

European Inventory

Findings from the primary research study

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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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1. INTRODUCTION

“My PD Journey” is a ground breaking multi-stakeholder project designed to assist those people suffering from Parkinson’s disease in Europe. With over 1.2 million people in Europe currently living with Parkinson’s and this number forecast to double by 2030, My PD Journey aims to ensure that all healthcare providers are coordinated and work together to remove the hurdles that prevent people with Parkinson’s from receiving early and appropriate treatment and individualised care.

The first major My PD Journey activity is a European inventory, which will identify where gaps in Parkinson’s care currently exist and seek out national examples of good practice that could be adopted in other regions. In addition to the inventory, a simple composite scale that measures quality of life in terms of both non-motor and motor symptoms will be developed and work will be done to identify tools and technologies that can strengthen interaction between healthcare professionals, people with Parkinson’s and their carers.

An independent research organisation (Millbank Social Marketing Ltd) was commissioned to conduct primary research, including a survey, as well as in-depth interviews with those affected by the disease and their families, and healthcare professionals to inform the inventory. Eleven countries were included in the primary research study, namely Germany, France, Netherlands, Sweden, UK, Slovenia, Spain, Italy, Hungary, Ireland, and Denmark. The findings are presented in this report.

This report focuses on the findings from the primary research only.

A report detailing the findings of a rapid review of the secondary research is also available. The secondary data report covering 36 European countries was initially conducted¹ and used to inform the current research by identifying the main ‘*knowledge gaps*’². The knowledge gaps were then used to guide the development of the survey questions and qualitative discussion guide.

¹ www.epda.eu.com/my-pd-journey/european-inventory

² By the term ‘knowledge gaps’, the research team are referring to identifying where gaps in the current literature/evidence-base remain.

2. METHODS

The limitations of this study, brought about by finite funding, are detailed in Section Seven of this report. However, in spite of the financial limitations, a mixed methods approach was possible, including both qualitative and quantitative methods:

- *Quantitative methods:* A questionnaire-based surveys for People with Parkinson's (PwPs).
- *Qualitative methods:* Semi-structured in-depth individual and paired interviews with PwPs, carers and healthcare professionals, and customer journey mapping interviews.

By collecting both qualitative and quantitative data from different sources, triangulation of the findings was possible, adding to the validity of the study.

2.1. Quantitative methods

2.1.1. Study population

Data collection took place between 1st November 2014 and 12th January 2015. The self-administered survey was conducted online, although in Slovenia, due to the reduced internet access, hard copies were distributed via the national Parkinson's Association. The survey was aimed at PwPs only, although in some cases the carer completed the survey on behalf of the PwP. The limitations and possible biases caused by using the national Parkinson's Associations to distribute the survey, and also due to it being an online survey are detailed in Section Seven.

2.1.2. Development of the survey

The survey questions were designed to gather information about the current state of the Parkinson's care pathways in the included countries. At the same time, the language was designed to ensure that the responses would not be biased by the way the questions were phrased and that, when translated, the wording would be interpreted in the same way by respondents within the different countries.

A conscious effort was made to limit the number of questions and therefore the time required to complete the survey so that respondents would not become fatigued towards the end of the survey leading to rushed and unconsidered responses that might skew the data.

The draft questionnaire was sent to the MPDJ Parkinson's specialist panel and selected EPDA members to gauge their views and input as to whether the questions covered the main areas sufficiently. Dr Anette Schrag was also consulted and commented on the survey questions. Finally, the survey was pre-tested with a selected group of PwPs (of differing ages and years since diagnosis), to ensure that the survey questions were interpreted correctly.

2.1.3. Survey instrument

The questionnaire was divided into sections focusing on diagnosis and treatment, with a mix of questions about experience and satisfaction. Questions to determine socio-demographic information (age, gender, and type of area in which respondents live) and a self-rated health analysis were also included. The validated survey tool - EuroQol (EQ-5D)³ - was used to determine quality of life. A measure of satisfaction in relation to their interaction with healthcare professionals was derived from asking PwPs to rate the satisfaction with which they are with the treatment they received across nine different professions. PwPs were asked to think back to the consultation in where they

³ The EuroQoL Group. EuroQoL-a new facility for the measurement of health related quality of life. Health Policy 1990;16:199-208

had been given the diagnosis and were asked to detail what information they were given at this time point, and also how helpful the information was.

In addition to the EQ-5D, the validated Schwab and England disability measure was used and satisfaction of overall care was rated using a likert scale. The Schwab and England Activities of Daily Living Scale estimates the abilities of individuals living with Parkinson's disease relative to a completely independent situation⁴.

2.1.4. Key measures

Within the survey instrument, a number of key measures have been utilised to measure QoL, satisfaction with care and treatment, frequency of medication review, and access to information.

- **QoL:** EuroQol (EQ-5D) was used to measure quality of life. The scale consists of five items (mobility, self-care, activities, pain/discomfort, anxiety/depression), with responses indicated on a 3-point scale. For each question, a score of '1' is taken to indicate a higher quality of life - for example, 'I have no problems walking' or 'I have no problems with self-care. Whereas a score of '3' indicates a lower quality of life - for example, 'I am confined to bed' or 'I am unable to wash or dress myself'. To enable statistical analyses to be completed, QoL profile states were converted to a single summary index score. This calculation followed the guidance provided by the EuroQol group⁵ and used the Europe-wide VAS validated value set to obtain the index summary score⁶. It was decided by the research team to use the Europe-wide value set as, although some countries in the research did have a distinct value set (e.g. UK, Denmark, France, Germany, Slovenia, Netherlands, Spain), this was not available for all the countries. Also, on examination of the value sets for the available countries, all were at a similar level. Hence, to ensure a standard approach, the Europe-wide VAS value system was utilised. The higher the index score, the better the quality of life. For example, a summary index score of '1' equates to 'full health', whereas a score of '0' equates to 'death'. Respondents can also score a negative value; essentially classifying QoL as 'worse than death'.
- **Satisfaction with care:** Satisfaction with care was measured via three questions in the survey. The first assessed satisfaction in relation to consultation when the initial diagnosis was given (*"How satisfied were you with the consultation when the initial diagnosis was given?"*). Responses were provided on a scale from 1 (very dissatisfied) to 5 (very satisfied); hence higher scores equate to higher levels of satisfaction with the consultation. In the analysis, this question was used as a single item measure.

The second question focused specifically on satisfaction with the care received from nine different clinical professions (*"How satisfied are you with the care you are receiving from GP, hospital doctor, general neurologist, neurologist with PD specialism, geriatrician, PD nurse, physiotherapist, occupational therapists, and speech and language therapist"*). Respondents rated satisfaction on a scale of 1 (very dissatisfied) to 5 (very satisfied)⁷; hence higher scores indicate higher levels of satisfaction with care received. In the analysis, responses from the nine items were totaled to form an overall satisfaction with care index.

The final question focused on satisfaction with treatment (*"How satisfied are you with each of the following aspects of your treatment and overall care?"*). Eight aspects of care were covered, for example, information received from healthcare professionals, how often treatment plan is reviewed. Respondents rated satisfaction

⁴ Schwab RS & England SC. Projection technique for evaluating surgery in Parkinson's disease. In Gillingham FJ, Donaldson IML, eds. Third symposium on Parkinson's disease. Edinburgh: E and S Livingston, 1969

⁵ Oemar, M., & Oppe, M. (2013). EQ-5D-3L user guide: basic information on how to use the EQ-5D-3L instrument.

⁶ Szende, A., Oppe, M., & Delvin, N. (2006). Eq-5D value sets: Inventory, comparative review and user guide. Springer

⁷ Respondents could also indicate 'does not apply'. These answers were treated as missing data and not included in the analysis.

on a scale of 1 (very dissatisfied) to 5 (very satisfied)^{7 8}; hence higher scores indicate higher levels of satisfaction with treatment received. In the analysis, responses from the nine items were totaled to form an overall satisfaction with treatment index.

- **Access to care:** Access to care was assessed by two questions in the survey. The first focused on how soon after diagnosis medication or treatment was received. Responses were collected on a scale from 1 (discussed but not taken at the time) to 7 (12 months or more)⁹; hence the higher the score, the longer the wait for treatment. In the analysis, this question was used as a single item measure.

The second question focused on how often medication was reviewed and by who. Six different professions were listed (GP, hospital doctor, general neurologist, neurologist with PD specialism, geriatrician, PD nurse specialist) and four different time points (every 3 months, every 6 months, once a year, once every 2 years).¹⁰ To enable the data to be used in statistical analyses, the time points were assigned a value of '1' to '4'. For ease of interpretation, the most frequent review (i.e. every 3 months) was assigned the value of '4' and the least frequent the value of '1'; hence higher scores indicate more frequent reviews of medication. In the analysis, responses covering the six professions were totaled to form an overall medication review frequency index.

- **Access to information:** Access to information at the time of diagnosis was assessed by asking respondents to identify if information covering 11 different topics (e.g. medication, non-drug treatments, surgical treatments, etc.) was provided. For each topic, respondents could choose one option from 'leaflets/signposting to online information', 'explained verbally', 'both handout and verbal', 'I do not want any information', 'no information provided' and 'cannot remember'.¹¹ To calculate an 'information availability total', responses were dummy coded a '0' for 'no information provided' or '1' for leaflet, verbal, or both (i.e. 'some information provided'). These numbers were then totaled across all the categories respondents were asked to consider, with higher numbers equating to a greater availability of information.

2.1.5. Data management and analysis

All data were double entered and 100% verified. The research team used descriptive statistics to examine PwPs characteristics as well as frequencies of reported access to healthcare professionals, treatments offered, and costs. All 1776 respondents answered most questions. If data was missing from an answer, respondents were excluded from the analysis. The data were also checked for outliers. Outliers are cases that have data values very different from the data values for the majority of cases in the data set. As statistical analyses can be distorted by outliers, data for the key measures (i.e. QoL, satisfaction with care, satisfaction with treatment) were examined for any potential cases. One way to identify outliers is to convert all scores to a standard score via a statistical method- for example, by creating what is known as a 'z' score. General convention for excluding data as 'outliers' is based on the number of cases- for example, if the sample size is small (80 cases or fewer) a case is an outlier if its standard score is ± 2.5 and if larger (80 cases +) a case is an outlier if its standard score is ± 3.0 . A 'z' score was created for the current data set and no respondents were excluded against these criteria.

⁸ Respondents could also indicate 'does not apply'. These answers were treated as missing data and not included in the analysis.

⁹ Respondents could also indicate 'cannot remember'. These answers were treated as missing data and not included in the analysis.

¹⁰ Respondents could also indicate 'do not know' and 'does not apply'. These answers were treated as missing data and not included in the analysis.

¹¹ Analysis excluded responses for 'I did not want information' and 'cannot remember'

To explore relationships between key measures (e.g. satisfaction with care, QoL) bivariate correlations were performed. Bivariate correlations test whether the relationship between two variables is linear (as one variable increases, the other also increases or as one variable increases, the other variable decreases).

To explore potential differences between key measures- for example, differences in levels of satisfaction with care between PwPs who pay for care compared to those who receive state funding- independent samples t-tests were utilised. 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).

Results from both statistical tests were tested at the standard level of significance ($p < .05$). If a result is statistically significant (i.e., demonstrates a 'p' value lower than .05) it is unlikely to have occurred by chance and we can assume the variables are either related (correlation) or demonstrate differences between the two independent groups (t-tests).

For correlations, alongside a 'p' value, the analyses also produce an 'r' value which represents the magnitude of the correlation (i.e., strength of the relationship between the two variables of interest). Standard levels to which the 'r' is judged against are as follows: .10 'small'; .30 'moderate'; .50 'large'.¹²

All analyses were conducted with SPSS (version 21)¹³.

¹² Cohen, J. (1988). Statistical power analysis for the behavioral sciences (2nd ed.). Hillsdale, NJ: Erlbaum.

¹³ IBM Statistical package for the social sciences

2.2. Qualitative methods

The methodology of a qualitative study changes as the study responds to the data gathering and analysis. The design is 'emergent' in that it reacts to the needs of the study question as the best way of answering it becomes clearer. For this reason, this methods section includes comments on modifications that were made after the study had commenced.

2.2.1. Approach

Principles of grounded theory were used throughout this study to guide sampling, data gathering, and data analysis (Glaser, B and Strauss, A, 1987)¹⁴. The phrase 'grounded theory' refers to theory that is developed inductively from a body of data, rather than from the preconceptions of the researchers. Therefore, findings from such studies should have high validity. The approach is iterative in that on-going sampling, data gathering and data analysis is cross-referenced and used to inform each other over time. Tentative theoretical explanations are generated during data analysis, which are subsequently tested against the further data as it is gathered. In this way, a circular process ensues in which theory is gradually, but robustly, developed.

2.2.2. Enhancing rigour

Qualitative studies are often criticised for: i) lacking scientific rigour, ii) being subject to researcher bias, iii) lacking reproducibility, and iv) lacking an ability to draw generalised conclusions. Therefore, the following strategies were employed to overcome these possible flaws and thus enhance the reliability and validity of this study.

- **Triangulation:** This study used investigator triangulation. Researchers from different disciplines designed the study, developed the data gathering methods and analysed the data.
- **Bracketing:** Before beginning this study, all those involved discussed their prior beliefs and hypotheses about the subject matter. Two researchers analysed all the transcripts individually, then discussed and agreed upon the themes.
- **Purposive sampling:** Where possible, purposive sampling of different types of participants was used to increase the quality of the generalisation of the study's findings. Throughout the interviews, the interviewers attempted to adopt a passive role, asking few questions, but encouraging a continued narrative through active listening.

2.2.3. Recruitment and sampling

Participants were predominantly recruited through the Parkinson's Associations of the participating countries (the limitations of which are discussed in Section Seven). Since the PwPs and carer interviewees were identified in this manner, they were involved in the country's Parkinson's Associations. However great effort was also made to try and recruit people who were not actively involved within the local Parkinson's Associations to ensure a broader base of the findings. Where possible, the research team also tried to recruit participants from across the country (as opposed to all from one area). Although this was not always feasible due to limited data collection time within each country, the research team did manage to ensure that a mix of participants were interviewed in relation to the following criteria:

1. Current age
2. Gender
3. Age at onset of symptoms

¹⁴ Glaser, B., Strauss, A. (1967). The discovery of grounded theory. Chicago: Aldine.

4. Age at diagnosis

For the healthcare professionals, the EPDA identified at least one healthcare professional from each country (except for Hungary), and snowball sampling techniques were then used to identify other professionals for the research team to interview. By healthcare professional, we mean anyone who works within a multi-disciplinary team (in a healthcare capacity), was included. Therefore, as well as doctors and nurses, occupational therapists, speech therapists, nutritionists and psychologists were also interviewed. In relation to the doctors and nurses, although most were specialised in the field of Parkinson's, a conscious effort was made to recruit medical professionals who did not specialise in this area, including general practitioners, non-specialised neurologists and nurses.

