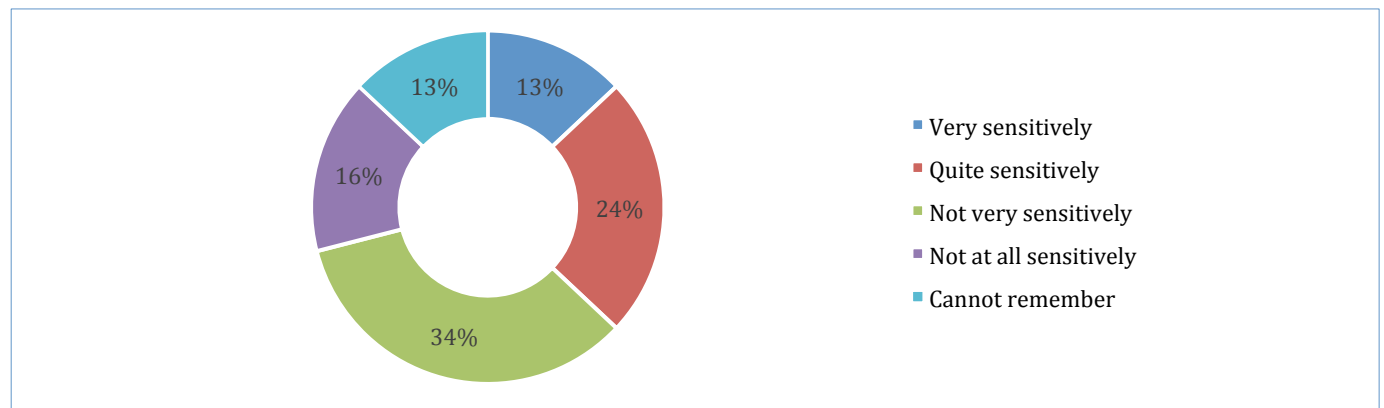
Most of the respondents received their diagnosis of Parkinson's from a general neurologist (66%), or from a specialist neurologist in Parkinson's (26%). Only one respondent received the diagnosis from their GP (Figure 4). None of the respondents were given the diagnosis by a hospital doctor or geriatrician.

Figure 4. Healthcare professional diagnosing Parkinson's (%)



In relation to the sensitivity in which the diagnosis was given, 37% of the respondents feel that they were told either very sensitively or quite sensitively, while 50% believe it was not given sensitively. When asked if they were satisfied with the consultation, 34% feel either dissatisfied (18%) or very dissatisfied (Figure 5).

Figure 5. Sensitivity of diagnosis (%)



1.6. Information given at diagnosis

At time of diagnosis, nearly half of the respondents report that they were given information verbally about the symptoms and causes of Parkinson's (46%) and 57% were given information about the medication. 18% were given information about clinical trials either verbally or with hand-outs. 32% said that they were given either written or verbal information (or both), on the importance of maintaining physical wellbeing (e.g. healthy eating, exercise, etc.) and of maintaining mental wellbeing (30%). Most of the respondents were *not* advised where to find information on Parkinson's (71%), or support organisations for patients (76%) as well as given information on available financial help (91%) (Table 5).

Table 5. Information given (%)⁶⁹

TOPIC AREA	Leaflet/ Handouts/ signposting to online information (%)	Explained verbally (%)	Both handouts and verbal information (%)	I did not want any information (%)	No information was provided (%)
Symptoms, diagnosis and causes of Parkinson's	3	46	14	3	32
Medication	8	57	14	0	22
Surgical treatments	3	21	3	3	64
Non-drug treatments	3	20	6	0	66
Maintaining physical wellbeing	6	20	6	0	63
Maintaining emotional wellbeing	3	24	3	0	67
Financial help available	0	3	0	0	91
Support organisations (e.g. patient associations)	9	12	0	0	76
Support for carers	0	6	0	0	88
Where to find more information on Parkinson's	12	9	3	0	71
Taking part in clinical trials	3	15	0	0	82

⁶⁹ Respondents were also able to answer no information was provided or cannot remember.

38% of the respondents found the information they were given either very or quite helpful. However, 11% answered 'neutral' and 16% felt that the information was not very helpful or not helpful. Two respondents could not remember and 35% stated that information was not provided.

In relation to the question enquiring whether or not respondents felt as if they had enough time to ask questions and discuss their concerns, only 19% feel that they were given enough time compared to 22% who felt that they were not given any time and 30% who would have liked more time (Table 6).

Table 6. Time to ask questions and discuss concerns – Question responses (%)

REPONSES	Response (%)
Yes, I was given enough time	19
Yes, but I would have liked more time	30
No, I was not given any time	22
I did not want to ask questions at that time	5
I did not feel able to ask questions or discuss concerns at that time	19
Cannot remember	5

1.7. Link between quality of life, satisfaction, and availability of information

A bivariate correlation was conducted to explore the relationship between availability of information and quality of life. To calculate an 'information availability total', responses were coded '1' for leaflet, verbal, or both (i.e., 'some information provided'). These numbers were then totalled across all the categories respondents were asked to consider (i.e., medication, support for carers), with higher numbers equating to a greater availability of information.

The correlation between the quality of life (QoL) index score (Mean = .51) and the information total (Mean = 2) does not reach a satisfactory level of statistical significance ($n = 58$, $r = .07$, $p = .63$). Therefore we are unable to conclude that QoL is affected by the availability of information.

The relationship between information availability and satisfaction with care received was also explored via a correlation. No significant relationship is observed ($n = 35$, $r = .14$, $p = .42$), suggesting levels of satisfaction with care are not associated with the availability of information.

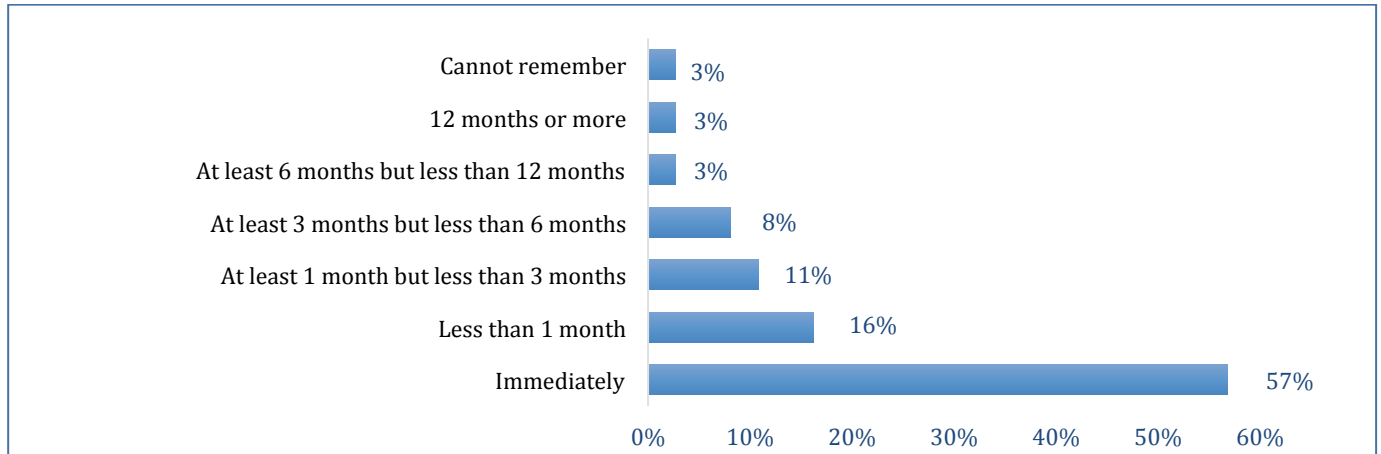
The relationship between satisfaction with treatment and information was also explored. A significant positive relationship emerges between availability of information and satisfaction with treatment ($n = 35$, $r = .47$, $p < .01$), suggesting levels of satisfaction with treatment are associated with availability of information. Specifically, a higher level of satisfaction with treatment is related to receiving more information about the disease.

Finally, the relationship between satisfaction with the consultation where the initial diagnosis was made and the amount of information provided was also explored via a correlation. Replicating the previous correlations, results suggest a positive relationship between the two variables ($n = 38$, $r = .48$, $p < .01$) – the amount of information provided (both verbal and written) is related to how satisfied respondents are with the initial diagnosis and consultation. Respondents who receive more information also feel more satisfied with the consultation where the initial diagnosis was made.

1.8. Treatment

The majority of respondents (57%) started medication or treatment within the first year after diagnosis, with over half of these starting immediately (Figure 6).

Figure 6. Medication and treatment timings (%)

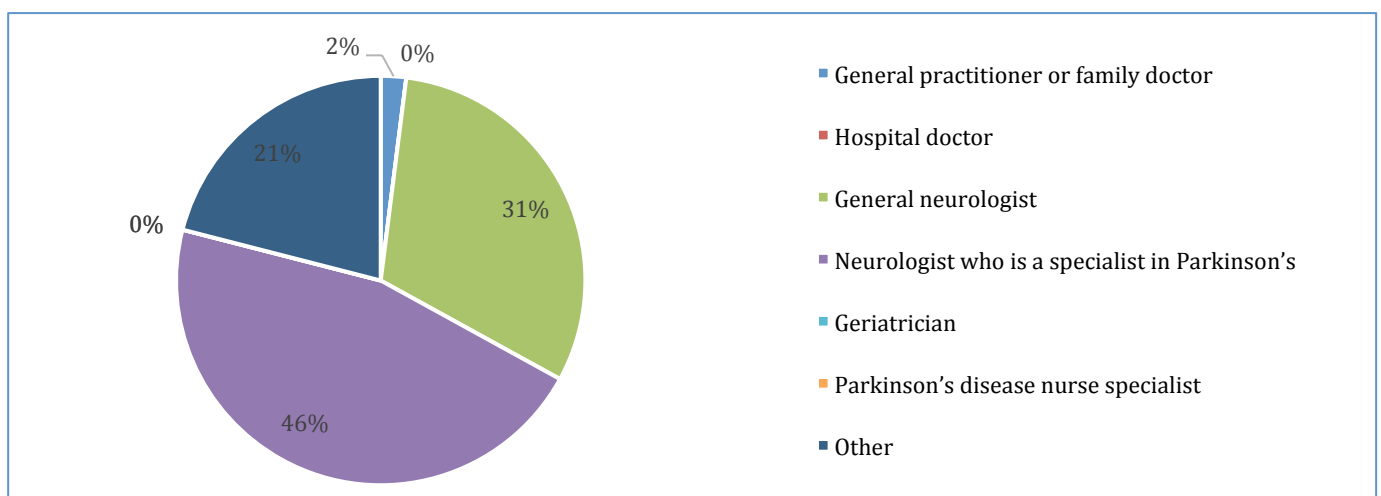


The most frequently taken medications include Sinemet (60% of respondents prescribed this medication) and Rasagiline (53%), which are predominantly prescribed by a general neurologist or a specialist neurologist. However, GPs do still on occasions prescribe both these medications (5-8% of the time).

Other medications which are prescribed include⁷⁰: Amantadine (15%); Apomorphine (5%); Entacapone (10%); Madopar (5%); Pramipexole (13%); Ropinirole (40%); Rotigotine (20%); Selegiline (18%); and Stalevo (18%).

The majority of the medications are prescribed by a general neurologist or a specialist neurologist and very occasionally a GP. No one reports being prescribed medication by a Parkinson's disease nurse specialist, hospital doctor or a geriatrician (Figure 7).

Figure 7. Healthcare professionals who prescribed the medication (%)



⁷⁰ Presented in alphabetical order

Two-third of the respondents report that the state currently pays for their medication (66%). However, 23% also state that they pay for some medication privately (themselves/family) or their insurance pays (29%)⁷¹. One of the respondents reports that a Parkinson's organisation pays for the medication and one respondent does not know who pays for their medication.

The relationship between satisfaction with care and paying for treatment was explored. Responses about paying for treatment were assigned a group based on whether care was state funded or by private/insurance⁷². An independent samples t-test⁷³ was conducted to investigate whether satisfaction with care differed according to whether respondents paid for the treatment or not. This analysis reveals no statistical difference. Mean levels of satisfaction do not differ between the groups. Respondents who pay for treatment (either through insurance or privately) report similar levels of satisfaction with care (n = 10, Msatisfaction = 11) to those respondents whose treatment is state funded (n = 16, Msatisfaction = 13) (t = .75, p = .46).

A second independent t-test was conducted to explore if access to health care professionals (as measured by frequency of medication review) differs according to how the health care is funded (i.e. state vs. private). Respondents who receive state funded care (n=16, Mreview = 3) report the same average frequency reviews as respondents who pay for treatment (n=10, Mreview = 3). Hence the comparison between the two groups reveals a significant difference according to the two types of funding (t= .09, p=.93).

Using length of time to gain access to treatment after diagnosis, as a proxy for availability, a further independent t-test was conducted to establish if length of time differs between state (n=16, Mtime = 3) versus private funding (n=10, Mtime = 3). No significant differences in treatment waiting times are noted between the two groups (t= -.60, p = .56).

Only 5 respondents report being refused care due to cost and 4 due to where they live; hence the samples are too small to conduct a valid analysis to explore links between QoL and refusal of treatment.

1.9. Satisfaction

Amongst respondents, levels of satisfaction with the care they receive are generally high. Most of the respondents state that they are satisfied or very satisfied with the care they are receiving from all of the healthcare professionals they were asked to comment on (including clinical practitioners in both primary and secondary care, as well as therapists). Respondents are least likely to be dissatisfied with the general neurologist (14% state they are dissatisfied or very dissatisfied), Parkinson's disease nurse specialist (6% dissatisfied or very dissatisfied), and hospital doctor (6% dissatisfied or very dissatisfied). None of the respondents state that they are dissatisfied or very dissatisfied (or even neutral) with their geriatrician or physiotherapist.