Identifying and interviewing PwPs and their carers was not difficult in most of the countries included in the study, and the PwPs and the carers were very eager to support the research and share their experiences. However, seeking the engagement of healthcare professionals and finalising a date for the interviews proved much more problematic. The reasons given were usually associated with pressure of work on their part and shortage of staff, which exacerbated the pressures on the professionals. In the countries with smaller populations, the healthcare professional approached would, in an endeavour to be helpful, refer the research team to another professional but this was often back to the professional who had given the team their name in the first place.

2.2.4. Data collection

- **Settings and interview schedule:** The interviews were either conducted over the phone, or face-to-face. When needed a translator was also present. All participants were interviewed once between 1st November 2014 and 29th January 2015. The median length of an interview was 41 minutes. A mixture of paired and individual interviews was conducted with the PwPs and carers. Individual interviews were conducted with the healthcare professionals.

Initially no individual interviews were planned with general practitioners (GPs) or non-specialised neurologists and nurses, however after the initial interviews had been conducted, it was obvious that extending the investigations to GPs was important, as was interviewing more generalised medical professionals.

- **Research questions:** For the qualitative part of this study, semi-structured interviews were conducted. At the start of each interview, loosely structured, open-ended questions were asked. In order to pursue an idea or response, more detailed questions were subsequently asked or prompts made. The wording was not standardised, as the interviewers tried to use the participant's own vocabulary when framing supplementary questions.

The questions for PwPs and carers covered the following areas:

- Initial experiences and waiting times
- Informational needs
- Involvement of partners by health professionals
- Different treatments throughout the whole journey and access to multi-disciplinary team healthcare professionals
- Perceptions towards current treatments/services being received
- Satisfaction with past and current treatment plans/healthcare professionals engagement

Healthcare professionals were asked questions around the following areas (in relation to their specialised areas, for example physiotherapy):

- Country guidelines and the perceived impact of these guidelines (if applicable)

- Treatments available and costs of treatments (for PwPs)
- Waiting times and referral systems
- Availability of multi-disciplinary teams
- Examples of good practice and areas for improvement
- Regional variations in quality of care and access to healthcare professionals
- **Translation:** In all of the non-English speaking countries, all participants were offered the chance to be interviewed in their own language, however many of the health professionals, as well as a few of the carers and PwPs chose to be interviewed in English. All of the translated transcripts were then translated into English, therefore all the quotes presented in this report are in English.

2.2.5. Data analysis

With permission, all of the interviews were recorded. The audio recordings were then transcribed verbatim. The transcripts used accepted procedures for indicating exclamations, pauses and emotion, providing additional information on how the participants expressed themselves (Field, PA and Morse, JM, 1985)¹⁵. Transcriptions were imported into the computer program NVIVO (Qualitative Solutions and Research Pty Ltd, 2011)¹⁶.

Qualitative analysis, in the sense of identifying key themes and piecing together their relationships, was on-going throughout the data collection phase. Once the audiotapes had been transcribed verbatim, a systematic working through of the data and final analysis took place.

There are many ways of dealing with the practical handling of qualitative data, but system and transparency are critical objectives. Therefore, the analysis of the transcripts and notes followed the established procedure of the National Centre for Social Research's Framework of Analysis initially developed in the 1980s¹⁷ that has now been formalised within NVIVO. The data analysis was conducted in three clear stages:

1. Data management – reviewing, labelling, sorting and synthesising the data
2. Descriptive accounts – identifying key themes, mapping the range of themes and developing classifications
3. Explanatory accounts – building of expectations behind the patterns and themes emanating from the data

Thus, the process we followed included:

- Listening to recordings and reading through transcripts/notes
- Marking and coding transcripts/notes to themes and issues and storing these to facilitate inspection and for use in support of analysis
- Development of emerging analyses
- Refinement and grouping of emerging themes

¹⁵ Field, P., Morse, J. (1985). Nursing research: The application of qualitative approaches. Aspen: Rockville.
 Seale, C., Silverman, D. (1997). Ensuring rigour in qualitative research. Eur J Public Health, 7, 379-84.

¹⁶ Qualitative Solutions and Research Pty Ltd (2011). NVIVO. Victoria, Australia.

¹⁷ Ritchie, J, Lewis J, McNaughton Nicholls, C, Ormston R, (eds) Qualitative Research Practice: A Guide for Social Science Students and Researchers, Second Edition, Sage, 2014

3. OVERALL SURVEY FINDINGS

3.1. Sample profile

A total of 1776 respondents took part in the survey across 11 European countries. 54% of these respondents were male. The average age at diagnosis was 58 years, with the youngest aged 25 and oldest aged 90 years. Only 19% of those surveyed were currently employed, and when asked to describe the area in which they live, 19% stated rural, 37% town, with the remaining 44% living in cities.

3.2. Quality of life (QoL) and disability scores

To explore quality of life the EQ-5D was utilised (see Section Three for details on the scale). This requires respondents to answer five questions focusing on mobility, self-care, usual activities, pain, and anxiety/depression.

Regarding mobility, 29% reported no problems walking, while 68% reported some problems. Only 3% of respondents indicated they were confined to a bed.

When responding to questions around self-care, 5% reported they are unable to wash or dress themselves and 32% answered that they have some problems with washing or dressing. However, the majority of respondents (63%) indicate they have no problems with self-care.

In response to assessing their current ability to perform everyday activities (e.g. work, family, leisure), over half of the respondents (63%) experienced some problems performing these activities, while 27% indicated no problems at all. Those who were unable to perform *any* everyday activities were the smallest group, accounting for 10% of the survey population.

Questions discussing current levels of pain and discomfort resulted in a high percentage of the sample (69%) indicating they suffer from moderate pain, while 21% indicated having no pain or discomfort. Again, those who suffered from extreme pain represented the smallest proportion of the sample at 10%.

The final question assessing current quality of life focused on levels of anxiety and depression. Half of respondents indicated they not anxious/depressed and 45% moderately so. The remaining 5% of the sample reported feelings of extreme anxiety or depression.

When considering their general health over the past 12 months, only 11% stated that their health was *better*. A similar number of respondents felt that their health was either *much the same* (45%) or worse (44%).

Respondents were asked to rate which statement best described how they felt about their independence. Three percent of the respondents reported to being bed bound, the lowest level of independence. The most commonly recorded response was '*I am able to do all chores with some degree of slowness, difficulty and impairment, and am beginning to be aware of difficulty*' (47%) (Table 1).

Table 1. Self-reported disability score (%)

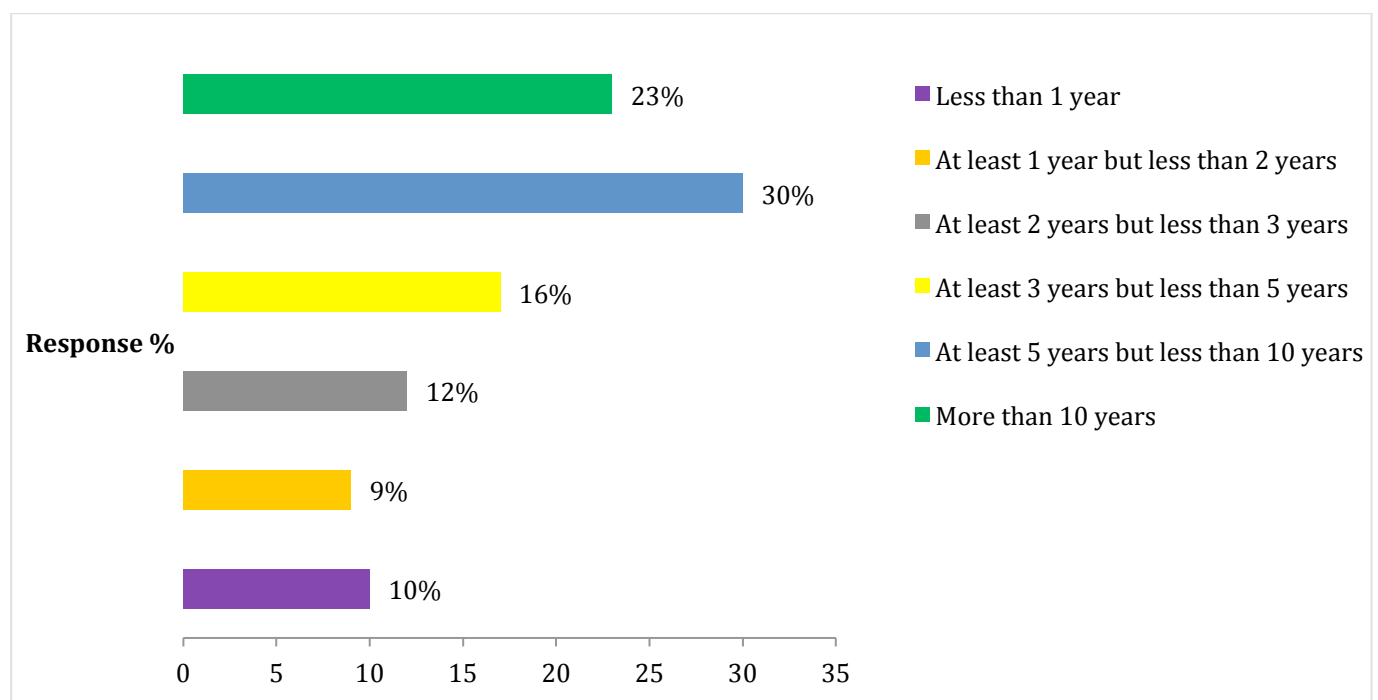
STATEMENTS	Response (%)
I am able to do all chores without slowness, difficulty or impairment	7
I am able to do all chores with some degree of slowness, difficulty and impairment, and am beginning to be aware of difficulty	47
Chores take twice as long and I am conscious of difficulty and slowness	17
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	3
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	3
I am totally dependent and helpless	3
I am bedridden	0

3.3. Receiving the diagnosis of Parkinson's disease

The earliest date a respondent was diagnosed with Parkinson's was 1970, while the latest was 2014. Five percent of respondents were diagnosed in 2014 and the median date of diagnosis was 2008.

The most frequently indicated length of time since diagnosis was at least year years (30%) (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.) - 81% of respondents experienced this symptom
- Slowness of movement - 61% of respondents experienced this symptom
- Tremor - 58% of respondents experienced this symptom
- Rigidity (stiffness) – Overall, 56% of respondents experienced this symptom
- Fatigue - 54% of respondents experienced this symptom
- Problems with speech - 54% of respondents experienced this symptom

Table 2 provides a full break down of symptoms, and the percentage of respondents who experienced these symptoms and length of time they had the symptoms before seeking professional help.

When asked how long it was before seeking medical help after first noticing symptoms, nearly one-third waited 12 months or more (29%). However, the majority sought help within 12 months (Figure 2).

Figure 2. Timelines for seeking medical help (%)

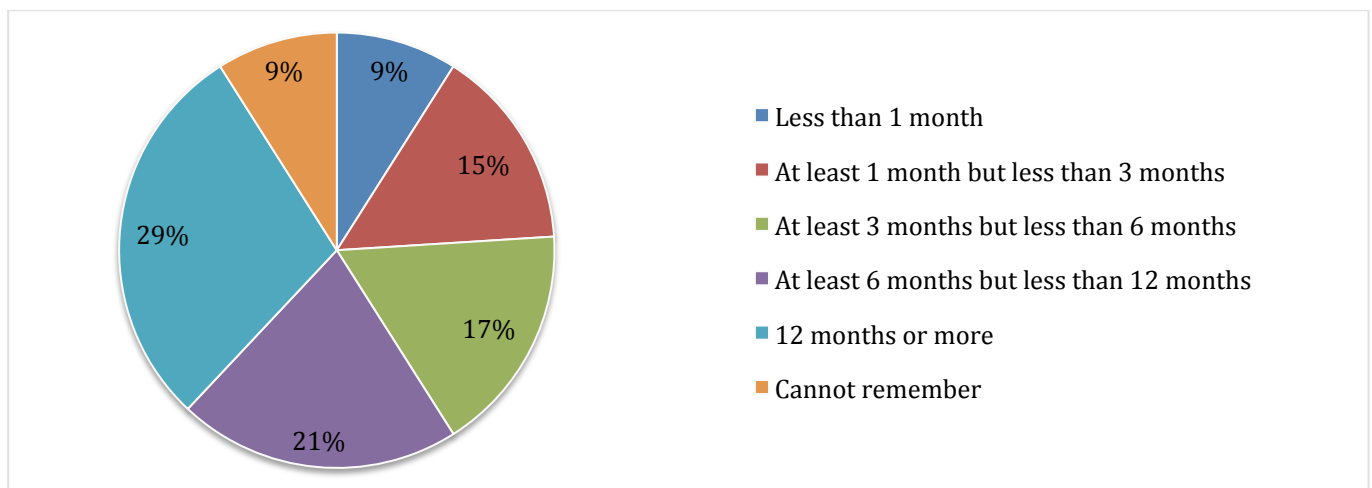


Table 2. Reported symptoms, and duration of these symptoms before seeking medical help (%)

SYMPTOMS/PERCENTAGE OF RESPONDENTS¹	Less than 1 year (%)	1 to 2 years (%)	3 to 4 years (%)	5 years or more (%)	Total % of respondents who experience symptoms
Anxiety	8	6	5	6	25
Apathy	6	7	3	3	19
Bladder and bowel problems	6	9	7	11	33
Changes in the way you move (incl. the way you walk, dragging a leg, not swinging your arm, etc.)	23	34	14	10	81
Depression	7	9	6	7	29
Difficulty eating and/or swallowing	8	7	1	3	19
Eye problems	8	7	3	6	24
Falls (balance problems)	12	10	6	4	32
Fatigue	15	17	11	11	54
Freezing	10	7	4	2	23
Loss of smell or taste	11	10	9	15	45
Low blood pressure or dizziness	9	9	6	8	32
Muscle cramps	14	14	8	7	43
Pain	11	13	8	9	41
Rigidity (stiffness)	18	19	10	9	56
Skin and/or sweating problems	7	8	6	7	28
Sleep problems	11	13	8	11	43
Slowness of movement	21	23	10	7	61
Speech and communication problems (incl. small handwriting and reduced facial movements)	20	19	9	6	54
Stress	10	13	9	11	43
Thinking or memory problems	13	12	7	5	37
Tremor (shaking)	25	19	7	7	58

3.4. During the first appointment

The most frequently cited occurrence during the first appointment with a healthcare professional was for respondents to be referred to another healthcare professional (53%), closely followed by observing symptoms (49%) and having a physical examination (44%).

Healthcare professionals explained to just over one-third were that they might have Parkinson's (36%). A relatively small proportion were told that nothing was wrong (8%), or that it was too early to tell if anything was wrong (8%) (Table 3).

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

EVENTS	Response (%) ¹
Discussed your general medical history	35
Carried out a physical examination	44
Observed your symptom(s)	49
Referred you to a specialist, or another doctor / healthcare professional	53
Said nothing was wrong	8
Said it was too early to tell if anything was wrong	8
Said something was wrong, but not sure what	16
Prescribed medication to relieve your symptom(s)	15
Explained that you may have Parkinson's	36
Explained that you may have another disease / condition	9

Respondents were asked, in cases where they were referred to another healthcare professional, what were the waiting times¹⁸. If a referral was made, it was mostly to a neurologist (either general (60%) or one specialised in Parkinson's (65%). A relatively small number of respondents were referred to a geriatrician (13%), while just over a third of the sample was referred to a Parkinson's disease nurse specialist (32%). In terms of referrals to therapy services, the respondents were most frequently referred to a physiotherapist (41%). The numbers referred to occupation therapists (22%) and speech and language therapists (21%) were at a similar level. As table 4 shows, the waiting times to see neurologists - specialised or general - were at similar levels, with 18-19% of respondents being seen within 1 month. However 17% of respondents also indicated a wait of four or more months to see a specialist neurologist. Fewer respondents indicated being referred to one of the three therapy services within a month (2-10%), compared to neurologists. Waiting times in excess of four months were highest for physiotherapy (18%).

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

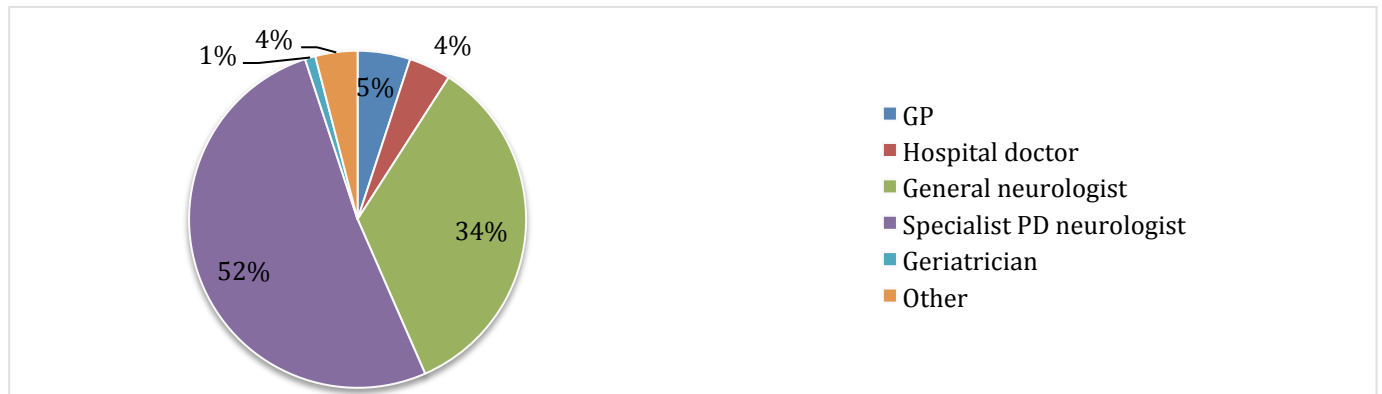
HEALTHCARE PROFESSIONAL	Within 1 month (%)	1-2 months (%)	2-3 months (%)	3-4 months (%)	4 months + (%)
General neurologist	19	14	9	6	13
Neurologist specialist in Parkinson's	18	14	10	8	17
Geriatrician	1	1	1	1	8
Parkinson's disease nurse specialist	5	5	4	3	15
Physiotherapist	10	6	5	3	18
Occupational therapist	3	2	2	2	13
Speech and language therapist	2	2	1	2	14

¹⁸ Respondents could select multiple options

3.5. Delivery of the diagnosis

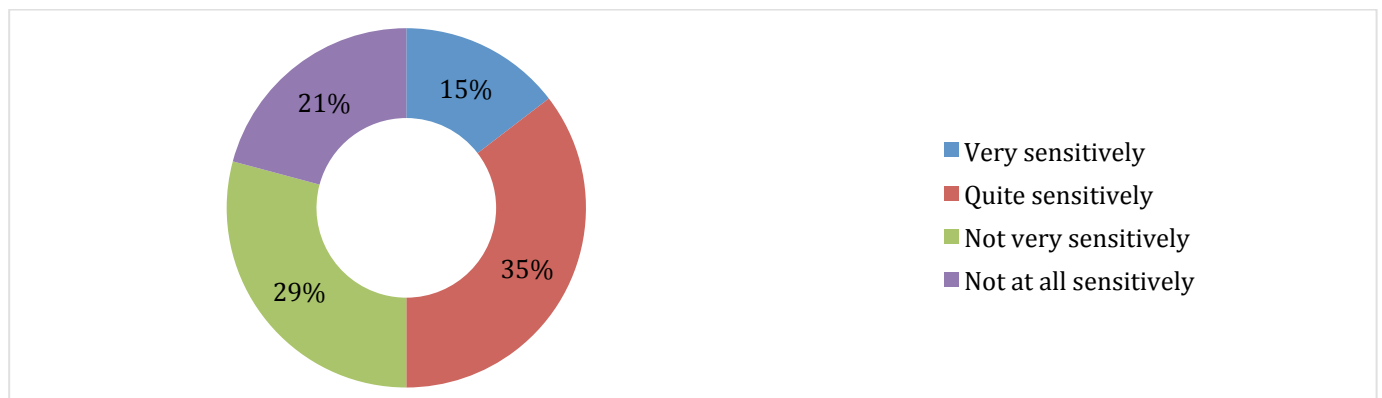
Just over half of the respondents received their diagnosis of Parkinson's from a neurologist specialised in the disease (52%). Only 5% received the diagnosis from their GP. 1% received the diagnosis from a geriatrician (Figure 3).

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



Responses were polarised in relation to the sensitivity in which the diagnosis was given. Half felt that they had been told either very sensitively or quite sensitively, while the remaining 50% indicated a lack of sensitivity when told the diagnosis (Figure 4).

Figure 4. Sensitivity of diagnosis (%)



Despite half of the respondents not feeling as if the diagnosis was given sensitively, only 21% felt dissatisfied or very dissatisfied with the consultation where the initial diagnosis was given. A relatively high percentage answered neutral (28%). However, 19% said they were very satisfied and 30% satisfied. The remaining respondents stated that they could not remember.

3.6. Information given at diagnosis

At the time of diagnosis, nearly half of the respondents reported that they were given information verbally about the symptoms and causes of Parkinson's (49%) and over half about the medication (56%). Only 4% were given information about clinical trials either verbally or with handouts. A third of respondents indicated receiving verbal information about maintaining physical wellbeing (31%). A relatively small 2-3% of respondents indicated no information was required (Table 5).

Table 5. Information given¹

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	8	49	21	2	13
Medication	8	56	17	2	10
Surgical treatments	3	9	3	2	54
Non-drug treatments	5	27	9	2	38
Maintaining physical wellbeing	7	31	10	2	33
Maintaining emotional wellbeing	5	21	8	2	43
Financial help available	3	6	3	3	60
Support organisations (e.g. patient associations)	11	16	10	2	43
Support for carers	5	13	5	3	48
Where to find more information on Parkinson's	16	18	11	2	36
Taking part in clinical trials	4	9	4	2	54

Over half of the respondents found the information they were given either very or quite helpful (51%). However, 29% found the information not very helpful or not helpful. The remaining respondents stated that they could either not remember or no information was provided.

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

A bivariate correlation¹⁹ 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, etc.), with higher numbers equating to a greater availability of information.

The correlation between the quality of life (QoL) index score (Mean = .59) and the information total (Mean = 3) was in a positive direction and reached a satisfactory level of statistical significance ($n = 1732$, $r = .07$, $p < .01$), suggesting respondents with a higher QoL also received more 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 positive relationship between the two variables. The more information provided (both verbal and written), the more satisfied respondents were with the consultation ($n = 1484$, $r = .28$, $p < .01$).

A further bivariate correlation was run to explore the relationship between quality of life and satisfaction with the initial diagnosis. Interestingly, a small significant positive correlation was noted between the two variables ($n = 1476$, $r = .13$, $p < .01$) indicating that respondents who report a higher QoL were also more satisfied with the initial diagnosis.

¹⁹ Bivariate Correlation tests whether the relationship between two variables is linear (as one variable increases, the other also increases or as one variable increases, the other variable decreases).

The highest percentage of respondents indicated enough time was given to discuss the diagnosis (38%). However, 21% of the sample felt unable to ask further questions or discuss the diagnosis. 8% stated that they did not want to ask questions at that time (Table 6).

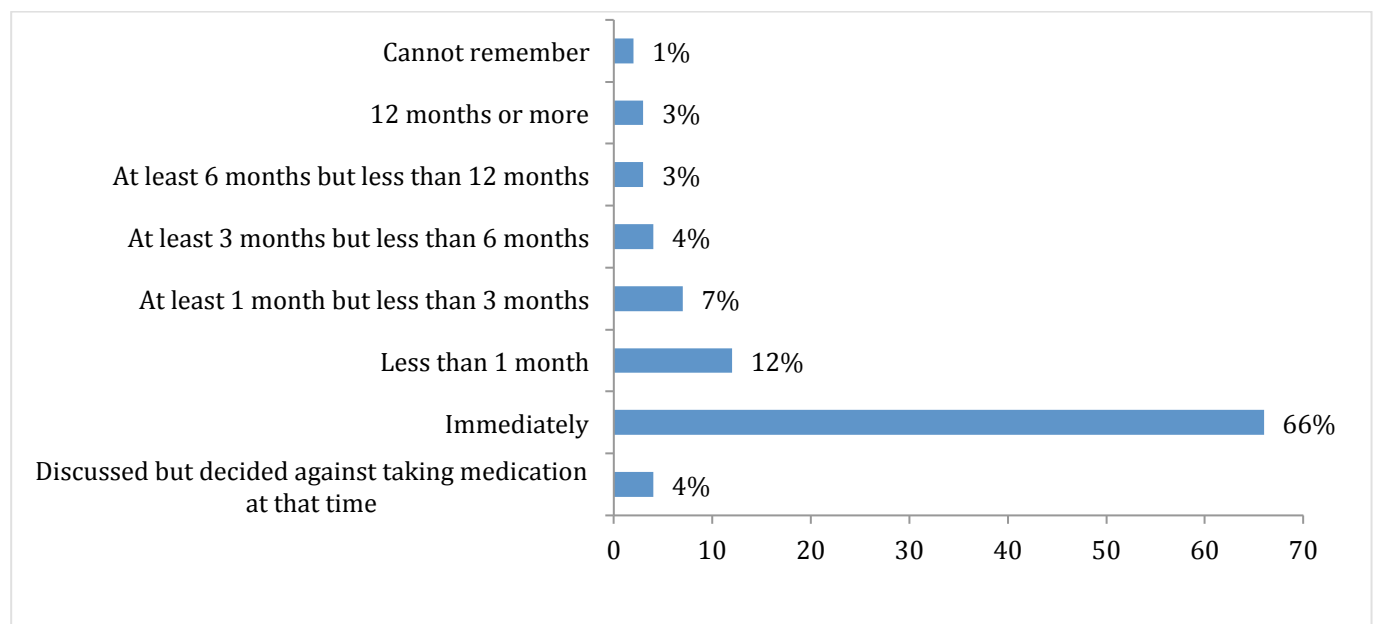
Table 6. Time to ask questions and discuss concerns – Question responses

REPONSES	Response (%)
Yes, I was given enough time	38%
Yes, but I would have liked more time	17%
No, I was not given any time	12%
I did not want to ask questions at that time	8%
I did not feel able to ask questions or discuss concerns at that time	21%
Cannot remember	4%

3.8. Treatment

The majority of respondents started medication or treatment within the first year after diagnosis, with 66% of these starting immediately (Figure 5).

Figure 5. Medication and treatment timings (%)



Looking at the types of drugs prescribed across Europe, all of the 17 included medications on the survey had been prescribed. Madopar, Sinemet, and Pramipexole were prescribed the most frequently (77% (for each of the medications) of respondents reported being prescribed the medications), followed by Stalevo at 76%.

Looking at who was responsible for the prescription of the three most popular medicines, in each case the most frequent response was a neurologist specialised in the disease – Madopar (29% of respondents prescribed the medication were prescribed by a specialist neurologist), Siement (49%), Pramipexole (51%). Across the other medicines, a neurologist specialised in the disease was again the most frequently cited clinician from whom drugs were prescribed (78%).

Nearly half of respondents (47%) indicated that the state currently paid for their medication. However, 37% also stated that they paid for some medication privately (themselves/family) or their insurance paid (16%)²⁰. Less than 1% of respondents said that a Parkinson's organisation paid for the medication, while 2% of respondents did not know who paid for their medication.

The relationship between satisfaction with care and paying for treatment was explored. Questions that probed levels of satisfaction across all the professions were totalled to form a 'satisfaction with care' index variable, with higher numbers equating to a higher level of satisfaction. Across the sample, the Mean level of satisfaction with care was 16 and ranged from a minimum of 1 to a maximum of 45.

Responses about paying for treatment were assigned to a group based on whether care was state funded or paid for privately/by insurance²¹. An independent samples t-test²² was conducted to investigate whether satisfaction with care differed according to whether respondents paid for their treatment or not. This analysis revealed no statistical difference. Mean levels of satisfaction between those paying versus those receiving state funded care did not differ between the groups. Respondents who paid for treatment (either through insurance or privately) reported similar levels of satisfaction with care ($n = 523$, $M_{\text{satisfaction}} = 15$) to those respondents whose treatment was state funded ($n = 505$, $M_{\text{satisfaction}} = 16$); hence the t-test was not statistically significant ($t = .57$, $p = .57$).

A second independent t-test was conducted to explore if access to health care professionals (as measured by frequency of medication review) differed according to how the health care was funded (i.e. state vs. private). Respondents who received state funded care ($n=507$, $M_{\text{review}} = 4$) reported the same frequency of reviews, compared to respondents who paid for treatment ($n=528$, $M_{\text{review}} = 4$); hence, the comparison between the two groups revealed no significant difference according to the two types of funding ($t = .35$, $p = .73$).

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 ($n=507$, $M_{\text{time}} = 3$) versus private funding ($n=528$, $M_{\text{time}} = 3$). Again, no differences in treatment waiting time was noted between the two groups - Mean waiting times for both were scored as a '3' (less than 1 month) ($t = .07$, $p = .94$).