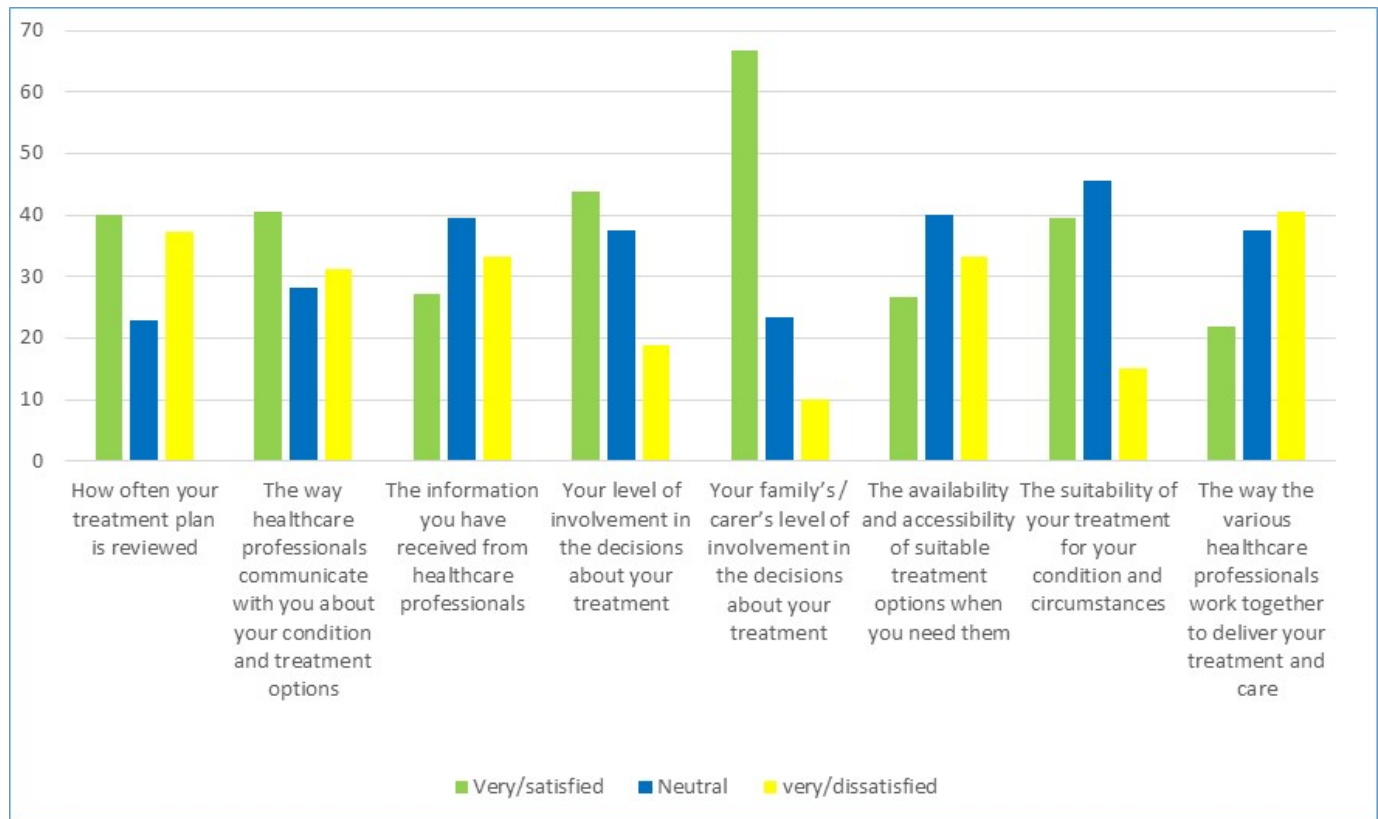
In relation to treatment and overall care, respondents are most satisfied with the level of their family's/carer's involvement in decisions about treatment (67%), how often their treatment plan is reviewed (40%), and with the level of involvement in the decisions about their treatment (43%). However, there is less satisfaction in relation to other aspects of care, in particular the way the various healthcare professionals work together to deliver the treatment and care (22%) and opinions were polarised in regard to how often their treatment plan is reviewed (40% satisfied versus 37% dissatisfied) (Figure 8).

⁷¹ Respondents could select multiple options

⁷² Insurance and private were joined together to enable a direct comparison between paying vs. non-paying care. Respondents who indicated more than one source of funding were excluded from the analysis so as to ensure valid comparisons between the groups.

⁷³ The independent-samples t-test (or independent t-test, for short) compares means values (averages) between two unrelated groups on the same continuous variable (i.e., scale scores).

Figure 8. Satisfaction with treatment and overall care (%)



The relationship between frequency of medication review and satisfaction with care was explored with a bivariate correlation. The analysis reveals no relationship between satisfaction with care and frequency of review, suggesting respondents who benefit from more frequent reviews, also report higher levels of satisfaction with care ($n = 35$, $r = .01$, $p = .59$).⁷⁴

Respondents also reported on the frequency of their medication reviews with different healthcare professionals (Table 7); because respondents may have more than one medication review a year, numbers in the table do not necessarily add up to 100%

For the medication reviews, respondents were asked to detail how often their medication is reviewed and who reviews it. Nearly half of the respondents have their medication reviewed by a neurologists who is a specialist in Parkinson's (45%). In relation to the other healthcare professionals: 16% of respondents have their medication reviewed by a GP; 25% by a general neurologist; 9% by a hospital doctor; 4% by a Parkinson's disease nurse specialist and 2% by a geriatrician.

For the medication reviews, respondents state that a neurologist who is a specialist in Parkinson's reviews their medication either every three (14%), or six months (34%), or once a year (20%). GPs reviewed the medication every three or six months, with the hospital doctor once every six months (Table 7).

⁷⁴ Respondents who indicated 'do not know' and 'does not apply' were not included in this analysis

Table 7. Medication reviews (%)⁷⁵

HEALTHCARE PROFESSIONALS	Every 3 months (%)	Every 6 months (%)	Once a year (%)	Once every 2 years or more (%)
General practitioner or family doctor	11	11	0	0
Hospital doctor	0	11	0	0
General neurologist	14	17	6	0
Neurologist who is a specialist in Parkinson's	14	34	20	0
Geriatrician	0	0	0	0
Parkinson's disease nurse specialist	3	0	0	0

A Bivariate correlation was conducted to explore the relationship between quality of life and frequency of medication review. No significant relationship is observed ($n = 58$, $r = .01$, $p = .97$), suggesting QoL is not associated with frequency of medication review.

In addition, a second bivariate correlation was run to assess the relationship between quality of life and satisfaction with care. Using the quality of life index and the satisfaction for care index, again no significant relationship emerges ($n = 35$, $r = -.28$, $p = .10$) suggesting QoL is not influenced by how satisfied respondents were with their care.

1.10. Advanced treatments

Eight of the respondents have received surgical treatments – seven state that they received “*Deep Brain Stimulation*” and one stated Duodopa. Three of the respondents received the surgery within five years of being diagnosed with Parkinson's, one between 6 to 10 years after diagnosis, and the remaining three respondents more than 15 years after diagnosis (and one respondent did no answer). The respondents' answers were polarised with four stating that the surgery has meet their expectations, whilst the remaining four feel it has not. Some the respondents gave further explanation as to why the surgical treatment has met/has not met their expectations:

“It has not met my expectations, because I'm still taking a lot of medication.”

“Significant improvement in bladder hyperactivity.”

“Yes, but not entirely, as I'm still shaking”

“It's very recent, and we are still adjusting the frequency, and I cannot say whether it has met my expectations.”

“Motor problems solved, but it has aggravated the non-motor (e.g. impulse control)”

The research team was not able to look at the correlations between receiving advanced treatments and QoL/satisfaction variables as there are too few respondents who had received advanced treatments.

⁷⁵ Respondents could have reviews from more than one healthcare professional and were also able to state that they did not know or that it did not apply for them

1.11. Findings in relation to the national guidelines

In Spain, there are various protocols/guidelines as regions often have their own, for example the Protocol management and referral of patients with Parkinson's disease⁷⁶ (prepared from Directorate General Patient Care in Madrid). Although they differ slightly, they are all based on the national Official guide clinical practice in Parkinson's disease (2009)⁷⁷.

The guidelines state:

- If Parkinson's disease is suspected, a patient should be referred to a neurologist in less than eight weeks. This should be done before any drug treatment is started. During the initial consultation, if deemed necessary, patients should be sent for further tests including CT, EEG, MRI, SPECT scans.
- Once diagnosis has been made, the patient should be monitored every 3 to 6 months, depending on the case. Advice and information should also be provided for patient and carers by appointment, telephone, or via email.
- If no drug treatment is regarded as necessary, the patient should be given information, and the details of available support groups. A health care professional should highlight to the patients the existence of the non-profit Parkinson's organisations for informative purpose, training, maintaining the disease, physiotherapy, and psychotherapeutic support.
- If a patient is assessed for drug treatment, Levodopa/carbidopa are prescribed, Dopamine agonists, as well as Selegiline and Rasagiline, and Amantadine.

The findings from the survey demonstrate that, in line with the guidelines, 39% had their first consultation within eight weeks, however another 39% stated that they had to wait more than eight weeks before being seen by a general neurologist. Only 14% of respondents were seen by a specialist neurologist within the 8-week recommended timeframe.

In line with the guidelines, 82% of the participants were scanned before diagnosis was made and 66% of the respondents had their symptoms observed. However, only 31% had their treatment reviewed every 3 to 6 months by a general neurologist and 48% by a specialist neurologist, as stated in the guidelines. The findings would also suggest that information on the non-profit Parkinson's organisations was not given out at the time of diagnosis.

⁷⁶ <http://www.madrid.org> *the protocol is aimed at professionals in the Madrid Health Service

⁷⁷ Protocol is based on the *Official guide clinical practice in Parkinson's disease*, (*Guía oficial de práctica clínica en la enfermedad de Parkinson*) Spanish society of neurology (2009) http://getm.sen.es/wp-content/uploads/2012/02/GUIA_SEN_Parkinson.pdf

APPENDIX II-J: SURVEY FINDINGS FOR SWEDEN

1.1. Sample profile

In total 806 respondents completed the survey from Sweden. Over half (56%) of respondents are male and the average age of respondents was 61 years when they were diagnosed with Parkinson's, with the youngest aged 27 and oldest aged 85 years. One third of respondents state that they are currently employed. When asked to describe the area in which they live, most state in a city (56%), 27% in a town and the rest in rural areas.

1.2. Quality of life and disability scores

To explore quality of life, EuroQol's EQ-5D measure was utilised. This is a standardised instrument for measuring of health status and requires respondents to answer five questions focusing on **mobility, self-care, usual activities, pain, and anxiety/depression**.

Regarding **mobility**, 31% report no problems walking, while 67% report some problems. Only 2% of respondents indicate that they are confined to a bed⁷⁸.

Moving on to **self-care**, 4% report they are unable to wash or dress themselves and 31% have some problems with washing or dressing. The majority of respondents (65%) indicate no problems with self-care.

When asked about their current ability to perform **everyday activities** such as work and leisure, 63% of respondents experience some problems performing these activities, while 27% indicate no problems at all. Those who are unable to perform any everyday activities are the smallest group, accounting for 10% of the sample.

When discussing current levels of **pain and discomfort**, the majority of the sample- 71%- indicate that they suffer from moderate pain, while 20% indicate having no pain or discomfort. Those who suffer from extreme pain represent 9% of the sample.

The final question assessing current quality of life focuses on levels of **anxiety and depression**. Moderate levels of anxiety or depression are reported by 41% of respondents, while 57% report no feelings of anxiety or depression. The smallest proportion of the sample (2%), report feelings of extreme anxiety or depression.

Compared with their general health over the last 12 months, only 7% of respondents feel that their health has improved while 46% say it has worsened. Only 47% state that their health is *much the same*.

When asked to rate which statement best describe how they feel about their independence, 2% of the respondents report to being bed bound or totally dependent and helpless. The most commonly recorded response is '*I am able to do all chores with some degree of slowness, difficulty and impairment, and am beginning to be aware of difficulty*' (51%) (Table 1).

⁷⁸ Results based on the number of respondents answering Question 7. This result may not tally with the number stating they are bedridden in Question 13, the results of which are shown in Table 1.

Table 1. Self-reported disability score

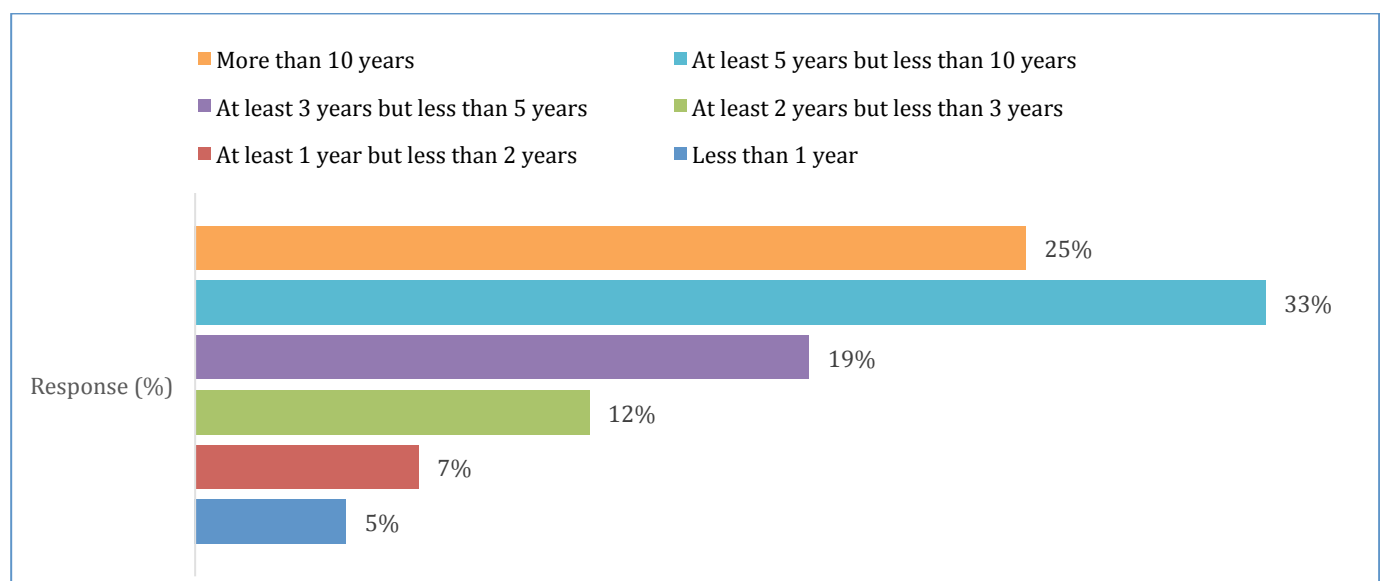
STATEMENTS	Response (%)
I am able to do all chores without slowness, difficulty or impairment	5
I am able to do all chores with some degree of slowness, difficulty and impairment, and am beginning to be aware of difficulty	51
Chores take twice as long and I am conscious of difficulty and slowness	19
Chores take three to four times as long and I spend a large part of the day doing these	3
I can do most chores, but exceedingly slowly and requiring a lot of effort	10
I need help with half the chores and have difficulty with everything	2
I can assist with all the chores, but am only able to do a few on my own	2
I can manage a few chores with some effort, but need a lot of help	5
I do nothing on my own, but can be a slight help with some chores	2
I am totally dependent and helpless	2
I am bedridden	0

1.3. Receiving a diagnosis of Parkinson's disease

1973 was the earliest date that a respondent had been diagnosed with Parkinson's and 2014 the latest (the median year of diagnosis was 2008). Nearly all of the respondents had been diagnosed with Parkinson's in Sweden (98%), with the exception of 11 respondents who had been diagnosed in the following countries: France (1); Germany (1); Ireland (1); Hungary (1); Netherlands (1); Spain (1); Norway (2); USA (1); and Finland (2).

For most of the respondents, it has been over three years since diagnosis (57%). 25% of respondents were diagnosed over 10 years ago (Figure 1).

Figure 1. Length of time since diagnosis (%)



The symptoms most commonly noticed before diagnosis included changes in the way you move (including the way you walk, dragging a leg, not swinging your arm, etc.) with 82% of the respondents reporting experience of this symptom. Interestingly people with these symptoms were more likely to seek help within two years. This was similar for tremor (shaking) and speech and communication problems with most people seeking help within two years (Table 2).

Table 2. Reported symptoms, and duration of these symptoms before seeking medical help

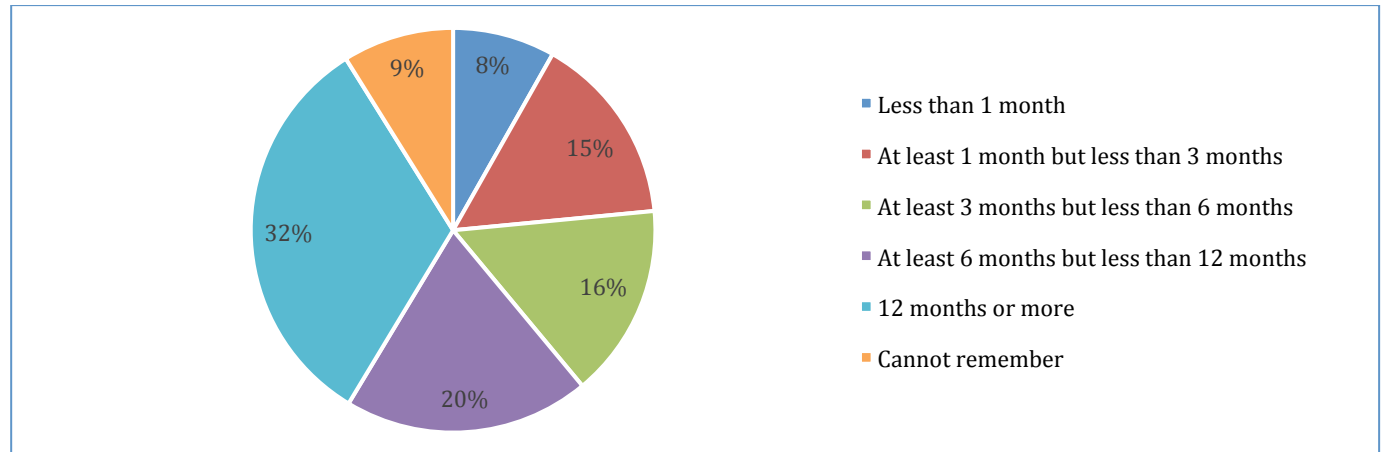
SYMPTOMS/PERCENTAGE OF RESPONDENTS⁷⁹	Less than 1 year (%)	1 to 2 years (%)	3 to 4 years (%)	5 years or more (%)	Total number of respondents experiencing symptoms
Anxiety	6	6	4	4	20
Apathy	4	6	2	2	14
Bladder and bowel problems	4	9	6	10	29
Changes in the way you move (incl. the way you walk, dragging a leg, not swinging your arm, etc.)	19	37	17	9	82
Depression	5	7	5	5	22
Difficulty eating and/or swallowing	7	6	1	2	16
Eye problems	7	6	4	5	22
Falls (balance problems)	9	10	6	4	29
Fatigue	11	18	12	9	50
Freezing	8	6	3	2	19
Loss of smell or taste	9	10	10	16	45
Low blood pressure or dizziness	7	8	6	9	30
Muscle cramps	11	12	8	6	37
Pain	9	14	7	9	39
Rigidity (stiffness)	16	21	10	9	56
Skin and/or sweating problems	5	8	6	5	24
Sleep problems	7	13	7	9	36
Slowness of movement	16	24	10	6	56
Speech and communication problems (incl. small handwriting and reduced facial movements)	17	18	10	6	51
Stress	9	15	10	11	45
Thinking or memory problems	11	11	7	4	33
Tremor (shaking)	21	20	8	7	56

Other symptoms added by the respondents included: problems with coordination; reduced fine motor skills; stiffness in the neck; back pain; shingles in the ear with facial paralysis; changes in facial expressions; hearing loss; and clumsiness.

⁷⁹ Respondents could select “do not apply” and select multiple options

When asked how long it was before seeking medical help after first noticing their symptoms, only 8% sought help within a month and one-third of respondents (32%) did not seek help for over 12 months. Just over one half of respondents sought help within 3 and 12 months of diagnosis (51%) (Figure 2).

Figure 2. Timelines for seeking medical help (%)



1.4. During the first appointment

For just over half of the respondents, during the first appointment with a healthcare professional, a physical examination was carried out (53%). Two-thirds of respondents stated that their symptoms were observed, while 10% of the respondents were told that they had another disease /condition. Two thirds of respondents were referred to another specialist and just under a half were told they might have Parkinson's disease (45%) (Table 3).

Table 3. Events during the first appointment with a healthcare professional (%)

EVENTS	Response (%) ⁸⁰
Discussed your general medical history	41
Carried out a physical examination	53
Observed your symptom(s)	66
Referred you to a specialist, or another doctor / healthcare professional	64
Said nothing was wrong	10
Said it was too early to tell if anything was wrong	10
Said something was wrong, but not sure what	19
Prescribed medication to relieve your symptom(s)	19
Explained that you may have Parkinson's	45
Explained that you may have another disease / condition	10

The other healthcare professionals that respondents were referred to include: a cardiologist; physiotherapist; psychiatrist; specialist consultant in epilepsy; ENT consultant; and chiropractor.

⁸⁰ Respondents could select multiple options

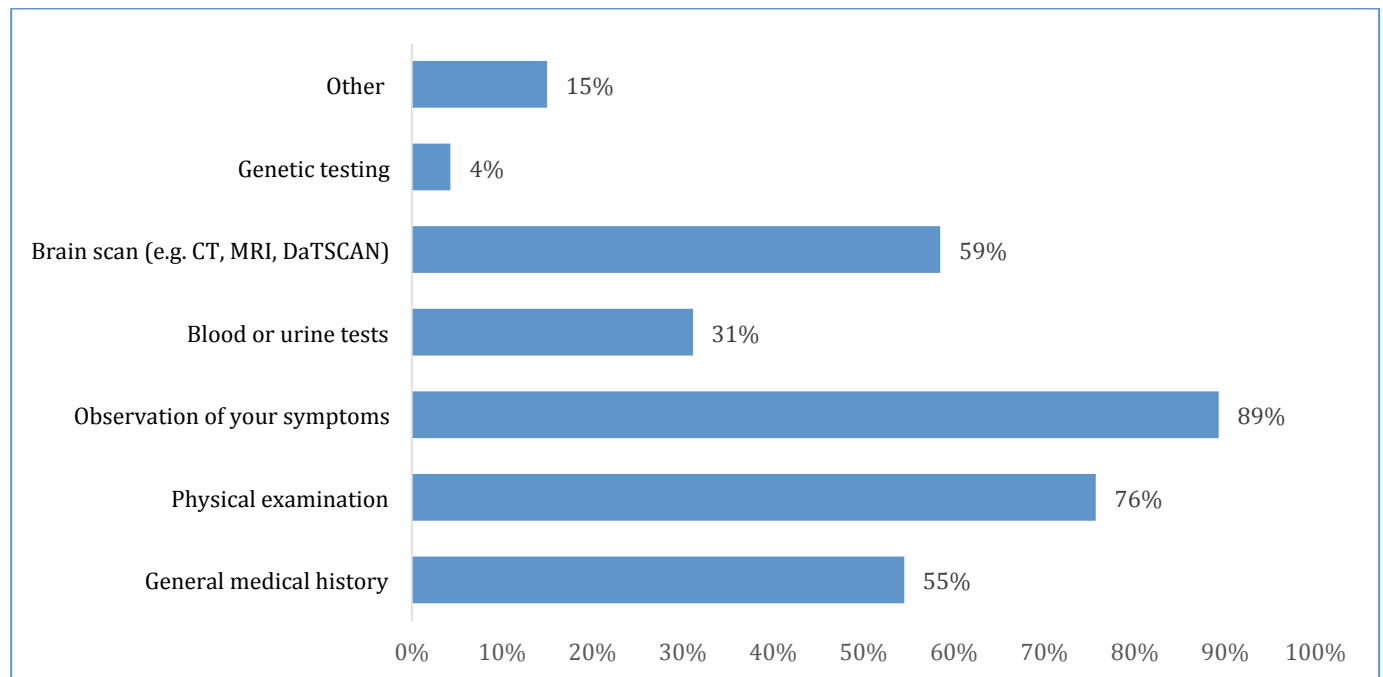
Respondents were asked, if they were referred to another healthcare professional, what the waiting times were. If a referral was made, mostly this was to a neurologist specialising in Parkinson's (60%) or a general neurologist (50%). The waiting times were predominantly under three months for the medical healthcare professionals, although they were longer for therapists (Table 4).

Table 4. Waiting times to see professionals from referral (%)⁸¹

HEALTHCARE PROFESSIONAL	Within 1 month (%)	1-2 months (%)	2-3 months (%)	3-4 months (%)	4 months +	% of respondents referred
General neurologist	8	13	11	8	11	50
Neurologist Specialist in Parkinson's	11	16	12	9	13	60
Geriatrician	1	1	1	1	2	6
Parkinson's disease nurse specialist	4	6	6	5	10	31
Physiotherapist	6	6	4	3	14	34
Occupational therapist	2	1	2	2	9	16
Speech and language therapist	1	1	1	2	8	13

The overwhelming majority of respondents report that an observation of symptoms was conducted (89%) to diagnose their Parkinson's. Most also reported that a physical examination was carried out (76%). 59% of respondents underwent a brain scan while genetic testing was conducted on only 4% (Figure 3).