Relationships between refusal of care due to cost, location, and quality of life were also investigated. Across the whole sample, a relatively small proportion ($n=167$, 9%) reported being refused care due to cost, while ($n=91$, 5%) reported being refused care due to where they live. To explore if refusal of care related to quality of life, two correlations were conducted. The refusal of care variable was dummy coded so that any refusal (medication, therapy or care) was coded as '2' and no refusals coded as '1'. The first analysis focused on refusal due to cost and quality of life (using the QoL index score) and demonstrated a significantly small negative correlation (as one variable increases, the other decreases) ($r = -.21$, $p < .01$). Those with higher QoL were also coded on the lower score (i.e. not refused care), therefore suggesting respondents with a higher quality of life were less likely to have been refused care.

When focusing on refusal of care due to where respondents lived, a similar pattern emerged with a significant small negative correlation ($r = -.13$, $p < .01$), suggesting again that those with higher QoL had not been refused care. Taken together these two correlations suggest that those reporting a lower quality of life also report higher incidences of being refused for care²³.

²⁰ Respondents were asked to select all that applied and therefore the responses do not add up to 100%

²¹ Insurance and private were joined together to enable a direct comparison between paying vs. non-paying care. Furthermore joining the two payment methods together enabled a more equal distribution of respondents in each group. Respondents who indicated more than one source of funding were excluded from the analysis so as to ensure valid comparisons between the groups.

²² 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).

²³ However, it should be stated that they type of care, therapy or treatments that had been refused was not

To investigate if the relationship differed according to the type refused (i.e., medication, therapy and care) the correlation was performed for each one separately. Taking refusal due to cost first, there was no relationship between QoL and refusal of medication (n=1732, $r = -.08$, $p = .48$). There was, however, a significant negative relationship between QoL and refusal of therapy (n=1732, $r = -.08$, $p < .01$) and care (n=1732, $r = -.20$, $p < .01$). This suggests those who were refused care to due cost, also report lower QoL.

Regarding refusal of care due to where respondents lived, the same pattern emerges. There was no relationship between QoL and refusal of medication (n=1732, $r = -.08$, $p = .49$). A significant negative relationship between QoL and refusal of therapy (n=1732, $r = -.07$, $p < .01$) and care (n=1732, $r = -.11$, $p < .01$). This suggests those who were refused care to due where they live, also report lower QoL.

A note of caution should be applied to both of these significant findings, as although the correlations do reach an acceptable level of statistical significance, overall the proportion of respondents who were refused treatment is relatively small (15%). Hence any conclusions drawn from these data need to recognise this limitation. At best we can say there is indicative evidence to suggest quality of life is related to access, but for more robust conclusions to be made results need to be replicated in other samples with more balanced groupings.²⁴

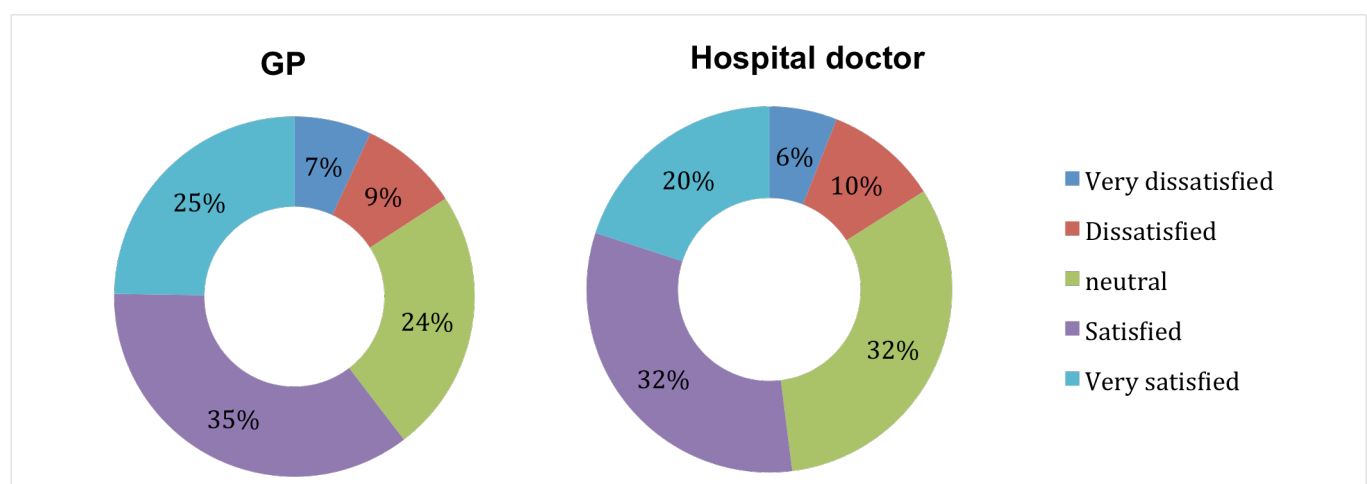
Finally, access to treatment did not seem to differ according to the type of location respondents lived. For example, there was no difference in the waiting times to receive medication after diagnosis or how often medication was reviewed regardless of whether respondents lived in a rural location or a town/city.

3.9. Satisfaction

Respondents were asked to rate nine different professions in terms of how satisfied they were with the care received from each one.

The majority of respondents expressed a level of satisfaction with the care received from the GP (60%), with a relatively small proportion dissatisfied (16%) (Figure 6). Care from hospital doctors was also rated positively, with 53% assessing the care to be satisfactory, while the same proportion as with GPs (16%) were dissatisfied.

Figure 6. Level of satisfaction with GPs and hospital doctors (%)



recorded. Therefore the survey respondents could have been referring to treatments/therapies that are not evidence-based, for example homeopathy.

²⁴ An independent t-test was also conducted to explore difference in QoL between those refused care vs. not. This analysis was significant and supported the indicative findings suggested in the correlation (i.e., higher QoL in those that have not been refused care); however as the two groups were so unequal any conclusions to be made are again limited.

In regard to neurologists, higher levels of satisfaction were noted for the care provided by specialist neurologists (74%) compared to general (57%), while there was also marginally lower levels of dissatisfaction for specialists (12%) compared to general (16%) (Figure 7).

Regarding Parkinson's disease nurse specialists, 77% of respondents were satisfied, while 9% were unhappy. For geriatricians, the most frequently cited response was 'neutral' at 42%, with the majority of remaining responses indicating a positive level of satisfaction (50%).

Finally, focusing on the allied health therapy services, all three displayed high levels of satisfaction with care. 77% for physiotherapy, 68% for speech and language, and 66% of occupational therapy (Figure 8).

Figure 7. Level of satisfaction with general and neurologist specialised in the disease (%)

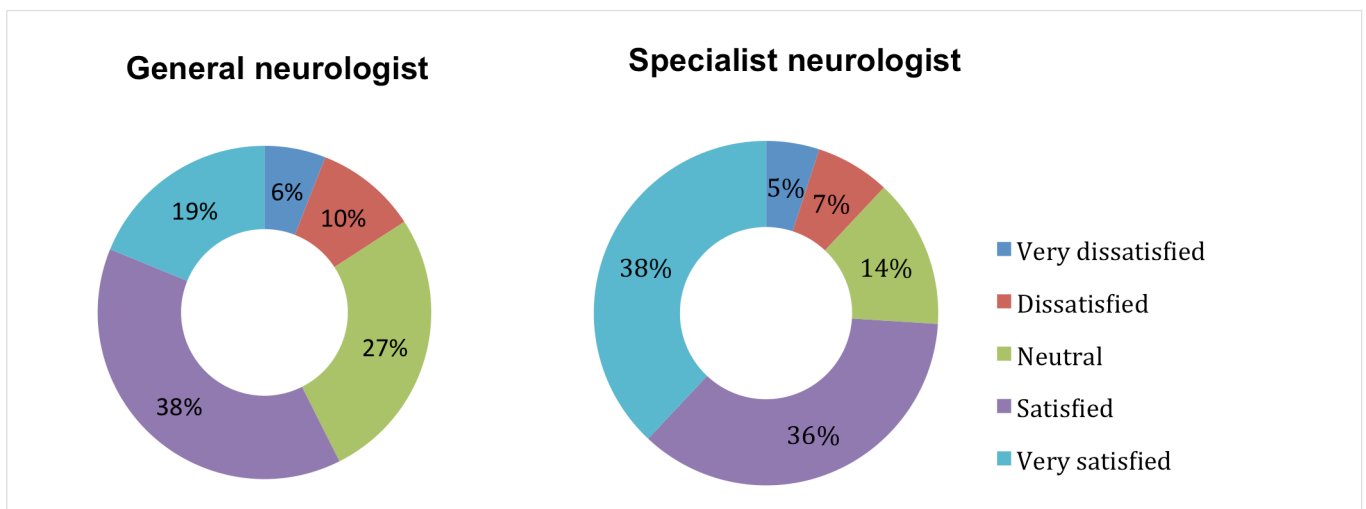
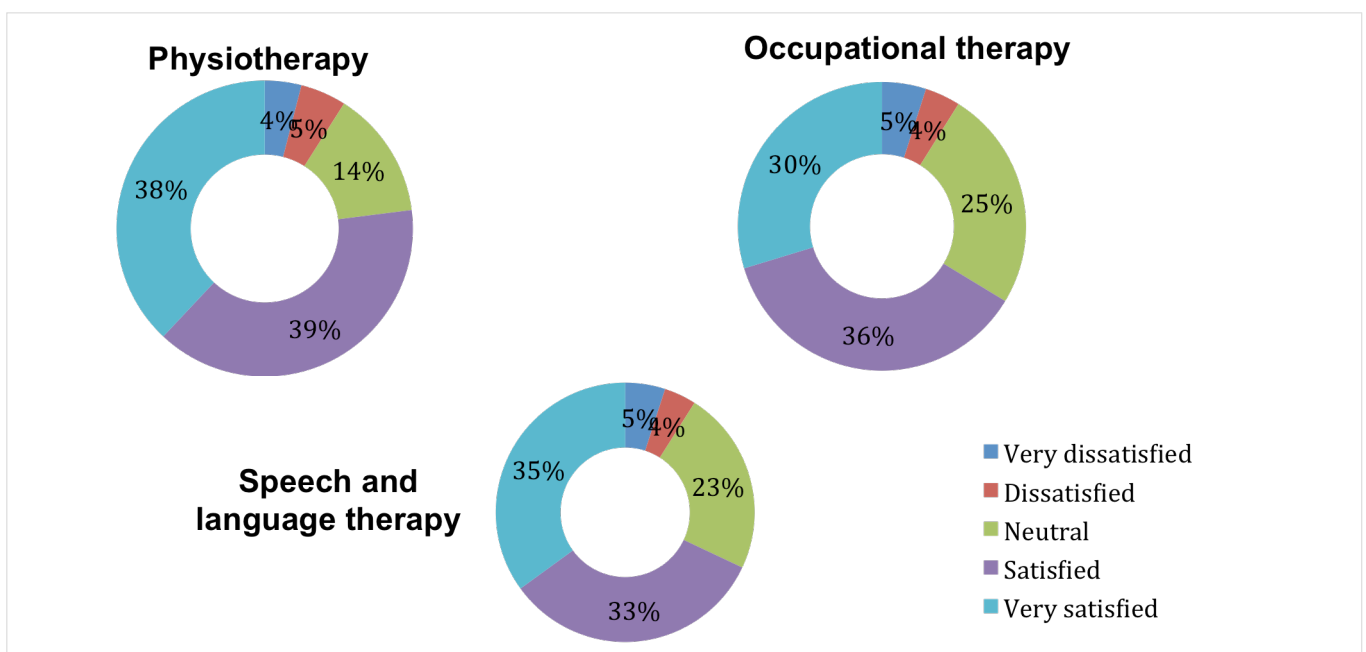


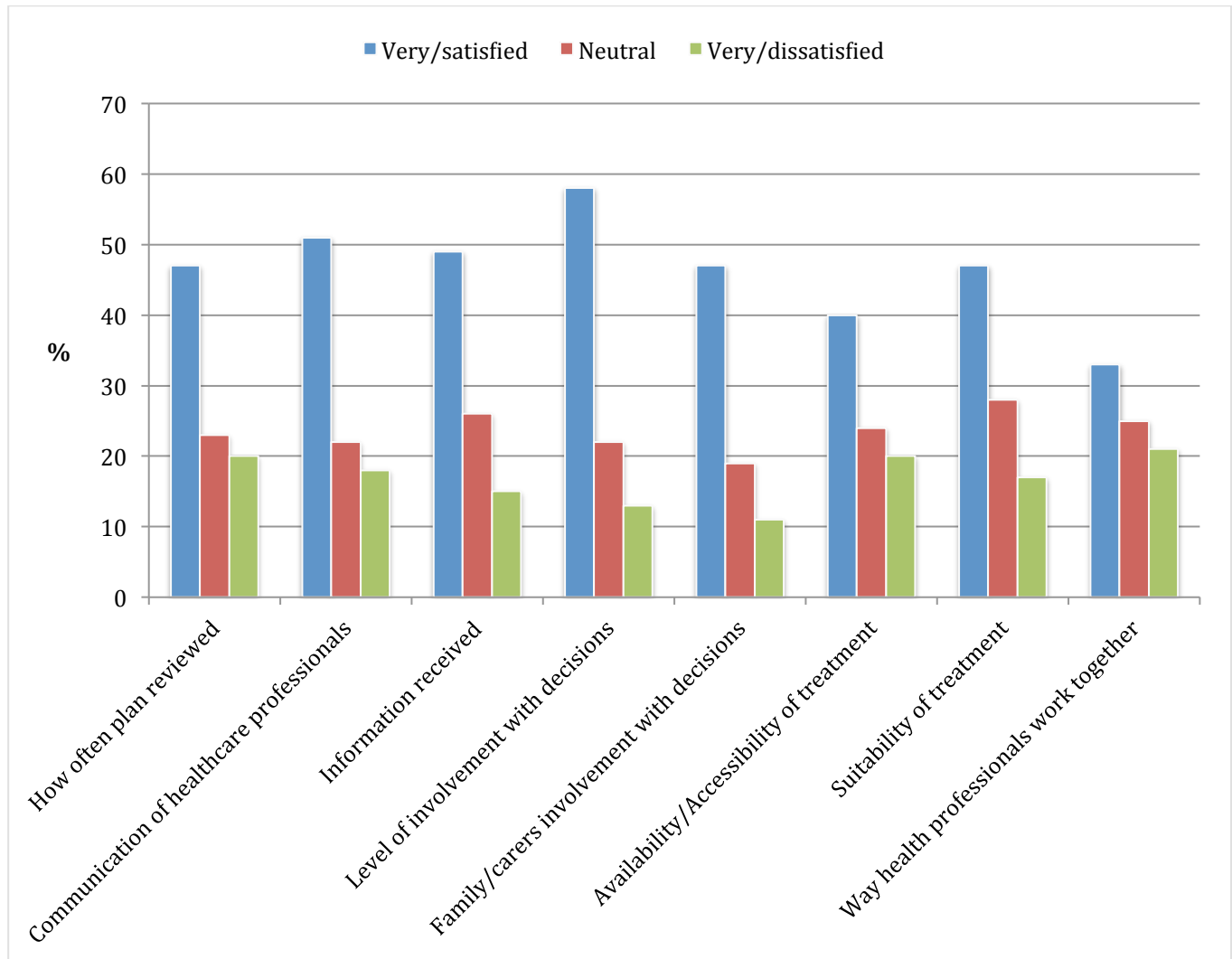
Figure 8. Level of satisfaction with therapy services (%)



In summary, across all professions physiotherapists and Parkinson's disease nurse specialists were rated with the highest levels of satisfaction (both 77%), while hospital doctors (53%) and geriatricians (57%) were the lowest.