Figure 3. Examinations and tests carried out

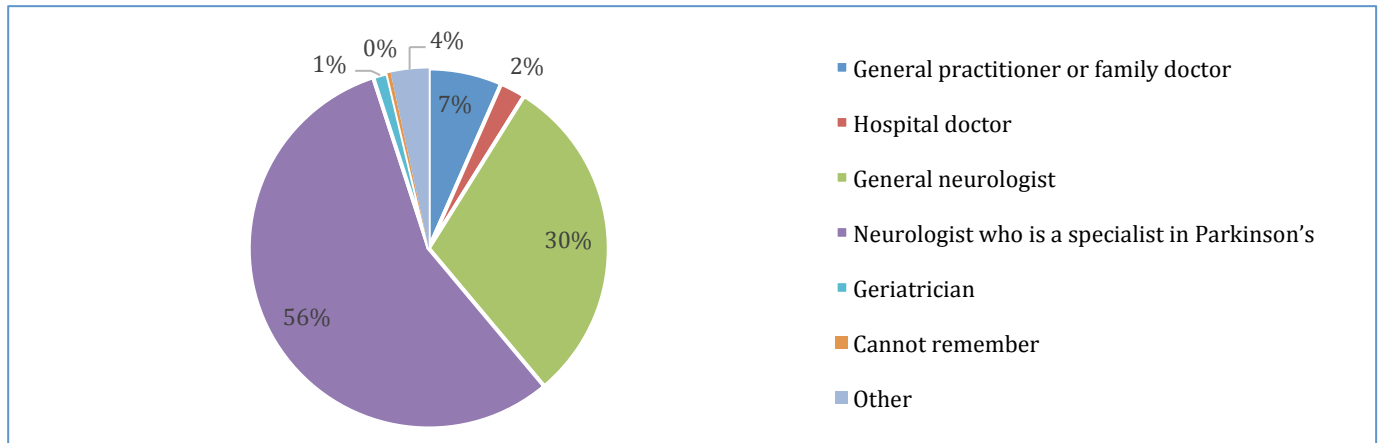


⁸¹ Respondents could select multiple options or state that they could not remember

1.5. Delivery of the diagnosis

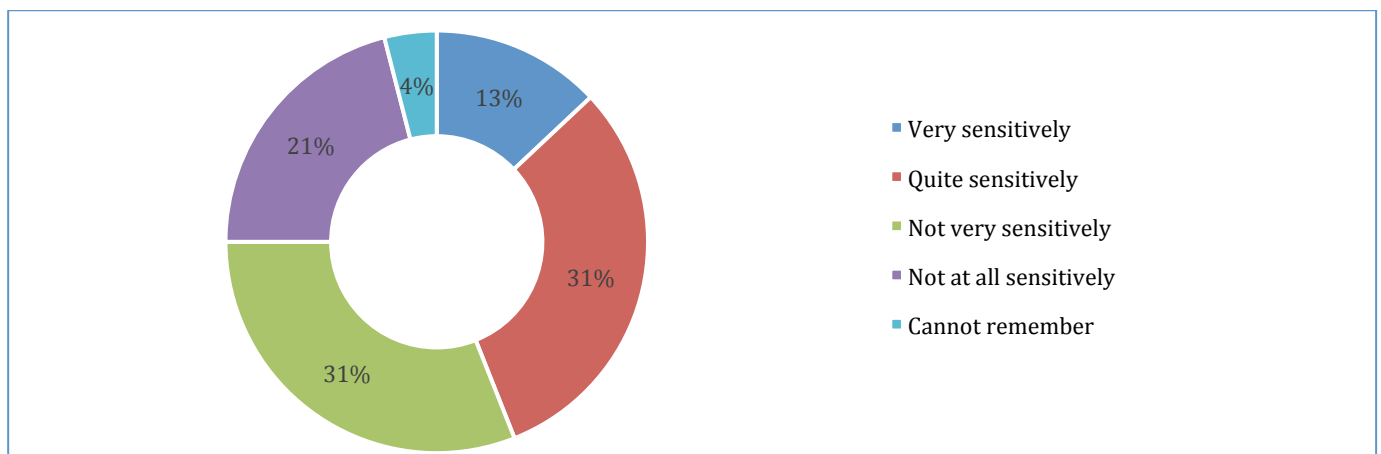
Over half of the respondents were given their diagnosis by a neurologist who specialised in Parkinson's (56%), while a one third were diagnosed by a general neurologist (30%), and a GP gave the diagnosis in 7% of the cases (Figure 4). All the respondents could recall who gave them their diagnosis. 4% mentioned other professionals, including: a 'Professor'; psychiatrist; Parkinson's nurse specialist; themselves (after reading news articles and later confirmed by a neurologist); and a Social Insurance doctor.

Figure 4. Healthcare professional diagnosing Parkinson's (%)



In terms of sensitivity in which the diagnosis was given, respondents are polarised with 54% stating that they had not been given the diagnosis sensitively compared to 44% who state the opposite (Figure 5). Despite over half of the respondents not feeling as if the diagnosis was given sensitively, only 15% feel dissatisfied or very dissatisfied with the consultation where the initial diagnosis was given. 48% said they are either very satisfied or satisfied. The remaining respondents answered *neutral* to this question.

Figure 5. Sensitivity of diagnosis (%)



1.6. Information given at diagnosis

At time of diagnosis, the overwhelming majority of the respondents were given information on symptoms, diagnosis and causes of Parkinson's (85%). 92% say that they were also given information on medication. Information on clinical trials however was only provided to just over a quarter of respondents (29%). On the whole, verbal explanations were more frequently reported compared to being given written information (Table 5).

Table 5. Information given (%)⁸²

TOPIC AREA	Leaflet/ handouts/ signposting to online information (%)	Explained verbally (%)	Both handouts and verbal information (%)	I did not want any information (%)	No information was provided (%)
Symptoms, diagnosis and causes of Parkinson's	6	52	26	0	11
Medication	7	59	19	0	7
Surgical treatments	2	9	2	1	59
Non-drug treatments	3	26	10	1	42
Maintaining physical wellbeing	5	33	11	1	33
Maintaining emotional wellbeing	3	21	8	1	45
Financial help available	2	3	2	1	65
Support organisations (e.g. patient associations)	11	14	12	1	45
Support for carers	5	19	7	2	42
Where to find more information on Parkinson's	16	15	13	1	37
Taking part in clinical trials	2	5	4	1	58

Half of the respondents found the information they were given either very or quite helpful (50%) while 37% found it unhelpful. The remaining 13% stated that they had not been given any information.

In relation to the question enquiring whether or not respondents feel as if they had enough time to ask questions and discuss their concerns, over one-third feel that they were given enough time (37%). However 22% did not feel able to ask questions or discuss concerns at that time. Disappointingly, 11% said they were not given any time (Table 6).

Table 6. Time to ask questions and discuss concerns – Question responses (%)

REPONSES	Response (%)
Yes, I was given enough time	37
Yes, but I would have liked more time	19
No, I was not given any time	11
I did not want to ask questions at that time	7
I did not feel able to ask questions or discuss concerns at that time	22
Cannot remember	5

⁸² Respondents were also able to answer no information was provided or cannot remember

1.7. Link between quality of life, satisfaction, and availability of information

A bivariate correlation was conducted to explore the relationship between availability of information and quality of life. To calculate an 'information availability total', responses were coded '1' for leaflet, verbal, or both (i.e. 'some information provided'). These numbers were then totalled across all the categories respondents were asked to consider (i.e. medication, support for carers), with higher numbers equating to a greater availability of information.

The correlation between the quality of life (QoL) index score (Mean = .60) and the information total (Mean = 4) is in a positive direction; however it does not reach a satisfactory level of statistical significance ($n = 790^{83}$, $r = .06$, $p = .09$). Therefore we are unable to conclude that QoL is affected by the availability of information.

The relationship between information availability and satisfaction with care received was also explored via a correlation. A significant positive relationship was observed ($n = 683$, $r = .25$, $p < .01$), suggesting levels of satisfaction with care are associated with the availability of information. Respondents with higher levels of satisfaction with their care also report receiving more information (both written and verbal).

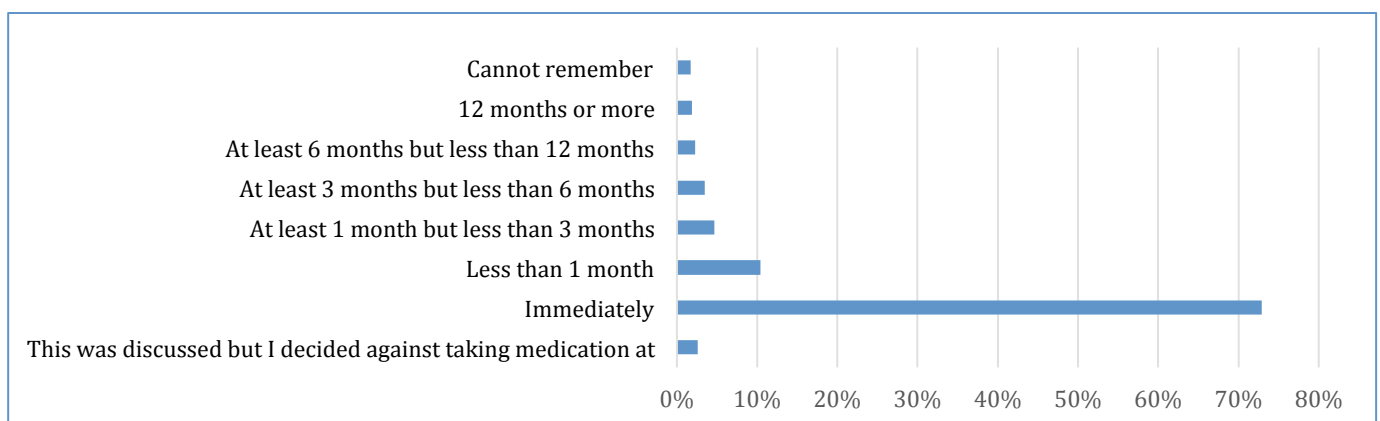
The relationship between satisfaction with treatment and information was also explored. Again, a positive small sized correlation emerges between availability of information and satisfaction with treatment ($n = 683$, $r = .24$, $p < .01$), suggesting levels of satisfaction with treatment are associated with availability of information. Respondents with higher levels of satisfaction with their treatment also report receiving more information (both written and verbal).

Finally, the relationship between satisfaction with the consultation where the initial diagnosis was given and the amount of information provided was also explored via a correlation. Replicating the previous correlations, a positive relationship between the two variables is observed ($n = 700$, $r = .34$, $p < .01$). The amount of information provided (both verbal and written) is associated with how satisfied PwP are with the initial diagnosis and consultation. Specifically, respondents who report high levels of satisfaction with the initial diagnosis also receive more information.

1.8. Treatment

Around 95% of respondents started medication or treatment within the first year after diagnosis, with 73% starting immediately. In comparison, 3% of respondents decided not to take medication at the time of diagnosis (Figure 6).

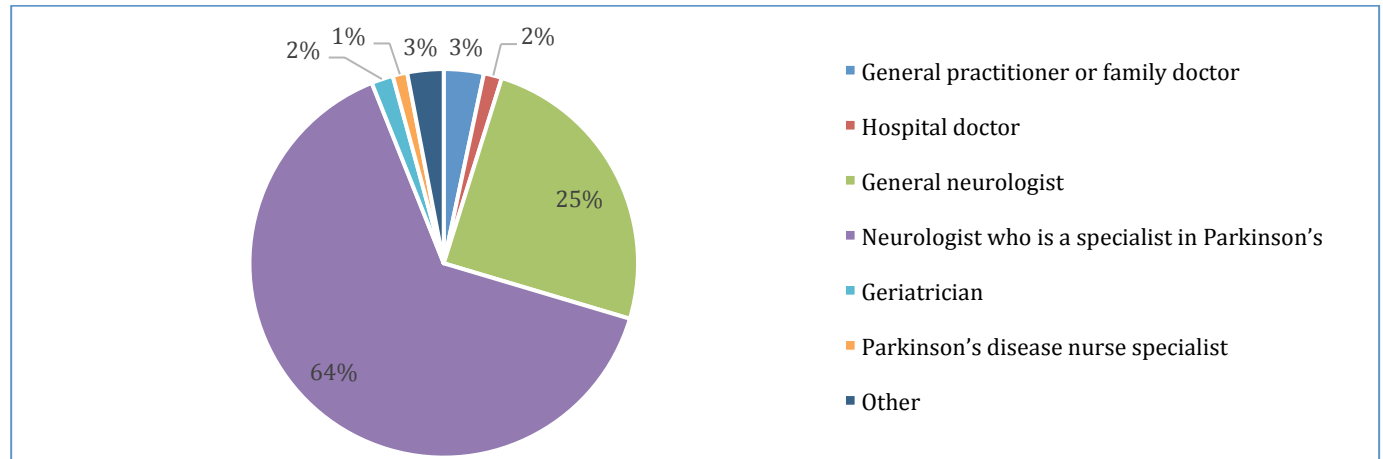
Figure 6. Medication and treatment timings (%)



⁸³ The sample size number is lower due to respondents who indicated 'I do not want any information' and 'cannot remember' being excluded.

Madopar is the most frequently prescribed medication, with over 85% of respondents stating they have been prescribed it (86%). No other medications was prescribed anywhere near as frequently as Madopar® with the second most frequently prescribed being Pramipexole. However, only 35% of respondents reported to have being prescribed this medication. Most of the medications are either prescribed by a neurologist who is specialised in Parkinson's (64%) or by a general neurologist (25%) (Figure 7).

Figure 7. Healthcare professionals who prescribed the medication (%)



Nearly two-thirds of the respondents state that the state currently pays for their medication (64%). However, 66% of the respondents state that they pay for some medication privately (themselves/family)⁸⁴ and 3% say that insurance pays for the medication⁸⁵.

The relationship between satisfaction with care and paying for treatment was explored. Responses about paying for treatment were assigned a group based on whether care was state funded or by private/insurance⁸⁶. An independent samples t-test⁸⁷ was conducted to investigate whether satisfaction with care differs according to whether respondents pay for the treatment or not. This analysis reveals a significant statistical difference between the two groups. Respondents who pay for treatment (either through insurance or privately) report lower levels of satisfaction with care ($n = 236$, $M_{\text{satisfaction}} = 14$) to those respondents whose treatment is state funded ($n = 217$, $M_{\text{satisfaction}} = 16$) ($t = 2.71$, $p < .05$).

A second independent t-test was conducted to explore if access to health care professionals (as measured by frequency of medication review) differs according to how the health care is funded (i.e. state vs. private). Respondents who receive state funded care ($n = 217$, $M_{\text{review}} = 4$) report the same frequency for reviews of medication as respondents who pay for treatment ($n = 237$, $M_{\text{review}} = 4$); hence, the comparison between the two groups reveals no significant difference according to the two types of funding ($t = -.12$, $p = .91$).

Using length of time to gain access to treatment after diagnosis, as a proxy for availability, a further independent t-test was conducted to establish if length of time differs between state ($n = 217$, $M_{\text{time}} = 2$) versus private funding

⁸⁴ In Sweden, PwPs pay for their medication up to 2,200 SEK per year. Anything over that amount is covered by the state.

⁸⁵ Respondents could select multiple options

⁸⁶ Insurance and private were joined together to enable a direct comparison between paying vs. non-paying care. Respondents who indicated more than one source of funding were excluded from the analysis so as to ensure valid comparisons between the groups.

⁸⁷ The independent-samples t-test (or independent t-test, for short) compares means values (averages) between two unrelated groups on the same continuous variable (i.e., scale scores).

($n=237$, $M_{time} = 2$). Again, no differences in treatment waiting times is noted between the two groups ($t = -.43$, $p = .67$).

63 respondents (8%) report being refused care due to either cost or where they live. As the sample is comparatively larger than those in the other countries (although for a robust correlational analysis a sample of over 100 is considered ideal), a correlation was conducted to explore the relationship between refusal of care and QoL. The number of incidences where care was refused (i.e., for medication, therapy or care) was totalled, with higher numbers equating to more incidences of refusal.

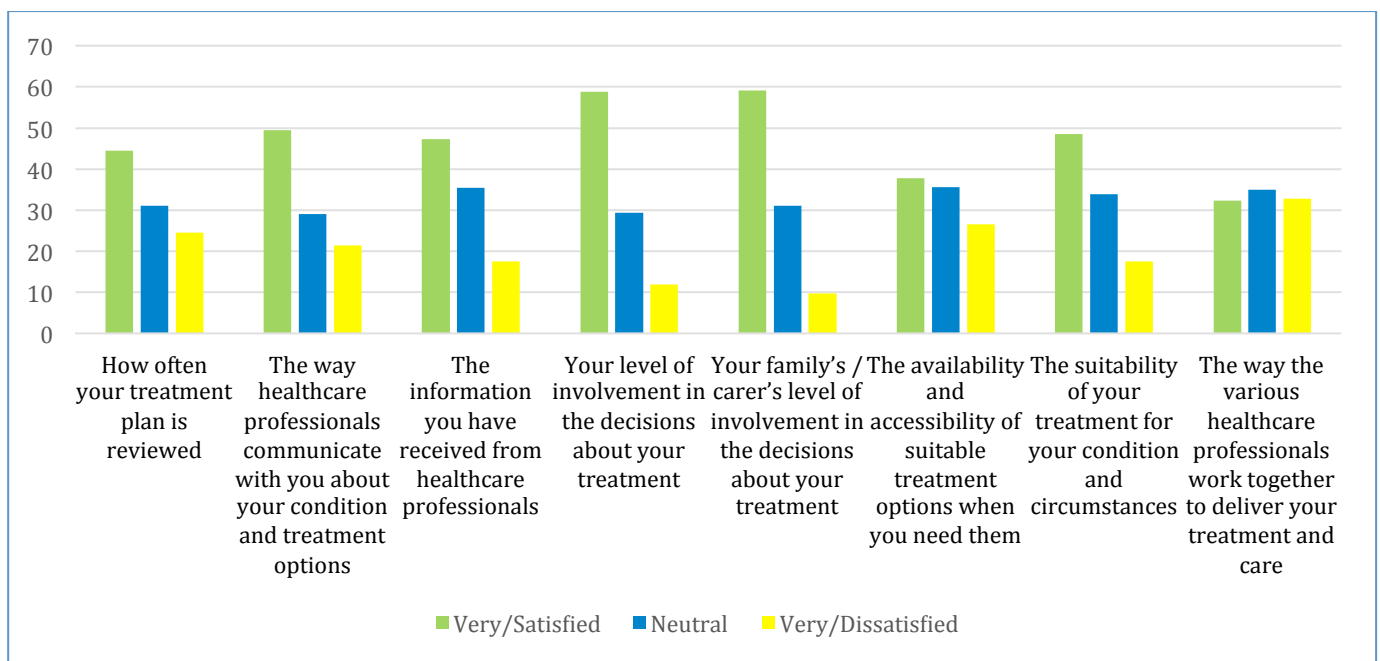
There was no significant relationship between refusal of care due to where the respondent lives and QoL ($n = 790$, $r = -.05$, $p = .21$). This suggests that QoL is not affected by refusal of treatment based on location. However, a significant correlation did emerge between refusal of care due to cost and QoL ($n = 790$, $r = -.15$, $p < .01$), suggesting QoL is higher for respondents who have experienced fewer incidences of care refusal.

1.9. Satisfaction

Most of the respondents are satisfied or very satisfied with the care they are receiving from all of the healthcare professionals they were asked to comment on (including clinical practitioners in both primary and secondary care, as well as therapists). Nearly two-thirds (65%) are either satisfied or very satisfied with both their speech and language therapist and occupational therapist, and 74% are either satisfied or very satisfied with their physiotherapist. In relation to the clinical healthcare professionals mentioned, the greatest satisfaction is with neurologists specialising in Parkinson's (76% of respondents said they were very or satisfied). This is followed closely by Parkinson's Disease Nurse Specialists (75% of respondents say they are very satisfied or satisfied). The highest dissatisfaction reported was with general neurologists; however the percentage of respondents who expressed dissatisfaction with this profession was only 17%.

In relation to treatment and overall care, respondents are generally satisfied; in particular with their level of involvement in decisions about treatment and family/carer's level of involvement (both 59% response rate for either satisfied or very satisfied). Respondents were less satisfied with the way various health professionals work together to deliver treatment and care with one-third (33%) reporting they are either dissatisfied or very dissatisfied (Figure 8).

Figure 8. Satisfaction with treatment and overall care (%)



The relationship between frequency of medication review and satisfaction with care was explored with a bivariate correlation. Responses provided for 'how often is your medication reviewed and by who' were coded so that most frequent reviews ('every 3 months') were assigned the highest number '4', through to '1' for 'once every 2 years'. The correlation reveals a significant medium sized relationship between satisfaction with care and frequency of review ($n = 683$, $r = .33$, $p < .01$).⁸⁸, suggesting, respondents who benefit from more frequent reviews also report higher levels of satisfaction with care

Respondents also reported on the frequency of their medication reviews with different healthcare professionals (Table 7); because respondents may have more than one medication review a year, numbers in the table do not necessarily add up to 100%.

For the medication reviews, respondents were asked to detail how often their medication was reviewed and who reviewed the medication. Nearly half of the respondents have their medication reviewed by a neurologists who is a specialist in Parkinson's (48%). In relation to the other healthcare professionals: 8% of respondents have their medication reviewed by a GP; 18% by a general neurologist; 5% by a hospital doctor; 17% by a Parkinson's disease nurse specialist and 4% by a geriatrician.

In relation to the frequency of the reviews, respondents mostly state that a review is conducted either annually or every six months (Table 7).

Table 7. Medication reviews (%)⁸⁹

HEALTHCARE PROFESSIONALS	Every 3 months (%)	Every 6 months (%)	Once a year (%)	Once every 2 years or more (%)
General practitioner or family doctor	1	3	6	2
Hospital doctor	1	1	4	1
General neurologist	1	10	12	3
Neurologist who is a specialist in Parkinson's	6	24	31	8
Geriatrician	0	1	3	1
Parkinson's disease nurse specialist	5	7	10	3

A Bivariate correlation was conducted to explore the relationship between quality of life and frequency of medication review. No significant relationship is observed ($n = 790$, $r = -.04$, $p = .22$), suggesting QoL is not associated with frequency of medication review.

In addition, a second bivariate correlation was run to assess the relationship between quality of life and satisfaction with care. Using the quality of life index and the satisfaction for care index, a significant negative relationship emerges ($n = 678$, $r = -.22$, $p < .01$) suggesting QoL is influenced by how satisfied respondents are with their care - those respondents reporting a higher QoL also report lower satisfaction.

1.10. Advanced treatments

7% of respondents report undergoing surgical treatment, with most stating that they had Deep Brain Stimulation, and the remainder Duodopa. Of respondents, 19% had the surgery within five years of diagnosis and 34% within 6 to 10 years. The remainder was evenly split between 11 to 15 years and more than 15 years.

⁸⁸ Respondents who indicated 'do not know' and 'does not apply' were not included in this analysis

⁸⁹ Respondents were also able to state that they did not know or that it did not apply for them.

The majority of the respondents (80%) said that the surgery had met their expectations, the remaining 20% said it had not. Some of the respondents gave further explanation as to why the surgical treatment had or had not met their expectations:

“Have not been able to reduce the medicines. Have difficulty walking.”

“DBS helps me tremendously. But after the surgery, I was too shaky / weak all over, it was noticeable especially in the legs.”

“There has been dosage failure of medication intake via the pump.”

“Super, I work as before.”

“I feel better, feel much clearer in my head! It has improved my self-confidence. And narrowed down firmly on the medication.”

“My mornings and evenings are quite ok compared to before. I can fly and go to the movies without shaking apart.”

To explore the relationship between length of time before opting to have surgical treatment and QoL, a correlation was conducted. Results suggest no relationship between the two variables ($n = 46$, $r = -.10$, $p = .56$), thus indicating QoL scores are not related to when treatment was provided.

Focusing on levels of satisfaction with overall treatment and length of time before surgical treatment, no relationship between the two variables is observed ($n = 47$, $r = .15$, $p = .32$) - how satisfied a respondent is with their treatment does not seem to influence how soon after diagnosis respondents opt for surgical options.

Finally, although respondents whose care was funded by the state, on average, received surgical treatment later ($n = 21$, $M_{wait} = 3$ (11 to 15 years)) than those privately funded ($M_{wait} = 2$ (6 to 10 years)), there is no significant difference the groups ($n = 11$, ($t = 1.98$, $p = .06$)).

1.11. Findings in relation to the national guidelines

In 2014, as part of its overall commitment to the care of people with chronic diseases, the Swedish government decided to develop national guidelines for treating multiple sclerosis (MS) in Sweden⁹⁰ to support those who make decisions about how resources should be allocated within the health service.

Working in association with Neuroförbundet, which represents people living with neurological diseases such as MS, Parkinson's disease, stroke or ALS in Sweden, SWEMODIS is developing the 2016 guidelines.

Due to the lack of national guidelines, for this section, the Swedish Movement Disorder Society (SWEMODIS) guidelines were used. These guidelines are updated annually. The guidelines are extremely detailed and are designed to facilitate the handling of the investigation, referral, treatment and follow-up of individuals with Parkinson's disease; therefore the research team extracted the data which is most relevant to the survey data collected for this study:

- There is no medical evidence basis for delaying treatment even early in the disease and early treatment is recommended.
- Reassessment of the diagnosis should be done regularly and the diagnosis may need to be revised.
- A large number of patients with atypical Parkinsonism condition sometimes get significant relief from medication but the effects usually disappear more or less quickly.
- Patients should be examined repeatedly, both in terms of progression if not obvious from history, and after treatment trials, with follow-up effects.

90 www.msif.org/news/2014/09/19/swedish-government-to-develop-national-guidelines

- A patient's symptoms should be assessed by a neurologist experienced in Parkinson's disease.
- No individual or laboratory tests can identify clearly Parkinson's disease.
- Levodopa (always in fixed combination with a decarboxylase inhibitor) is the most effective medicine for Parkinson's disease.
- Levodopa's most common side effects are nausea and orthostatic hypotension. To avoid this, especially at the start of therapy, use the peripherally acting dopamine receptor antagonist domperidone Erb® 10-20 mg 3 times daily (the agent is registered but has no subsidy). Other funds Primperan® usually produces excessive anti- dopaminergic effect after regular use so it is not a realistic option). A short-term treatment is usually sufficient for this discomfort is to be reduced.
- Diagnosis and therapy for very young patients with suspected Parkinson's disease should be made by physicians who have experience with this group of patients, primarily by neurologists with special interest in movement disorders.
- Generally, the neurosurgical treatment of Parkinson's disease should only be used when medical treatment is no longer effective. To be considered for surgical treatment, the patient should be referred to the multi-disciplinary Parkinson's team, who are at university hospitals with a careful neurological diagnostic evaluation therefore requires preoperative neuroimaging investigation with CT / MRI. After considering a patient for intraduodenal levodopa treatment, the patient and also the spouse must be adequately informed about the treatment and the expected results of treatment. The patient must also be given information about the surgical procedures. Information about long-term experiences with Duodopa and the circumstance of living with a pump and the complications must be shared.

In line with the guidelines, the survey findings show that two-thirds of the respondents are referred to a neurologist specialising in Parkinson's (66%) for diagnosis. However, it is of possible concern that 10% were told that there was nothing wrong, with a further 10% being told it was too early to tell.

Before being diagnosed with Parkinson's, the majority of respondents report that an observation of symptoms was conducted (89%) and most also reported that a physical examination was conducted (76%). A brain scan was conducted for 59% of respondents. This could occur due to the guidelines stating that no individual or laboratory tests can identify clearly Parkinson's disease.

The vast majority of respondents started medication or treatment immediately (73%) (with a further 10% starting within a month). This is in line with the guidelines that early treatment is recommended. However, the reviews are usually conducted every 6-12 months. As the guidelines do not explicitly state the time frames when PwPs reviews should take place, it is unclear from this survey if the number of reviews each PwP receives each year has increased due to the introduction of the guidelines.