In relation to treatment and overall care, satisfaction was highest in regard to the level of involvement in decisions (58%) and the way healthcare professionals communicate with them about their care (51%). However there was less satisfaction in relation to other care aspects, in particular the way healthcare professions work together (21%) and the availability and accessibility of treatments (20%) (Figure 9).

Figure 9. 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 revealed a significant moderately sized relationship between satisfaction with care and frequency of review. Respondents who benefited from more frequent reviews also reported higher levels of satisfaction with care ($n = 1409$, $r = .35$, $p < .01$).²⁵

The relationship between frequency of medication review and satisfaction with treatment plan was also explored with a bivariate correlation. Questions that probed for levels of satisfaction across a number of treatments were

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

totalled to form a 'satisfaction with treatment' index variable, with higher numbers equating to a higher level of satisfaction. This total was then entered in to a correlation with the treatment frequency variable, created for the previous analysis, to establish frequency related to satisfaction about treatment. The correlation was significant ($n = 1391$, $r = .08$, $p < .01$) indicating a connection between frequency of review and satisfaction with treatment. The direction of the relationship suggests those who are more satisfied with treatment, also experience more frequent medication reviews.

For the medication reviews, the most frequently cited response for all time slots was a neurologist specialising in Parkinson's disease, who reviewed medication mainly either every six months (27%) or once a year (31%). Fewer GPs or hospital doctors reviewed the medication compared to a general neurologist (Table 7).

Table 7. Medication reviews (%)²⁶

HEALTHCARE PROFESSIONALS	Every 3 months (%)	Every 6 months (%)	Once a year (%)	Once every 2 years or more (%)
General practitioner or family doctor	2	6	5	6
Hospital doctor	1	3	3	2
General neurologist	2	9	12	7
Neurologist who is a specialist in Parkinson's	6	27	31	10
Geriatrician	0	2	2	1
Parkinson's disease nurse specialist	2	9	8	4

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 was demonstrated ($n = 1732$, $r = -.01$, $p = .83$), suggesting review of medication did not impact on respondents QoL.

Focusing on the relationship between how quickly treatment became available after diagnosis and the QoL, no significant relationship was observed ($n = 1450$, $r = -.04$, $p = .16$). QoL was not affected by length of time respondents had to wait for treatment.

In addition, another 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 emerged ($n = 1401$, $r = -.14$, $p < .01$) suggesting quality of life is influenced by how satisfied respondents were with their care. The direction of the correlation indicates that as QoL scores increase, satisfaction with the care they receive decreases. This pattern of results may seem counterintuitive as satisfaction with care may be expected to relate positively to QoL. However, it may be that respondents who report a higher QoL are anxious for their standard of life to continue, thereby contributing to feelings of dissatisfaction if the treatment is perceived to be mismatched. Again, it is difficult to make firm conclusions based on the current survey data, hence further investigation should be encouraged to explore possible mechanisms for why respondents with a higher QoL express increased levels of dissatisfaction with the care received.

3.10. Advanced treatments

A relatively small proportion of the sample (8%) reported having some surgical treatment; however, 81% of this population indicated the treatment had met their expectations. Regarding how soon after diagnosis did respondents receive treatment, the most frequently cited timeframe was '6-10 years' (37%), with 'up to 5 years' being the least cited.

²⁶ Respondents were also able to state that they did not know or that it did not apply for them

To explore the relationship between length of time before opting to have surgical treatment and QoL, a correlation was conducted. Responses were coded so the least amount of waiting time was assigned the lowest number '1' (up to 5 years) and the longest waiting time, the highest number '4' (more than 15 years).

Results suggest a small negative relationship between the two variables ($n = 124$, $r = -.17$, $p = .05$), thus indicating those who had surgical treatment sooner, also reported higher QoL.

Focusing on levels of satisfaction with overall treatment and length of time before surgical treatment, no relationship between the two variables was observed ($n = 120$, $r = .07$, $p = .45$). How satisfied a respondent is with their treatment does not seem to influence how soon after diagnosis respondents opted for surgical options.

Finally, there was no difference between respondents who paid for treatment ($n = 41$, $M_{\text{length}} = 2$) versus state funded ($n = 57$, $M_{\text{length}} = 2$) regarding the length of time ($t = .37$, $p = .71$). Both groups on average waited 6-10 years before treatment

3.11. Comparisons between countries

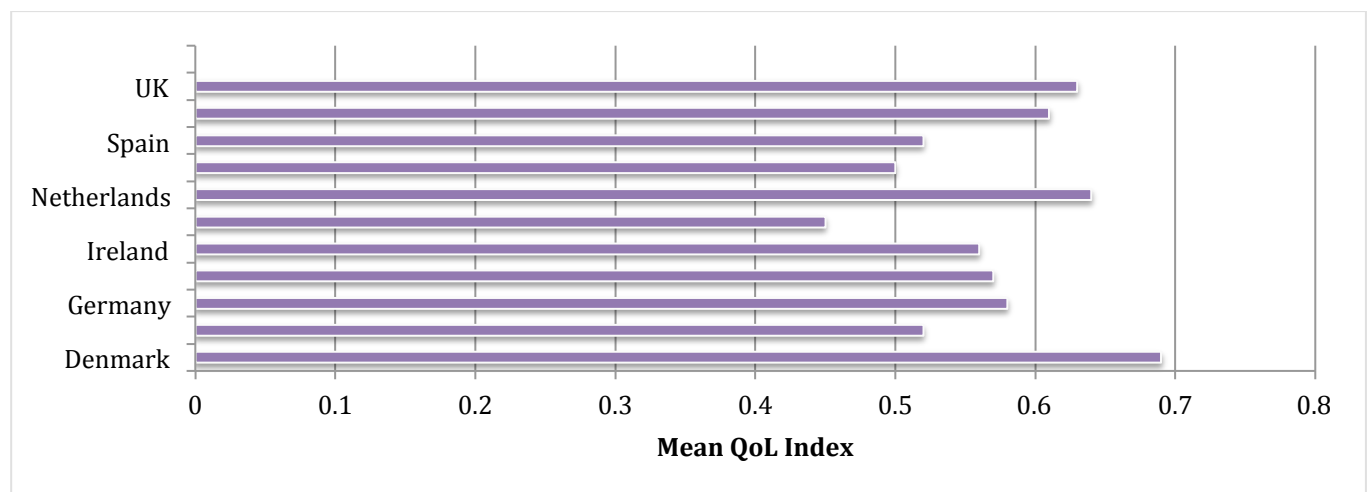
Alongside reporting on the overall findings, it would also be beneficial to illustrate any potential differences between countries regarding quality of life (QoL), levels of satisfaction with care, and access to care.

3.11.1. Quality of life and disability

For this study, quality of life was calculated using Quality Adjusted Life Years (QALYs)²⁷. To explore quality of life, the EQ-5D was utilised. This requires respondents to answer five questions focusing on mobility, self-care, usual activities, pain, and anxiety/depression.

First, focusing on the QoL index, the highest mean index was seen in respondents from Denmark (0.69), closely followed by Netherlands (0.64), and the UK (0.63)²⁸. The lowest mean QoL index was reported in Italy (0.45) (Figure 10). Therefore PwPs reported quality of life was highest in Denmark and lowest in Italy.

Figure 10. Quality of life index in each country

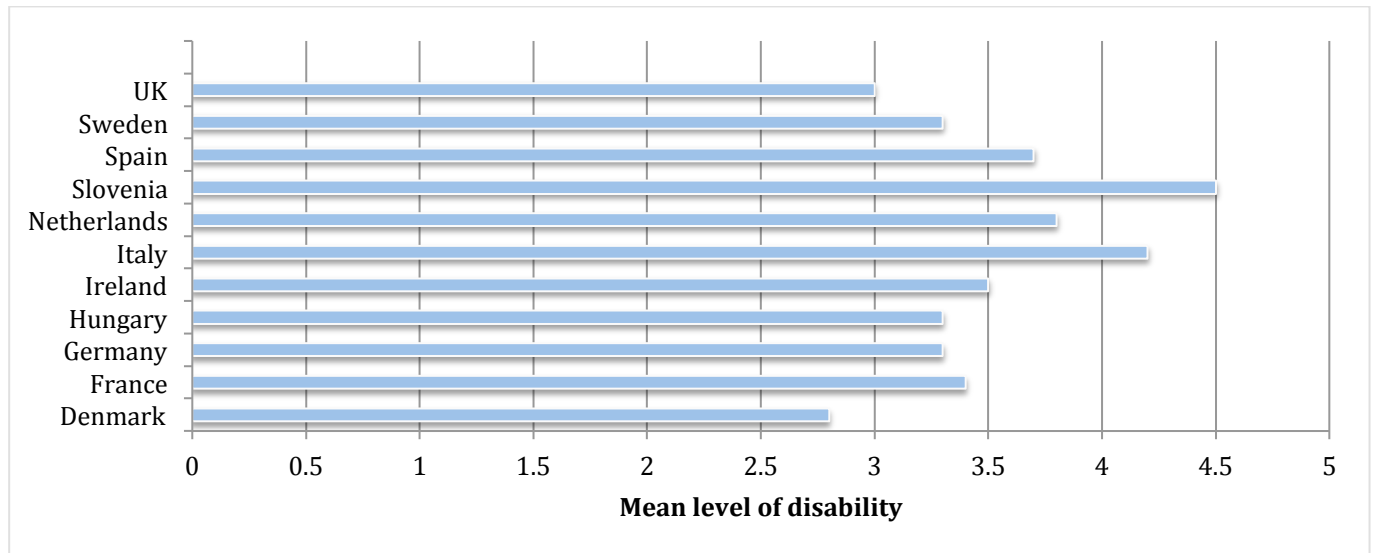


²⁷ The quality-adjusted life year or quality-adjusted life-year (QALY) is a measure of disease burden, including both the quality and the quantity of life lived.

²⁸ QALY places a weight on time in different health states. A year of perfect health is worth 1 and a year of less than perfect health is worth less than 1. Death is considered to be equivalent to 0; however, some health states may be considered worse than death and have negative scores.

Disability was also measured by asking respondents a single item question on which they were asked to rate current independence on a scale of 1- 11, with higher scores indicating higher levels of disability. The lowest levels of disability were recorded in Denmark (Mean = 2.8) and the UK (Mean = 3.0), while Slovenia (Mean =4.5) and Italy (Mean = 4.2) report the highest (Figure 11).

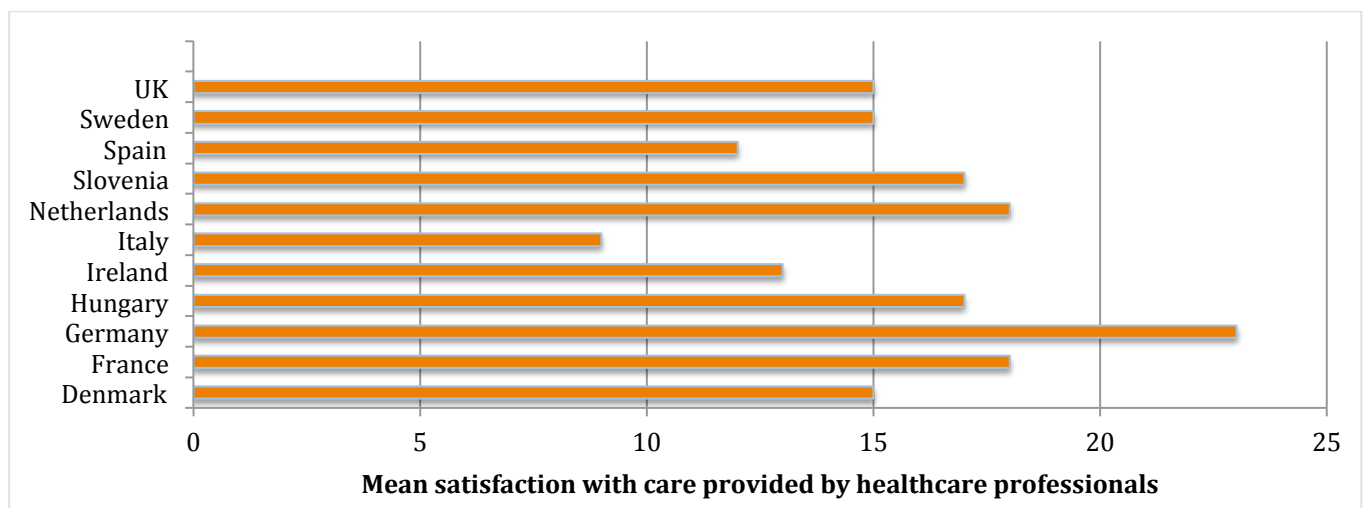
Figure 11. Disability level in each country (Mean)



3.11.2. Satisfaction with care

Moving on to how satisfied respondents were with care provided by healthcare professions, Germany reported the highest levels of satisfaction with care (Mean²⁹ = 23), followed by Netherlands and France (Mean = 18). As with quality of life, Italy also scores the lowest on satisfaction with care (Mean = 9) (Figure 12).