Finally, the survey results show that Levodopa medications were the most frequently prescribed, in particular Madopar®.

APPENDIX II-K: SURVEY FINDINGS FOR THE UNITED KINGDOM

1.1. Sample profile

In total 85 respondents completed the survey from the United Kingdom. 47% of respondents are male and the average age of respondents was 55 years when they were diagnosed with Parkinson's disease, with the youngest aged 30 and oldest aged 82 years. Only 33% are currently employed. When asked to describe the area in which they live, 24% state rural, 48% town, with the remaining 28% living in cities.

1.2. Quality of life and disability scores

To explore quality of life, EuroQol's EQ-5D measure was utilised. This is a standardised instrument for measuring health status and requires respondents to answer five questions focusing on **mobility**, **self-care**, **usual activities**, **pain**, and **anxiety/depression**.

Regarding **mobility**, 34% report no problems walking, while 66% report some problems. No respondents indicate that they are confined to a bed⁹¹.

Moving on to **self-care**, no one reports they are unable to wash or dress themselves and 30% that they have some problems with washing or dressing. However, the majority of respondents - 70% - indicate no problems with self-care.

When asked about their current ability to perform **everyday activities** such as work and leisure, the majority of respondents (70%) experience some problems performing these activities, while 27% indicate no problems at all. Those who were unable to perform *any* everyday activities are the smallest group, accounting for 3% of the sample.

When discussing current levels of **pain and discomfort**, a high percentage of the sample - 67% - indicate that they suffer from moderate pain, while 26% indicate having no pain or discomfort. Again, those who suffer from extreme pain represent a relatively small proportion of the sample at 7%.

The final question assessing current quality of life focuses on levels of **anxiety and depression**. Over half of respondents (59%) indicated no feelings of levels anxiety/depression, while 39% report moderate feelings of anxiety/depression. The smallest proportion of the sample (3%), reported feelings of extreme anxiety or depression.

Compared with their general health over the last 12 months, only 13% state that their health is *better*. The majority of respondents feel that their health is *much the same* (55%).

When asked to rate which statement best describes how they feel about their independence, none of the respondents report to being bed bound. The most commonly recorded response is '*I am able to do all chores with some degree of slowness, difficulty and impairment, and am beginning to be aware of difficulty*' (58%) (Table 1).

⁹¹ Results based on the number of respondents answering Question 7. This result may not tally with the number stating they are bedridden in Question 13, the results of which are shown in Table 1.

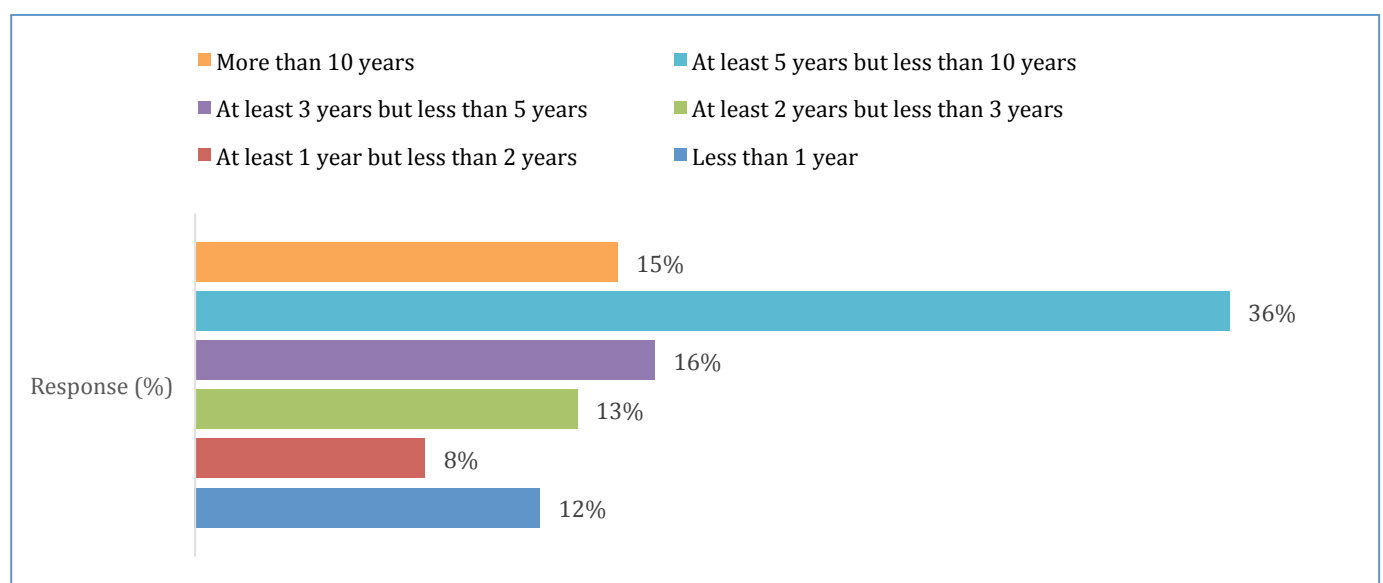
Table 1. Self-reported disability score (%)

STATEMENTS	Response (%)
I am able to do all chores without slowness, difficulty or impairment	10
I am able to do all chores with some degree of slowness, difficulty and impairment, and am beginning to be aware of difficulty	58
Chores take twice as long and I am conscious of difficulty and slowness	12
Chores take three to four times as long and I spend a large part of the day doing these	1
I can do most chores, but exceedingly slowly and requiring a lot of effort	9
I need help with half the chores and have difficulty with everything	3
I can assist with all the chores, but am only able to do a few on my own	3
I can manage a few chores with some effort, but need a lot of help	2
I do nothing on my own, but can be a slight help with some chores	2
I am totally dependent and helpless	0
I am bedridden	0

1.3. Receiving a diagnosis of Parkinson's disease

1980 was the earliest date that a respondent had been diagnosed with Parkinson's and 2014 the latest (8% had been diagnosed in 2014; the median date of diagnosis was 2009). 96% of respondents had been diagnosed with Parkinson's in the United Kingdom, with the exception of three respondents (4%) who had been diagnosed in either Australia, New Zealand or Hong Kong. For half of the respondents, it has been less than 5 years since diagnosis (49%) (Figure 1).

Figure 1. Length of time since diagnosis (%)



The symptoms most commonly noticed before diagnosis included changes in the way you move (including the way you walk, dragging a leg, not swinging your arm, etc.), tremor, slowness of movement and speech and communication problems. Interestingly people with these symptoms were more likely to seek help within a year. However with other symptoms, such as fatigue, loss of smell or taste and sleep problems, these symptoms could often continue for over five years before help was sought (Table 2).

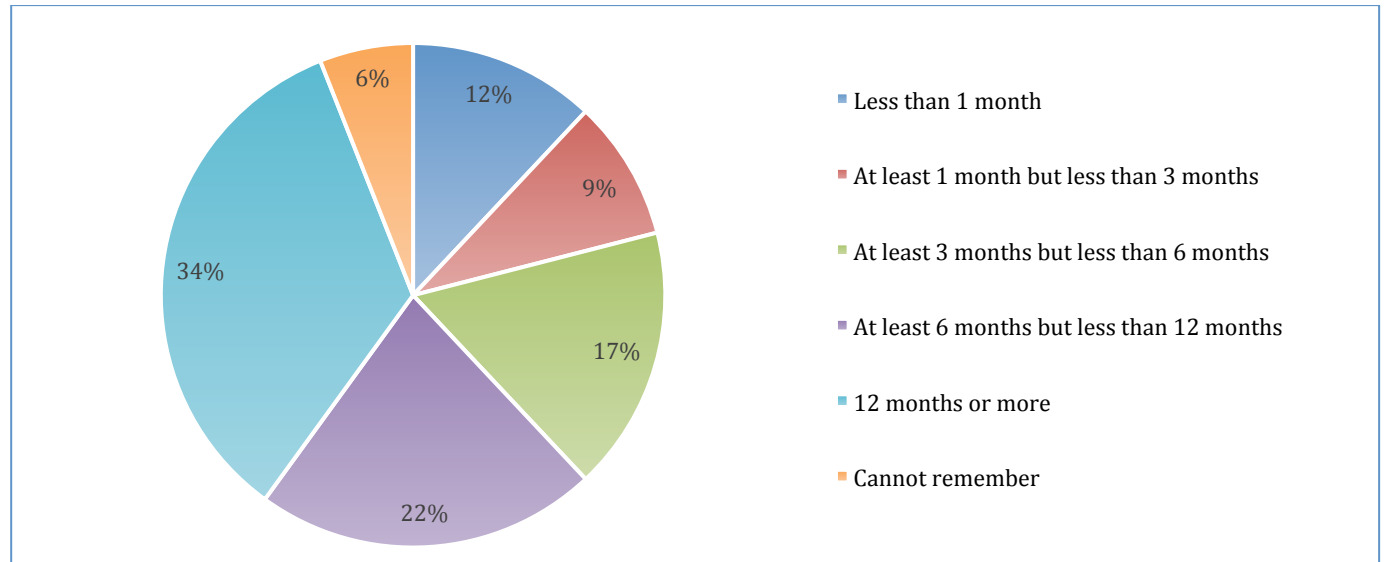
Table 2. Reported symptoms, and duration of these symptoms before seeking medical help (%)

SYMPTOMS/PERCENTAGE OF RESPONDENTS¹	Less than 1 year	1 to 2 years	3 to 4 years	5 years or more	Total number of respondents experiencing symptoms
Anxiety	6	9	4	4	24
Apathy	3	6	1	1	12
Bladder and bowel problems	9	13	3	7	33
Changes in the way you move (incl. the way you walk, dragging a leg, not swinging your arm, etc.)	30	30	12	6	78
Depression	4	12	4	4	25
Difficulty eating and/or swallowing	4	6	1	1	13
Eye problems	4	4	0	4	13
Falls (balance problems)	16	7	4	0	28
Fatigue	9	12	9	9	39
Freezing	6	4	1	1	13
Loss of smell or taste	3	7	7	16	34
Low blood pressure or dizziness	0	1	6	7	15
Muscle cramps	13	12	7	1	34
Pain	7	21	6	1	36
Rigidity (stiffness)	16	16	6	4	43
Skin and/or sweating problems	7	3	3	7	21
Sleep problems	9	10	6	9	34
Slowness of movement	22	19	9	1	52
Speech and communication problems (incl. small handwriting and reduced facial movements)	21	21	6	3	51
Stress	7	9	12	6	34
Thinking or memory problems	4	15	4	1	25
Tremor (shaking)	24	16	13	3	57

Other symptoms added by the respondents included hyper salivation, pins and needles and a frozen shoulder. One respondent said: "Difficulty beating an egg, clapping, whistling, hanging out washing, playing golf and chopping vegetables."

When asked how long it was before seeking medical help after first noticing your symptoms, just over one-third waited 12 months or more (34%). Just under half of respondents sought help within three to 12 months (48%) while 12% sought immediate help (within 1 month) (Figure 2).

Figure 2. Timelines for seeking medical help (%)



1.4. During the first appointment

During the first appointment with a healthcare professional, around two-thirds of respondents underwent an observation of their symptoms (66%), while around one half discussed their general medical history (48%) or underwent a physical examination (52%). One quarter of respondents were told that they might have Parkinson's (25%), although another one fifth of the respondents were told that something was wrong; however the healthcare professional was unsure of the exact diagnosis (20%). Nearly two thirds of respondents (62%) were referred to another doctor or healthcare professional following their first appointment (Table 3).

Table 3. Events during the first appointment with a healthcare professional

EVENTS	Response (%) ¹
Discussed your general medical history	48
Carried out a physical examination	52
Observed your symptom(s)	66
Referred you to a specialist, or another doctor / healthcare professional	62
Said nothing was wrong	5
Said it was too early to tell if anything was wrong	3
Said something was wrong, but not sure what	20
Prescribed medication to relieve your symptom(s)	9
Explained that you may have Parkinson's	25
Explained that you may have another disease / condition	14

A few respondents detailed other events which had happened at the first appointment; these included:

- Being told they defiantly did not have Parkinson's
- That the symptoms were caused by anxiety
- Diagnosed as a trapped nerve initially
- Diagnosed as a benign tremor
- Told it was just "*getting old*"

Respondents were asked, if they were referred to another healthcare professional, what the waiting times were. If a referral was made, this was mostly to a neurologist (either general or one specialised in Parkinson's). Only a small percentage of respondents were referred to a therapist or a Parkinson's disease nurse specialist.

The waiting times to see neurologists were less than to see a therapist, with most of the respondents seeing a neurologist (either general or specialised) within three months (Table 4).