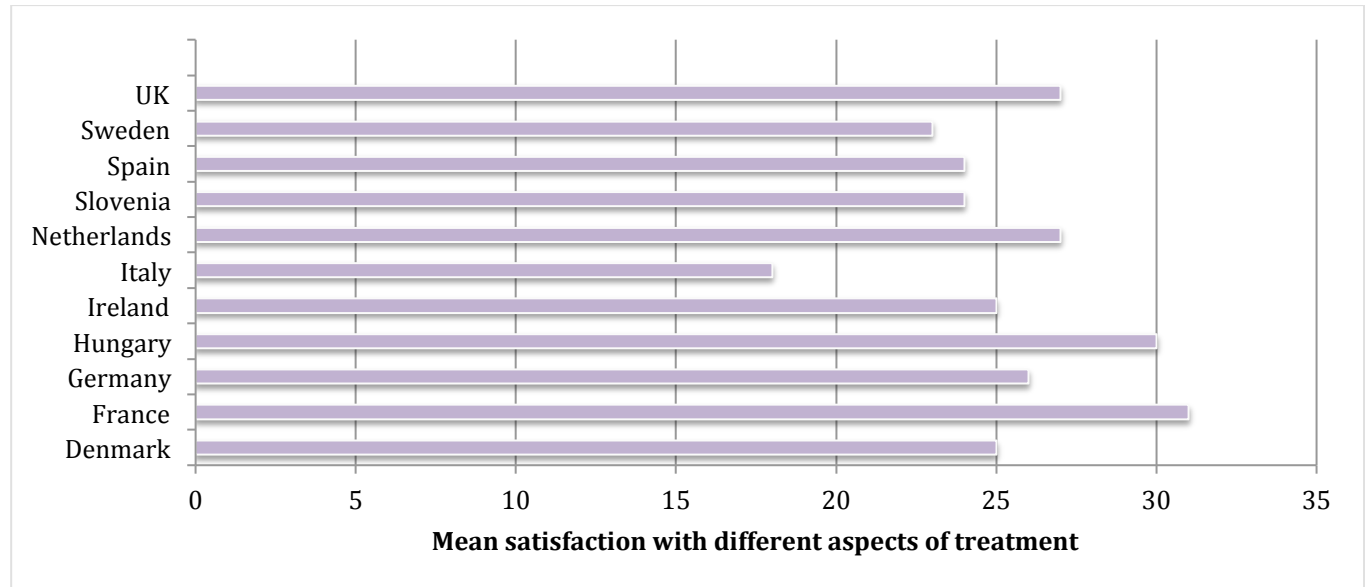
Figure 12. Levels of satisfaction with care by country (Mean)



²⁹ This is the average 'satisfaction with care total' obtained from adding responses from the 9 items that assess satisfaction with care received from 9 different professions. Points on the scale ranged from '1' very dissatisfied to '5' very satisfied. Totals range from 9 – 45, with higher numbers equating to higher levels of satisfaction.

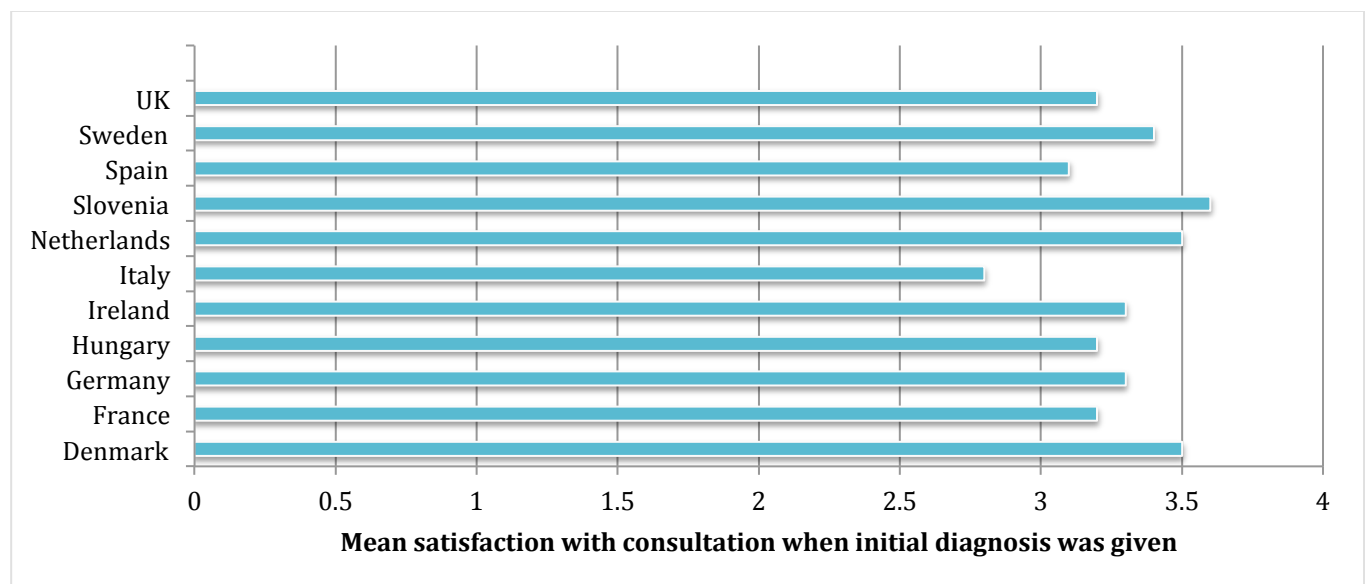
Regarding satisfaction with the different aspects of the treatment, levels suggest respondents in France are most satisfied (Mean = 31), followed by Hungary (M = 30) and the UK (Mean = 27). Once again, Italy remain at the bottom of table (Mean = 18) (Figure 13).

Figure 13. Mean levels of satisfaction with different aspects of treatment by country



A third measure of satisfaction was assessed in regard to the initial diagnosis. In contrast to satisfaction with treatment and healthcare professionals, Slovenia is rated highest (Mean = 3.6), followed by Denmark and Netherlands (Mean³⁰ = 3.5). Replicating the previous measures of satisfaction, Italy appears at the bottom (Mean = 2.8) (Figure 14).

Figure 14. Mean levels of satisfaction with initial diagnosis by country



³⁰ Respondents rated satisfaction on a scale of '1' very dissatisfied to '5' very satisfied; therefore higher scores indicate more satisfaction with consultation.

3.11.3. Relationships between QoL and satisfaction

Moving on to the relationships between QoL and satisfaction with those providing care, Table 8 displays the correlation (r) for each country. Significant correlations between the variables are highlighted- Denmark, Hungary, Netherlands, and Sweden all demonstrate a significant negative relationship, suggesting as QoL index increases, satisfaction with the care received decreases (Table 8).

Table 8. Correlations between QoL and satisfaction with care received

(** correlation significant at $p < .01$, *correlation significant at $p < .05$)

Country	n	r
Denmark	127	-.31**
France	35	-.10
Germany	70	-.20
Hungary	52	-.27*
Ireland	40	.04
Italy	101	-.11
Netherlands	130	-.19*
Slovenia	80	-.17
Spain	38	-.30
Sweden	666	-.12**
UK	62	-.11

3.11.4. Access to care

Respondents were asked to identify how soon after diagnosis they received medication or treatment. To enable an average response to be calculated, choices were assigned a number ranging from '1' (discussed but decided against) to '7' (12 months or more); hence a higher score would indicate a longer wait for treatment. The highest average score was reported by the UK (Mean = 3.1), suggesting the longest average waiting times; however, remembering the scoring system for this question, a response of '3' indicates a wait of less than a month.

All countries were, on average, less than 1 month. Germany (Mean = 2.3) demonstrated the lowest score (i.e. quickest time frame). Interestingly although respondents from Italy reported the lowest values regarding satisfaction, time to receive treatment was in line with the other European countries (Figure 15).

Regarding refusal of care due to cost, Germany recorded the highest percentage of respondents who indicated medication, therapy or care had been refused (29%), followed by Slovenia (26%) and Italy (23%). Ireland was the country with the lowest incidences of refusal (3%) (Figure 16).

Figure 15. How soon after diagnosis was treatment received (Mean response on scale)

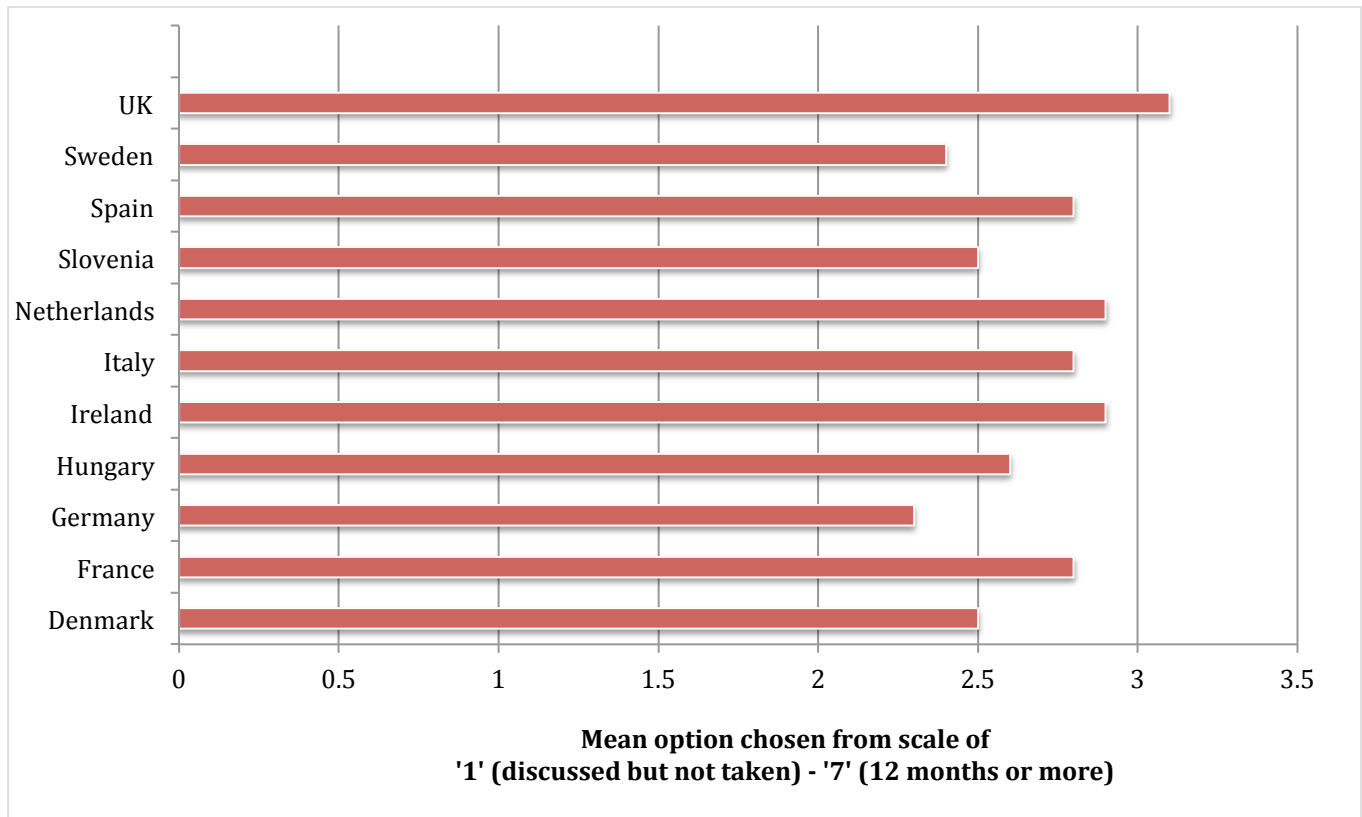
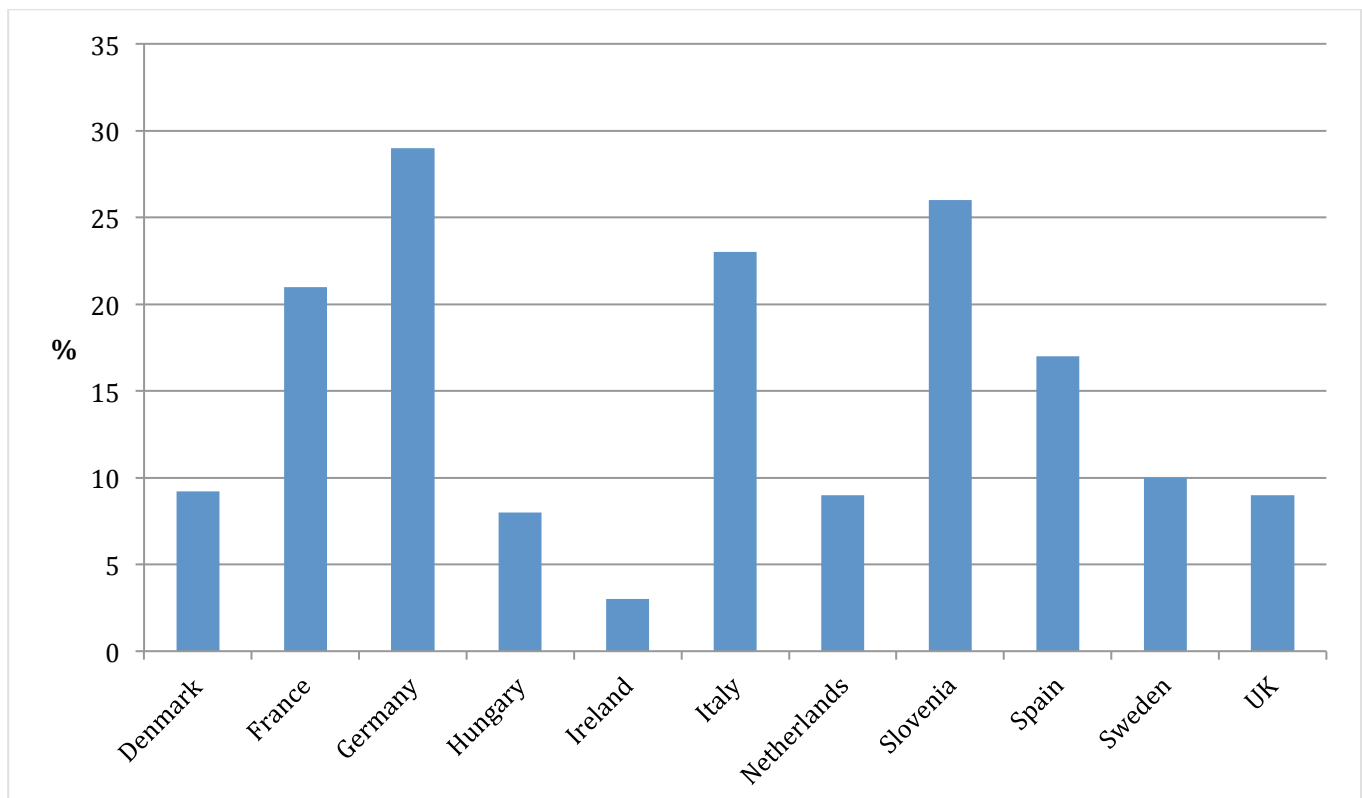
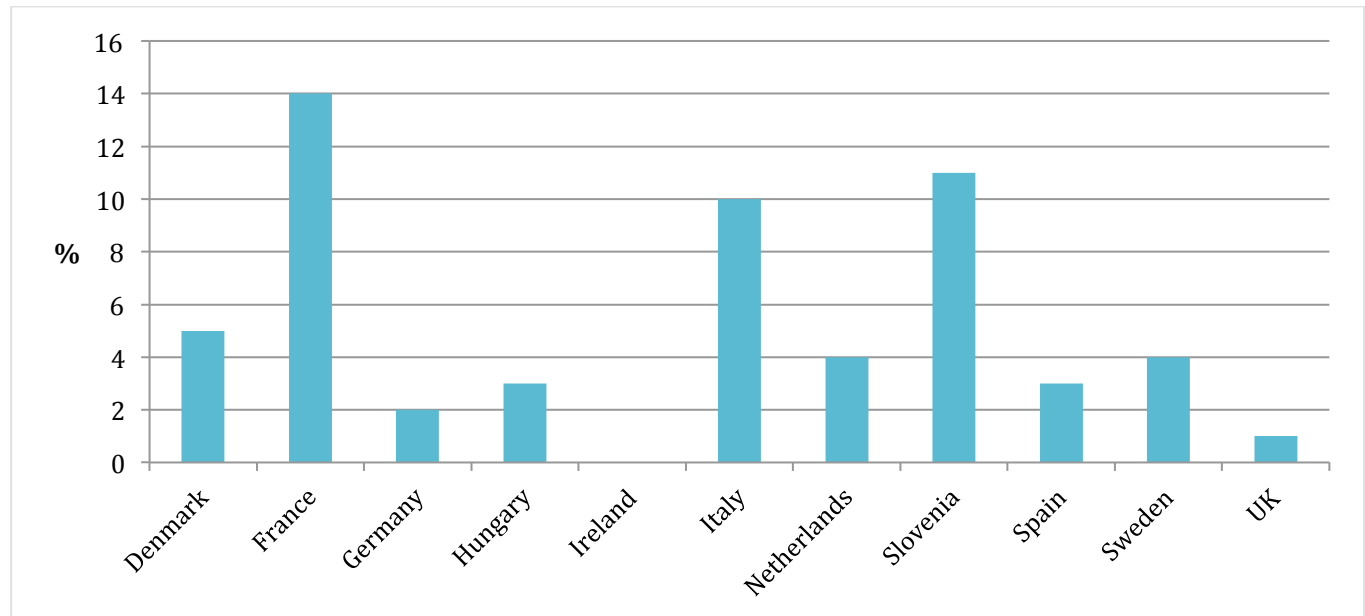