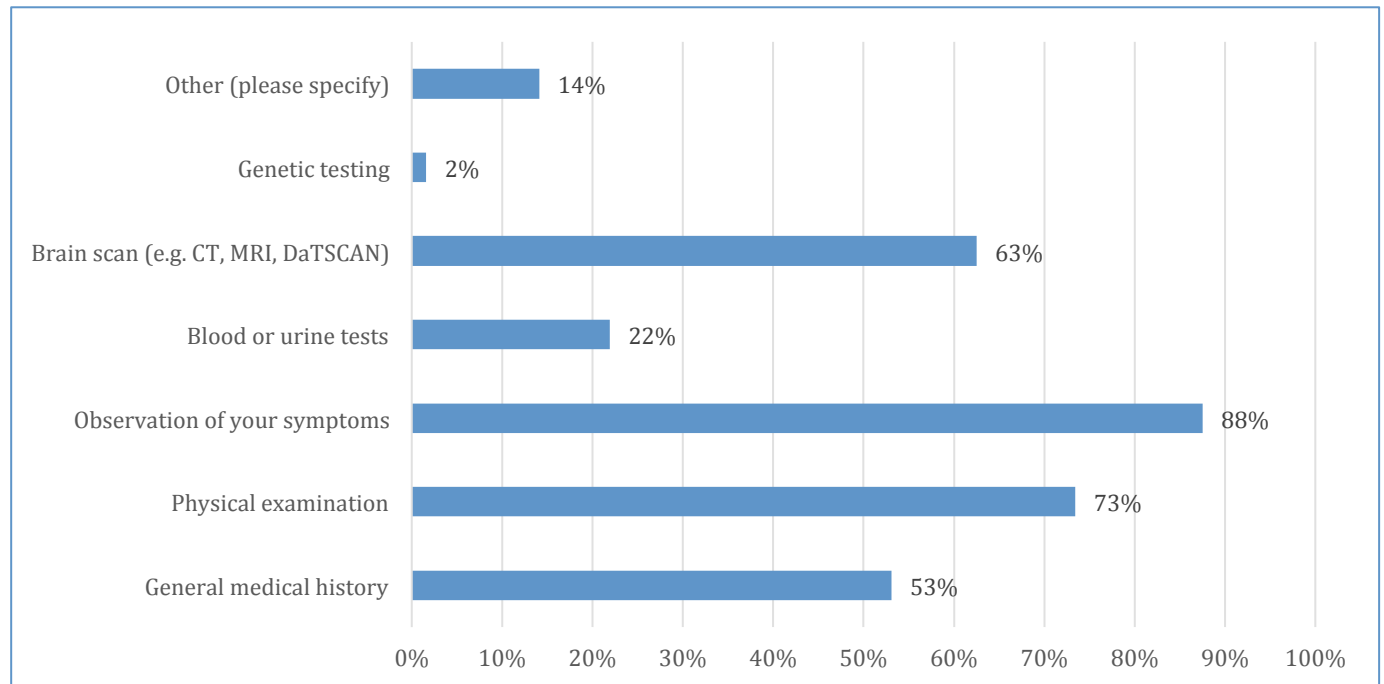
Table 4. Waiting times to see professionals from referral (%)¹

HEALTHCARE PROFESSIONAL	Within 1 month (%)	1-2 months (%)	2-3 months (%)	3-4 months (%)	4 months +	% of respondents referred
General neurologist	9	11	5	9	6	41
Neurologist Specialist in Parkinson's	22	19	13	9	13	75
Geriatrician	0	3	2	2	3	9
Parkinson's disease nurse specialist	2	6	11	5	23	47
Physiotherapist	3	3	11	6	11	34
Occupational therapist	2	2	6	0	11	20
Speech and language therapist	0	2	5	3	16	

The overwhelming majority of respondents had their symptoms' observed to diagnose their Parkinson's disease (88%). Nearly three quarters of respondents underwent a physical examination (73%) and almost two thirds had a brain scan carried out (63%). 14% of respondents mention that they also underwent other types of examinations and tests during diagnosis (Figure 3). These included:

- Chest x-ray
- Nerve conduction tests

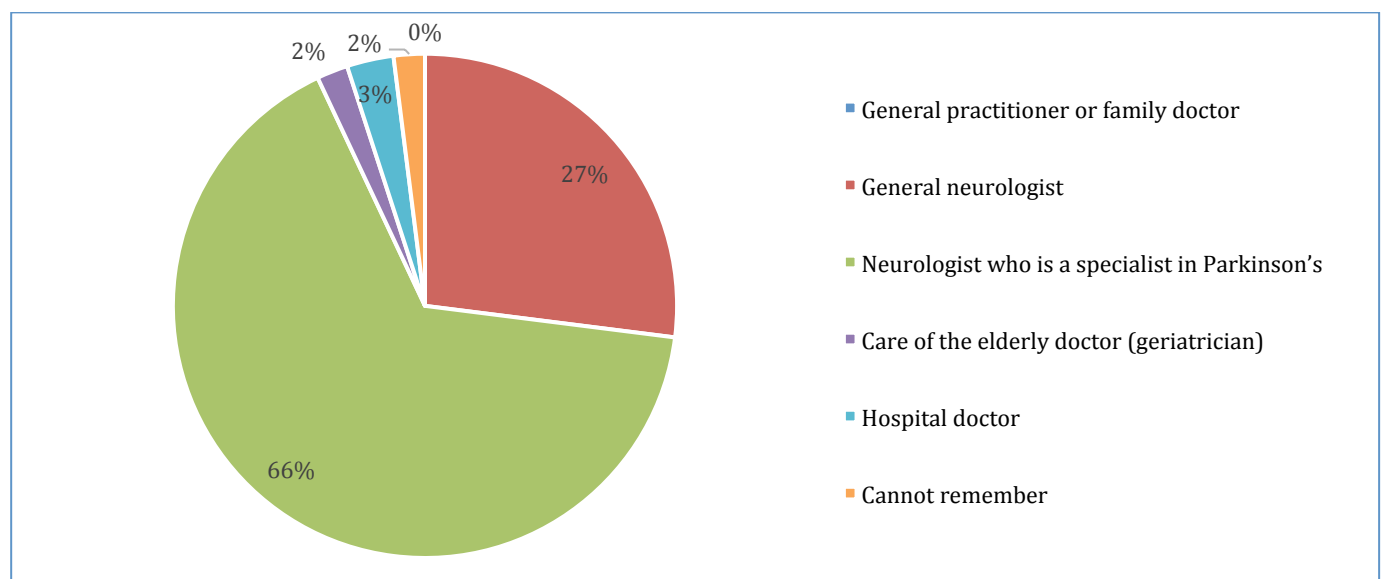
Figure 3. Examinations and tests carried out



1.5. Delivery of the diagnosis

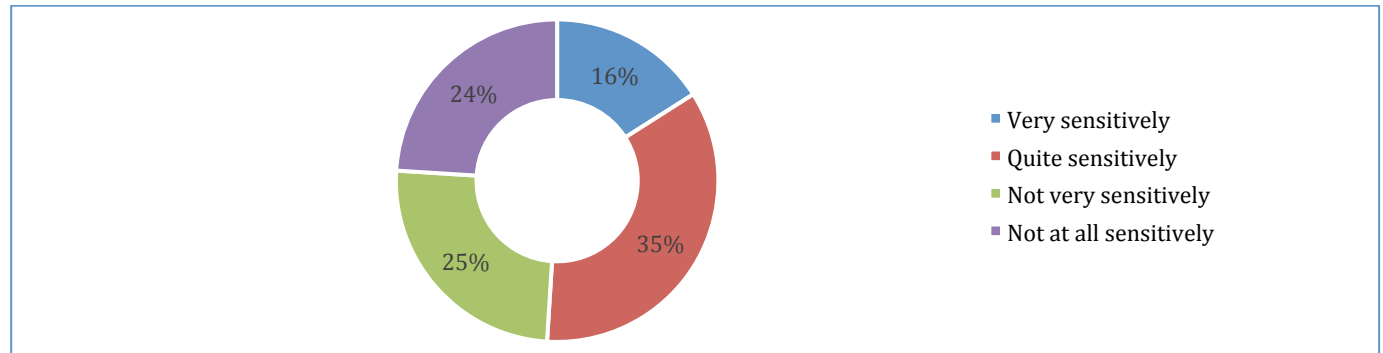
Two thirds of respondents received their diagnosis of Parkinson's from a neurologist specialised in the disease (66%), while a further 27% were diagnosed by a general neurologist. Only 5% received the diagnosis from either a geriatrician or a hospital doctor and none of the respondents were given the diagnosis by their GP (Figure 4).

Figure 4. Healthcare professional diagnosing Parkinson's (%)



Responses were completely split in relation to the sensitivity in which the diagnosis was given. (Figure 5). 51% of respondents feel that they were told either very sensitively or quite sensitively, while the remaining 49% believe that the diagnosis was not given sensitively. However, only 27% feel dissatisfied or very dissatisfied with the consultation where the initial diagnosis was given. In comparison, 29% of respondents have a neutral opinion of their consultation, while 44% say they are satisfied or very satisfied.

Figure 5. Sensitivity of diagnosis (%)



1.6. 11.6. Information given at diagnosis

At time of diagnosis, just under a half of the respondents reported that they were given information verbally about the symptoms and causes of Parkinson's (46%) while nearly two thirds were told about medication (62%). Only 13% were given information about clinical trials either verbally, with handouts or through signposting to online information; 2% of respondents said they did not want any information on this subject. Just 25% of respondents stated that they were given either written or verbal information about how to maintain physical wellbeing (e.g. healthy eating or exercise) while 18% were given advice on maintaining mental wellbeing (Table 5).

Table 5. Information given (%)¹

TOPIC AREA	Leaflet/ handouts/ signposting to online information (%)	Explained verbally (%)	Both handouts and verbal information (%)	I did not want any information (%)	No information was provided
Symptoms, diagnosis and causes of Parkinson's	10	46	16	2	22
Medication	3	62	11	0	18
Surgical treatments	0	3	0	5	78
Non-drug treatments	2	10	5	0	70
Maintaining physical wellbeing	3	12	10	2	59
Maintaining emotional wellbeing	5	8	5	2	63
Financial help available	2	0	0	2	85
Support organisations (e.g. patient associations)	12	27	8	2	39
Support for carers	3	2	2	7	73
Where to find more information on Parkinson's	12	22	12	2	43
Taking part in clinical trials	3	5	5	2	74

Amongst respondents who received information, 59% found the information they were given either very or quite helpful. However, 38% found the information either not very helpful or not helpful.

In relation to the question enquiring whether or not respondents felt as if they had enough time to ask questions and discuss their concerns, 38% felt that they were given enough time compared to the 18% who felt unable to ask questions at that time. A further 15% of respondents stated that they would have liked further time to ask questions while 10% responded that they did not want to ask questions at that time (Table 6).

Table 6. Time to ask questions and discuss concerns – Question responses (%)

REPONSES	Response (%)
Yes, I was given enough time	38
Yes, but I would have liked more time	15
No, I was not given any time	16
I did not want to ask questions at that time	10
I did not feel able to ask questions or discuss concerns at that time	18
Cannot remember	3

1.7. Link between quality of life, satisfaction, and availability of information

A bivariate correlation was conducted to explore the relationship between availability of information and quality of life. To calculate an 'information availability total', responses were coded '1' for leaflet, verbal, or both (i.e. 'some information provided'). These numbers were then totalled across all the categories respondents were asked to consider (i.e. medication, support for carers), with higher numbers equating to a greater availability of information.

The correlation between the quality of life (QoL) index score (Mean = .65) and the information total (Mean = 2) does not reach a satisfactory level of statistical significance ($n = 82$, $r = .20$, $p = .07$). Therefore we are unable to conclude that QoL is affected by the availability of information.

The relationship between information availability and satisfaction with care received was also explored via a correlation. No significant relationship is observed ($n = 58$, $r = -.07$, $p = .60$), suggesting levels of satisfaction with care are not associated with the availability of information.

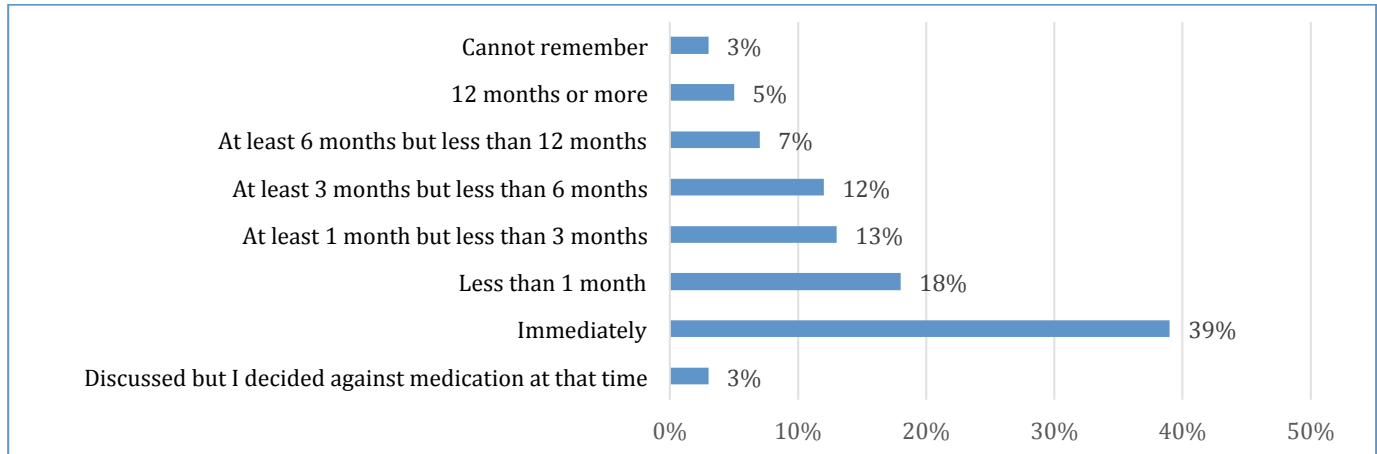
The relationship between satisfaction with treatment and information was also explored. Again, no significant relationship emerges between availability of information and satisfaction with treatment ($n = 58$, $r = -.04$, $p = .76$), suggesting levels of satisfaction with treatment are not associated with availability of information.