Figure 16. Refusal of care due to cost across the different countries (%)



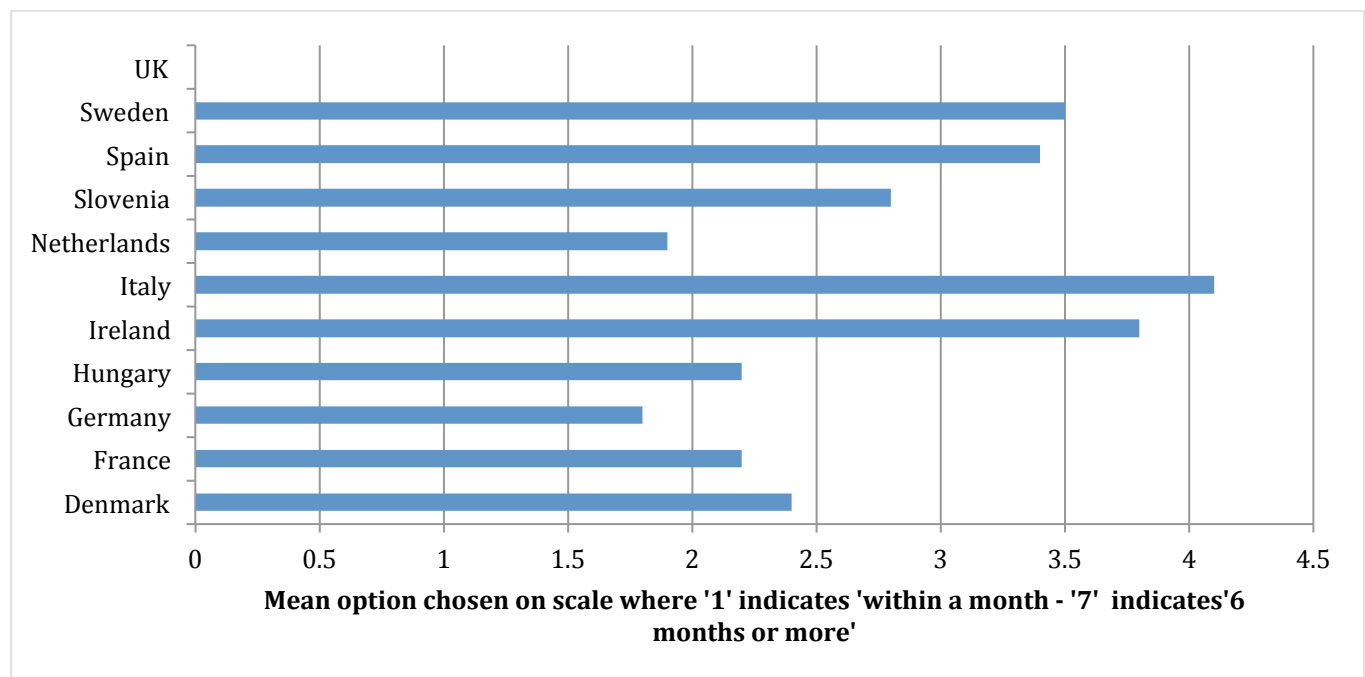
The picture looks slightly different when considering refusal of treatment according to where the respondent lived, with France reporting the highest rate (14%), followed again by Slovenia (11%). No respondents from Ireland reported refusal of care, while in the UK only 1% of the sample indicated refusal on the grounds of where they lived (Figure 17).

Figure 17. Refusal of care due to where respondent lived across the different countries (%)



In terms of accessing a neurologist specialised in Parkinson's disease - as measured by length of time from first referral- the longest referral times were reported in Italy (4), followed by Ireland (3), then Sweden (3.5). The shorter referral times are indicated in Germany and Netherlands (Figure 18).

Figure 18. Accessing a specialist PD neurologists by country (Mean response)



4. QUALITATIVE RESEARCH FINDINGS

This section includes the findings from the in-depth interviews with PwPs, carers and healthcare professionals. Due to the purposive nature of the sampling, a quantitative description of the qualitative data would be inappropriate. However, the frequency with which particular comments were made is indicated by terms such as 'all', 'most', 'many', 'some', 'a few', 'a couple' or 'one'.

The findings were very similar across the countries included in the study. Therefore the results are not presented separately for each of the countries. Instead, where it was noted that there were differences across the countries, these are discussed.

4.1. Findings from the in-depth interviews – PwPs

In total, in-depth interviews were conducted with 60 PwPs for this study. At least five PwPs were interviewed in each of the included eleven countries. The average age was 63 years, with the youngest aged 45 and oldest aged 78 years. 52% were male. The average age at diagnosed was 55 years, with the youngest age at diagnosis being 29 and the oldest 73 years. Further details of the carers who participated are given in Appendix I.

4.1.1. First signs and symptoms

- **Noticing of physical symptoms**

The first symptoms noticed by many of the PwPs were lack of movement in their arms and/or legs, and often (although less frequent than movement issues), was the tremor. Often their partner (usually the main carer) noticed the symptoms first.

“My wife, she noticed it. My gait....Then my brother asked if I was OK, so it had started to become obvious to other people that something had changed.” (PwP, UK)

“What made me go to the doctor was that I remember I was waving to my children, and my hand stayed in that position.” (PwP, Hungary)

For a few of the PwPs, they knew someone (usually a close family relative) with, or who had had, Parkinson's. In most cases this made them think that they too might have Parkinson's when the symptoms started. However, this was not always the case as the symptoms often varied.

“In the family we are three brothers and all three of us have Parkinson's – each of us a different non-specific form.” (PwP, Slovenia)

“I have this nephew who has advanced Parkinson's and his symptoms compare to mine were different, so I didn't link them to Parkinson's.” (PwP, Italy)

In hindsight, a few of the PwPs commented on the presence of other non-motor symptoms. However at the time they did not think for one moment that such symptoms, such as stress and anxiety, were linked to their movement problems.

“I used to lie awake worrying about my work. I was never a person who used to be prone to anxiety.” (PwP, Sweden)

- **Barriers to seeking help**

Most of the PwPs did not seek help immediately, on average waiting between one and two years before seeking medical help. However, with the younger participants, it was in one case around ten years before they

sought help and received the diagnosis. The delay was often caused by the PwP attributing the symptoms to stress, tiredness, caused by a virus, or nerve problems.

“I thought I had a virus and after three years I finally got a diagnosis” (PwP, Ireland)

“I didn’t think about it much [some of the earlier symptoms he experienced], I worked with computers and I thought it [the stiffness] was a result of that work.” (PwP, Sweden)

“I thought I was just tired.” (PwP, France)

For a few of the PwPs, they tried to hide their symptoms from people, and it was only when they were unable to do their job or to disguise their symptoms from their close family members, that they would seek help.

“When I sat at the table both my partner and my daughter saw I was shaking. I realised I could not hide it any longer and I went to the general practitioner.” (PwP, Netherlands)

The exception to the rule was if the PwPs main symptom was dizziness. When having this symptom, most sought help quickly, as they feared they had “a tumour, or brain cancer, something life threatening”.

“No I went quickly [to the GP] and was referred on quickly. I think we all thought it was a brain tumour.” (PwP, UK)

• **GP engagement and the referral process**

Nearly all of the PwPs first booked an appointment with the GP, and their GP then referred them on to a neurologist. However, this was not always a quick process. While for some of the participants, the GP suspected Parkinson’s immediately (although they did not officially diagnose the disease) and made the referral, for others, the GP failed to realise there was anything seriously wrong.

“I was diagnosed 2 ½ years ago, although I had it for five years. I went to 14 appointments with different neurologists and they all failed to recognise I had the disease. We have it in the family, but I never told them...my father got it at the same age I did. First symptoms were slowing down, general tiredness.” (PwP, Italy)

“The GP asked me to write my name and it was perfectly written. He told me I didn’t have Parkinson’s.” (PwP, Denmark)

“I went to the GP first and after three years of getting no answers I changed GPs as she was not listening to me and he said ‘have you ever been to a neurologist?’ And I said ‘no’ and he said, ‘well you are going to one now.’” (PwP, Ireland)

With the younger people, the referral delay was often even greater as the GPs’ thought that a diagnosis of Parkinson’s would be very unusual in someone so young.

Often PwPs had to return to the GP many times and they would fail to receive the correct diagnosis in some instances even after they had been seen by a neurologist.

“I remember how the assistant said, ‘maybe it could be PD?’ And I still hear the neurologist shout out, ‘Impossible.’ – After five years I said to the neurologist: if you don’t give me a referral to a neurological clinic specialist [suggested by my daughter] I know, I will go myself.” (PwP, Germany)

“The first thing the neurologist told me was that she had a meeting in ten minutes and she would do a neurological assessment quickly. After three months I was called back into see the neurologist in order to do an L’dopa test...I had to wait five years for a diagnosis.” (PwP, Sweden)

4.1.2. Receiving the diagnosis

- **Initial appointment with the neurologist**

For many of the PwPs, once they were being seen by a neurologist, they were quickly diagnosed with Parkinson's after what seemed to them rather basic tests had been conducted.

"At the first appointment he [the neurologist] carried out some tests, simply walking up and down and touching my nose, and made the diagnosis of having mild Parkinson's." (PwP, UK)

"I wish I they [the neurologist] had done some proper tests before the diagnosis was made." (PwP, France)

"I wasn't really asked any questions, I just had to do some movement tests. All he [the neurologist] said was that I have Parkinson's, and I didn't even know what it was. I had never even heard of it. After I went home and searched the internet and I realised that this is very, very bad." (PwP, Hungary)

"The neurologist told me [that I had Parkinson's] after a few simple tests...but he did not tell me what Parkinson's disease was, only that I probably was no longer able to do my job in five years." (PwP, Netherlands)

For the younger PwPs, more detailed tests were usually conducted to try and rule out other conditions. In addition to this, for those who were experiencing dizziness, they were sent for brain scans (often within Oncology departments).

"Within six weeks I was in a neurologist's office and she said she thought I had early PD but because I was young she wanted to run a few more tests, brain scans and different things but they all came back clear." (PwP, Ireland)

Even when the PwPs themselves mentioned the possibility of it being Parkinson's, they were often told that this was not the case and that they should not "self-diagnose" and advised to "leave it to the experts." However, this was not always the situation and the PwPs welcomed it when the neurologist asked them what they thought they might have.

"The neurologist asked me if I knew what I had and I told him, 'I think I have Parkinson's' and he said, 'yes you do, let's make some tests.'" (PwP, Denmark)

"I went to my GP and he said it was a non-essential tremor and to come back in 20 years. But I was convinced it was Parkinson's so he referred me to a neurologist anyway....I went back to the neurologist [after some years of worsening symptoms] and he said, yes you are right, it is Parkinson's....I have occasionally been annoyed with the neurologist when he has been patronising." (PwP, UK)

- **Shock and relief at hearing the diagnosis**

For most of the PwPs, being told they had Parkinson's was a huge shock, even though nearly all of them, by that time, expected something was wrong. Most of them knew nothing or very little about the disease, resulting in their first question being: "Will I die from Parkinson's?"

"The neurologist told me, 'no you do not die from Parkinson's, but you will die with it'." (PwP, Sweden)

"He [the neurologist] said don't worry you will not die of Parkinson's. Just take the pills....he said I will have time to die of something else." (PwP, France)

"I was shocked. Why did it happen to me? Why not someone else?" (PwP, Denmark)

“My doctor told me it was Parkinson’s disease, and I probably looked worried, or I don’t know, because she told me that there was no reason to be frightened because although this is an incurable disease, it does not cause death. She said that for certain.” (PwP, Hungary)

For a few of the PwPs, they suspected it was Parkinson’s. However, it was still a huge shock for them when their fears were confirmed.

“I thought it was Parkinson’s, but when the neurologist said it was, I was shocked.” (PwP, Spain)

Although it was a shock, a few of the PwPs were relieved as they had feared it was something deadly, such as a brain tumour and that they would be told they had only a short time to live. Others talked about the relief of having an actual diagnosis, as they felt that now they knew what it was, they could start to deal with the disease.

“At first it was a relief as once you have a name for it, you can start to deal with it but we knew nothing about it. But she said it was a progressive disease so we had to go home and educate ourselves about it and of course we went through all the different stages.” (PwP, Ireland)

“My initial reaction was mixed. I had been for three brain scans at a cancer clinic and so I was prepared for a worse diagnosis.” (PwP, UK)

“First I thought the world goes down. My husband had a positive reaction. We finally knew what it was. If I had known then how good I would feel now, I would not have worried so much.” (PwP, Germany)

The younger the PwP, the more shocked they were to receive the diagnosis as they thought that “Parkinson’s was an old person’s disease”. The shock turned quickly into anxiety as they worried how they would continue working and look after their children (who were often only young at the time).