Finally, the relationship between satisfaction with the consultation where the initial diagnosis was made and the amount of information provided was also explored via a correlation. In contrast to the previous correlations, results suggest a positive relationship between the two variables ($n = 63$, $r = .36$, $p < .01$) – the amount of information provided (both verbal and written) is related to how satisfied respondents are with the initial diagnosis and consultation. Respondents who receive more information also feel more satisfied with the consultation where the initial diagnosis was made.

1.8. Treatment

Nearly 90% of respondents started medication or treatment within the first year after diagnosis, with around 40% of them starting immediately (Figure 6).

Figure 6. Medication and treatment timings (%)

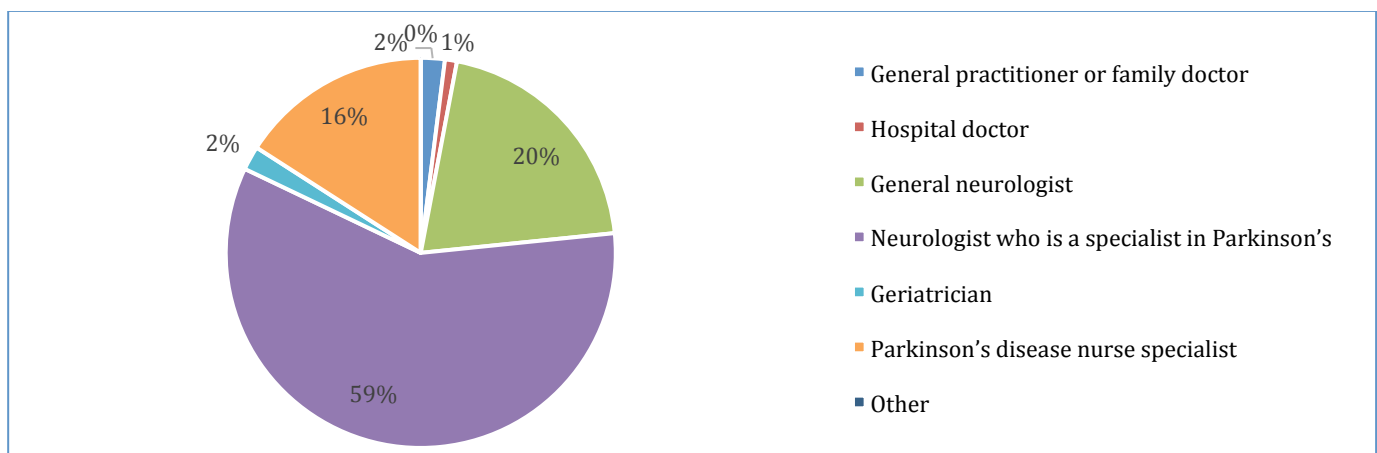


The most frequently taken medications are Rasagiline (54% of respondents prescribed this drug), Ropinirole (52%) and Sinemet (52%); these drugs are predominantly prescribed by a general neurologist or a specialist neurologist. However, a smaller number of respondents report that these drugs are prescribed by their GP (2-3% of respondents) or Parkinson's disease nurse specialist (5-8% of respondents). According to respondents, these three drug are the only ones to be prescribed by GPs.

Other medications which are prescribed include¹: Amantadine (23% of respondents); Madopar (30%); Pramipexole (20%); Rotigotine (13%); Selegiline (13%); and Stalevo (20%).

As with Ropinirole, Sinemet and Rasagiline, for the majority of the time, these medications are prescribed by a general neurologist or a specialist neurologist, and less frequently a Parkinson's disease nurse specialist. Only 1% of respondents mention a hospital doctor prescribing any medication (they prescribed Ropinirole and Sinemet), while 2% mention a prescription from a Geriatrician (Sinemet, Stalevo, Ropinirole and Rasagiline) (Figure 7).

Figure 7. Healthcare professionals who prescribed the medication (%)



The overwhelming majority of respondents report that the state currently pays for their medication (80%). However, 15% also state that they pay for some medication privately (themselves/family) or their insurance pays (2%)¹. None of the respondents say that a Parkinson's organisation pay for the medication and nearly 7% of all respondents do not know who pays for their medication.

The relationship between satisfaction with care and paying for treatment was explored. Responses about paying for treatment were assigned a group based on whether care was state funded or by private/insurance¹. An independent samples t-test¹ was conducted to investigate whether satisfaction with care differed according to whether respondents paid for the treatment or not. This analysis reveals no statistical difference. Mean levels of satisfaction do not differ between the groups. Respondents who pay for treatment (either through insurance or privately) report similar levels of satisfaction with care ($n = 8$, $M_{\text{satisfaction}} = 13$) to those respondents whose treatment is state funded ($n = 48$, $M_{\text{satisfaction}} = 15$) ($t = 1.17$, $p = .25$)¹.

A second independent t-test was conducted to explore if access to health care professionals (as measured by frequency of medication review) differs according to how the health care is funded (i.e. state vs. private). Respondents who receive state funded care ($n = 48$, $M_{\text{review}} = 5$) report more frequent reviews of medication, compared to respondents who pay for treatment ($n = 9$, $M_{\text{review}} = 3$). Furthermore, the comparison between the two groups reveals a significant difference according to the two types of funding ($t = 2.26$, $p < .05$).

Using length of time to gain access to treatment after diagnosis, as a proxy for availability, a further independent t-test was conducted to establish if length of time differs between state ($n = 48$, $M_{\text{time}} = 3$) versus private funding ($n = 9$, $M_{\text{time}} = 4$). No significant differences in treatment waiting times are noted between the two groups ($t = .57$, $p = .57$).

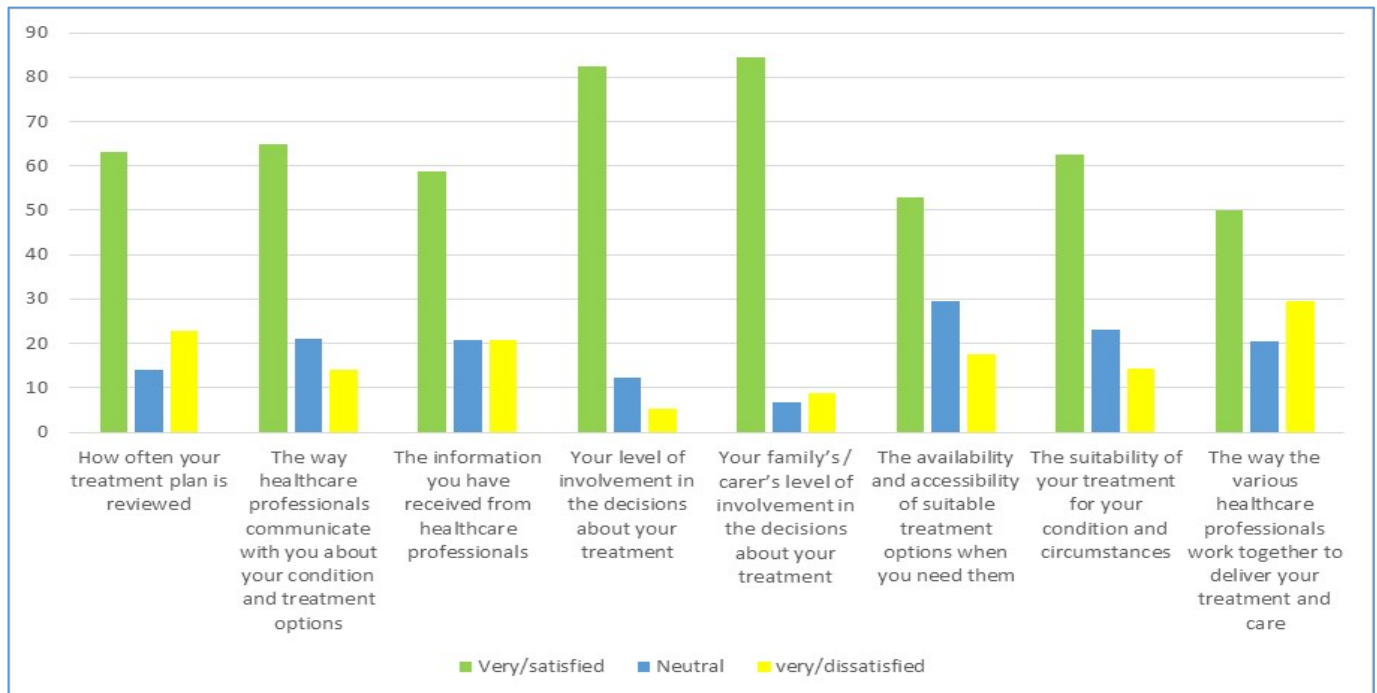
Only 5 respondents reported being refused care due to cost and 2 due to where they lived; hence the samples are too small to conduct a valid analysis to explore links between QoL and refusal of treatment

1.9. Satisfaction

The majority of respondents receive care from their GPs, neurologists specialising in Parkinson's or Parkinson's disease nurse specialists. Around 70% of respondents are satisfied or very satisfied with the care they are receiving from these professionals, while between 10-20% are dissatisfied or very dissatisfied with their care. Amongst other health professionals where a significant number of respondents are receiving care from, the highest level of dissatisfaction is with general neurologists where 21% are dissatisfied or very dissatisfied. Levels of dissatisfaction are lowest with physiotherapists (4%) and occupational therapists (0%).

In relation to treatment and overall care, respondents are most satisfied with both their own and their family's/carer's levels of involvement in decisions about treatment. However, there is less satisfaction in relation to other care aspects; in particular, 30% of respondents are dissatisfied by the way the various healthcare professionals work together to deliver their treatment and care (Figure 8).

Figure 8. Satisfaction with treatment and overall care (%)



The relationship between frequency of medication review and satisfaction with care was explored with a bivariate correlation. The analysis reveals a significant small sized relationship between satisfaction with care and frequency of review, suggesting respondents who benefit from more frequent reviews, also report higher levels of satisfaction with care ($n = 58$, $r = .27$, $p < .05$).¹

Respondents also reported on the frequency of their medication reviews with different healthcare professionals (Table 7); because respondents may have more than one medication review a year, numbers in the table do not necessarily add up to 100%.

For the medication reviews, respondents state that a neurologist who is a specialist in Parkinson's reviews their medication either every six months (34%) or once a year (32%). A large number of respondents also state that their medication is reviewed by a Parkinson's disease nurse specialist either every 6 months (32%) or once a year (25%). Just 10% of respondents report that they have their medication reviewed at least every 3 months by a healthcare professional (Table 7).

Table 7. Medication reviews (%)¹

HEALTHCARE PROFESSIONALS	Every 3 months (%)	Every 6 months (%)	Once a year (%)	Once every 2 years or more (%)
General practitioner or family doctor	3	7	10	2
Hospital doctor	0	0	0	0
General neurologist	0	17	3	2
Neurologist who is a specialist in Parkinson's	2	34	32	5
Geriatrician	0	5	0	0
Parkinson's disease nurse specialist	5	32	25	3

A Bivariate correlation was conducted to explore the relationship between quality of life and frequency of medication review. No significant relationship was observed ($n = 82$, $r = .21$, $p = .06$), suggesting QoL is not associated with frequency of medication review.

In addition, a second bivariate correlation was run to assess the relationship between quality of life and satisfaction with care. Using the quality of life index and the satisfaction for care index, again no significant relationship emerged ($n = 58$, $r = -.12$, $p = .39$) suggesting QoL is not influenced by how satisfied respondents are with their care.

1.10. Advanced treatments

Only one of the respondents has received surgical treatment in the form of “*Deep Brain Stimulation*”; it is not known how soon after diagnosis the respondent had this treatment. However the respondent states that the surgery has met their expectations:

“I feel a lot better in myself since surgery and I can walk better and for longer periods of time. I am generally more positive and people tell me I have more facial expressions and look well. I can get out and about more and generally live a more active life style than before surgery.”

The research team was not able to look at the correlations between receiving advanced treatments and QoL/satisfaction variables, as there are too few respondents who have received advanced treatments.

1.11. Findings in relation to the national guidelines

The National Institute of Health and Care Excellence (NICE) published guidelines on the diagnosis and treatment of Parkinson's disease in 2006. These state that

- People with suspected Parkinson's should be referred quickly (within 6 weeks) and untreated to a specialist with expertise in the differential diagnosis of the condition;
- The diagnosis of Parkinson's should be reviewed regularly (every 6 to 12 months);
- People with Parkinson's should have regular access to the following, which may be provided by a specialist Parkinson's nurse: monitoring and medication adjustment, a continuing point of contact for support, including home visits when needed, and a reliable source of information about clinical and social matters of concern to people with Parkinson's and their carers;
- Access to physiotherapy, speech and language therapy and occupational therapy should be available; and
- Palliative care requirements should be considered in all phases of the condition. People with Parkinson's and their carers should be given the opportunity to discuss end-of-life issues with appropriate healthcare professionals.

Only 41% and 20% of respondents saw either a neurologist who is a specialist in Parkinson's or general neurologists (respectively) within two months of referral. This would suggest that for many, the six-week target is not achieved. However, most respondents see their neurologist at least every year for a review meeting (88%). For these respondents, 68% have an annual review with a specialist neurologist while the other 20% have their review carried out by a general neurologist. Nearly two thirds of respondents also report that they have medication reviews with Parkinson's disease nurse specialists at least once a year (62%).

From the survey we cannot determine what access to physiotherapy, speech and language therapy and occupational therapy there is; however, the survey does show that referrals to these services are small in number. The survey also shows that where respondents are referred to these professionals, the waiting times are long. For example, the majority of respondents referred to occupational therapists and speech and language therapists have to wait at least four months for an appointment.