“I was completely shocked. I thought it was for older people and I didn’t know much about it.” (PwP, Ireland)

“I didn’t know someone that young could have Parkinson’s.” (PwP, Spain)

• **Information given and involvement of nurse specialists**

The way the diagnosis was given was often criticised. Although many of the PwPs were happy with the clinical decisions the neurologist was making (for example, what medication to try first), the communication and personal skills of the neurologist were often heavily criticised.

“I was a bit disappointed with the neurologist, because the diagnosis was given quite abruptly. She said, ‘You have Parkinson’s, nobody has died of this disease yet’.” (PwP, Slovenia)

“He [the neurologist] said: You should be happy, you don’t have cancer, you don’t have AIDS and not everyone gets dementia. That was quite a hit in the face I thought.” (PwP, Germany)

“The way I received my diagnosis from a neurologist was quite cruel. I don’t even want to talk about it.” (PwP, Hungary)

“I wanted to kill myself after the diagnosis. I was just left...with no information.” (PwP, France)

The neurologists were often very abrupt when making the diagnosis, simply informing the PwPs that they had the disease and not giving further information. Although a few of the PwPs appreciated this matter-of-fact tone.

“I was completely unprepared but it was just the way he said I’m 90% sure you have PD. If he had maybe said have you heard of PD, it was just a total shock and I was alone.” (PwP, Ireland)

“After I was told by the first neurologist, I sat there and cried. But she told me she had to go onto a meeting, I was allowed to stay in her office and stay until I stopped crying.” (PwP, Sweden)

“The neurologist told me the diagnosis in a matter-of-fact way. He kept it realistic – no histrionics, just presented the facts as they were...I found this the best way to hear the news.” (PwP, UK)

“I was just being reassured it was a long disease, that I wouldn't die...the doctor took away the drama, he tried to make it sound very, very simple.” (PwP, Italy)

On the whole, if the neurologist spent time discussing the disease and treatment options with the PwPs the more satisfied they were with the consultation. However, they did not want too much information as they did not think it was helpful always to know what might happen in the future; they mainly wanted to know about the medication/treatment options and the pros and cons of each of the options and what they could do to help themselves.

“He [the neurologist] sat down with me for one hour explaining. That really helped. If I had left immediately I would not have coped so well.” (PwP, Germany)

Despite the obvious increase in satisfaction when a clear verbal explanation about the disease was made, many of the PwPs could not clearly state what information they were given during the appointment at which they were diagnosed. For many, it was “like a black hole” where they just remembered being given the diagnosis, but could not remember what exactly was discussed (except for the fact that they would not die from Parkinson's). Most also stated that they preferred hearing the information first verbally from the healthcare professional, and then being given something to take away so they could remind themselves of what was said.

“I think I was in shock. I couldn't take it all in. But he [the neurologist] gave me information on the Parkinson's association. It was good as I could go away and read everything in my own time [on their website]. I think every neurologist should give information about the association, and tell people how they can join.” (PwP, Spain)

In a few of the consultations a PD nurse was also present at the appointment and then took on a coordinating role (coordinating any necessary appointments with other members of the multidisciplinary team). When there was a PD nurse in attendance, this was appreciated by the PwPs as, even if they did not feel able to ask the Consultant questions, they felt the nurse was very approachable.

“The PD nurse was very caring, especially. She can never do anything wrong to me again in my whole life!” (PwP, Netherlands)

“If I want a visit, I call the nurse. She is the one to activate a lot of the things to happen. It does help to know something will happen, some activity.” (PwP, Denmark)

• **Starting on medication**

Many of the PwPs started on medication quickly (often immediately). They often expressed concerns about the side effects and did not feel that these had been explained to them clearly enough. A few also felt that alternative remedies/therapies had not been discussed with them, and the treatment was very “drug focused” and people often felt “over medicated.”

“They were just adding new medication, so at the end of my medication treatment I took as much as 13 different pills at once.” (PwP, Slovenia)

“I would appreciate more information on alternative health care, such as acupuncture.” (PwP, Hungary)

“If I did not search for alternative medicines which could help me, I would never forgive myself.” (PwP, Netherlands)

Of note, when they had been explained the possible side effects in detail, this information actually prevented a few of the PwPs from starting the medication as they were worried that the side effects would be worse than the actual symptoms. This was, in fact, sometimes the case; in others they experienced none of the side effects.

“I’ve started taking Sinemet in July 2013. I went to see the GP to ask about potential side effects as I was worried about this and did not want to start the medication. Currently I take one three times a day and as of yet, I’ve not noticed any side effects.” (PwP, UK)

“I take around ten different medicines, some of them for the Parkinson’s, some of them for the side effects of the medicine I take.” (PwP, Italy)

4.1.3. Other peoples’ reactions

- **Telling people about their diagnosis**

Whilst some of the PwPs would tell family members and friends about the diagnosis immediately, most preferred just to tell their close family at first. A few only told their partner/spouse and did not even tell their children or siblings for months, or in a couple of cases years, as they wanted to be able to come to terms with the diagnosis before telling people. This could sometimes put pressure on his or her partner, who felt unable to confide in anyone and discuss their fears and concerns with.

“I went home [after the diagnosis] and told my husband, who must have heard something about the disease because he said something along the lines of, he would look after me and rock me in front of the fire place until I got old.” (PwP, Hungary)

“I didn’t want to accept it, I didn’t want anyone to know; my wife was not allowed to tell anyone.” (PwP, Denmark)

“I told people. I don’t mind saying I have Parkinson’s. I am still the same person, only slower.” (PwP, Spain)

“I don’t mind telling people, but I will do so only if necessary.” (PwP, France)

With work colleagues, most PwPs did not mention their Parkinson’s until the symptoms became obvious and/or they needed to reduce their hours or change the type of work they did as part of their day-to-day job.

“In the beginning, when the signs weren’t visible yet, I didn’t say anything to work because I was afraid I will be seen as less capable of work and my future status will be negatively impacted.” (PwP, Slovenia)

However, if one of their symptoms was to appear drunk, then they often told their colleagues earlier as they rationalised that they would rather their colleagues knew they had Parkinson’s than think they had a drink problem.

“I told my immediate family straight away. I debated about telling people at work. When my colleague [who had PD] didn’t tell anyone, it became difficult for all of us [at work] ...but sometimes I seem as if I am drunk, so I would rather they know.” (PwP, UK)

“When I am walking on the street shaking from side to side, I don’t want people to think that I am drunk so I prefer they are aware.” (PwP, Germany)

- **Reaction of family and close friends**

Although shocked and often very upset by the diagnosis initially, nearly all of the family members then started to try and support the PwPs (and their carer), either by helping them with their task/jobs, going on the internet to find out further information, and/or attending support groups with the PwPs.

“Good friends asked us: ‘What does this mean? And what can we do for you? What will help you?’ Then I held a kind of brain storming session with two friends about what I need and how I could make life easier for myself.” (PwP, Netherlands)

“My wife and children looked for information about medication and some of my family members also.... I notice when I talk to them they know more than I expect.” (PwP, Netherlands)

The calm and positive reaction of a few of the family members was greatly appreciated by a couple of the PwPs as they did not want a fuss to be made.

“When I told my family members, no one was over emotional, really quite low key. I look OK, so I think that helps.” (PwP, UK)

“My son’s reaction was: ‘it’s better it’s Parkinson’s than being diagnosed with a brain tumour.’” (PwP, Italy)

Although the family members and friends were only trying to help, it could cause frustration on the part of the PwP if they tried to help by doing tasks that the PwP still wanted to do. It would also cause frustration if the PwP were constantly being asked: ‘Can you still manage to do that?’ and ‘Why don’t I just do it as I can do it quicker?’ Even though the PwP knew they were only trying to be helpful, still they wanted to keep active and retain their independence for as long as possible.

“I say: Let me [referring to close family members] handle my daily chores alone as long as I can, if I can’t I will let you know. But it’s difficult to get people used to not spoiling me.” (PwP, Germany)

“Everyone pitied me. They all helped me, but I don’t really accept any help unless it is really necessary.” (PwP, Hungary)

“I said to my friend, ‘until I really knockdown or until I ask for it, stay here with your hands in your pocket, even though your fingers are already itching.’” (PwP, Netherlands)

PwPs were particularly worried about how they would cope and how they would tell their family members if they were young. However, although managing the disease was often difficult for PwPs, their children reacted well and their positive attitude (that life goes on), was often helpful for the PwPs.

“My youngest daughter asked me whether I was still able to come to school tomorrow and see her presentation. My eldest daughter was the first home so unfortunately she got the first tears over her, and the middle one had to process it for herself....The next morning they stood next to my bed at half past seven saying, ‘come on Mom, its day again, we will start this new day’. And I thought, yes, for them life continues and they should be able to eat and they just need to go to school.” (PwP, Netherlands)

- **Reaction of work colleagues**

Only a couple of PwPs talked about receiving negative comments from work colleagues. On the whole, most PwPs were pleased and sometimes surprised by how positively their work colleagues reacted. Often the Human Resources team became involved and arranged for an occupational therapist to visit the work place to check that there was nothing in particular the PwPs needed to support them in their work environment. When

the PwPs needed to reduce their hours or change the type of work they did, they were again met, on the whole, with support.

“I told the school more or less straight away, I made it a policy if you don’t ask you don’t get. By in large people are helpful and do things for you.” (PwP, Ireland)

“They reacted positively in terms of reassuring me about the length of time I could work. They showed empathy and kindness in handling the situation.” (PwP, France)

However, a couple of the PwPs who had tried to change jobs or find employment after receiving the diagnosis, found the situation more difficult; often finding that people were deterred from employing them due to their diagnosis. However, after several interviews, they always found employment.

4.1.4. Support needs

- **Internet usage and informational needs**

As mentioned previously, the PwPs did not want to receive too much information about what might occur in the future/problems they might experience. However they did want to have basic information about the disease and information on the treatments available (and their pros and cons).

“Information is important, but you have to be strong enough yourself also when you receive some bad information, you have to handle it well. You hear about what’s happening to somebody and then you ask yourself, am I ending up this way too?” (PwP, Slovenia)

Despite not wanting too much information, most of the PwPs had gone on to the internet to find further information. However a few stated that they were cautious about using the internet as often the information on the web was not accurate and was scaremongering. With this in mind, PwPs preferred to go to official sites, such as the Mayo clinic (if English speaking), or the national Parkinson’s associations’ sites. Although few of the participants felt that the national association sites were somewhat outdated with the information they provided, in particular that they lacked information around new research and the medication.

“I think the Internet is the public enemy, I try to resist it checking online about the disease. But I’ve read a lot of books about Parkinson’s.... have a large library about it.” (PwP, Italy)

A couple of the participants from the Netherlands expressed confusion at all the Dutch specific sites and felt that they seemed to be in competition with each other instead of working together.

“I always get very confused by the terms Parkinson’s Fund, Parkinson’s Net, Parkinson’s Association, and then we still have another one and it feels like they are competing with each other.” (PwP, Netherlands)

- **Engaging with the national Parkinson’s associations and support groups**

Views about attending support groups were mixed. Those that went to the groups, often found great comfort in attending them and valued the emotional and social support they gained from attending the meetings (usually held monthly). They also gained information about their disease and enjoyed the presentations from healthcare professionals. However these were usually secondary to the social benefits of attending.

“It [the self-help group] was a blessing for me. It took my fear away seeing what other people can do with their lives despite PD.” (PwP, Germany)

“The support group has been going since 1999 and it is growing all the time and people are coming earlier, closer to diagnosis when before people were shying away, but we are finding they are coming a

lot earlier and are feeling the benefits of that....The more active you are the better you are, plus there is the social aspect also.” (PwP, Ireland)

“It’s quite interesting. You meet others with Parkinson’s and you can have chats plus you can listen to the specialists from the field that are conducting research within PD.” (PwP, Sweden)

The younger people also gained benefits from attending, however they usually did not start attending the groups until they had given up work (occasionally over ten years after diagnosis). However, they often found it rather “depressing” seeing people at a later stage than them, or speaking to the older people, who were diagnosed with the disease much later on in life.

“When talking to an older PD patient, when they say, ‘I also have Parkinson’s, it’s not that bad.’ Yes, but you do not have the time to live through the worst part of it.” (PwP, Netherlands)

The fear of seeing people who were at a later stage with their Parkinson’s was what prevented a lot of the PwPs attending such groups.

“No I don’t go [to a support group]. There is a local one and...if it was full of people like me [at same stage of disease], then I would go. But I think it would be depressing seeing what life has in store for me.” (PwP, UK)

• Self-help

The way the diagnosis was often given (by ruling out other conditions), and the different medications that the neurologist would try the PwPs on before finding one that worked, made a few of the participants postulate about the treatments they were being given – they wondered if anyone really knew what was going on in their brains and how to solve the problem.

“I hope they find a cure or the right medical dose. Doctors shouldn’t be guessing, they should be better with making decisions about the prescribed medicine and the side effects they cause. The disease is something extremely individual.” (PwP, Denmark)

“I changed a few doctors, as all of them were guessing what medicine could help me, but I never improved...” (PwP, Italy)

With this in mind, many of the PwPs, especially those who had been diagnosed with early on-set Parkinson’s, explored ways to help themselves. Many of the PwPs found that keeping active, both physically and mentally, was very important and improved their quality of life immensely.

“I went to a huge international conference on Parkinson’s when it was in the UK. I listen to lots of the presentations and I went with my close friend, who is actually a GP. And at the end of it, I turned to her and said, ‘the only thing that works for sure is exercise.’ and she said, ‘well we knew that didn’t we.’ she is also my jogging partner.” (PwP, UK)

A few of the participants took up a new hobby, such as stamp collecting, whilst many others took up some form of exercise, such as swimming, yoga, dancing, or Nordic walking to name a just a few of the activities mentioned.

“It’s important to fight against Parkinson’s with a healthy lifestyle, to do sports, to ease the negative symptoms with all the physiotherapeutic techniques. I do Pilates, yoga, Nordic walking.” (PwP, Slovenia)

Sometimes the group exercise activities were organised by the national Parkinson’s associations, however often the PwPs organised the activities themselves, and in fact, enjoyed it when they could join in with non-specialised classes, and people did not notice they have Parkinson’s.

"I love it when I am in an exercise group for months before they notice [the PD symptoms]." (PwP, UK)

- **Points of difference**

Although there were more similarities between the countries than differences, there were some important variations which should be highlighted.

Once the referral had been made, a few of the respondents decided to seek private healthcare as they had been warned by their GP of the long waiting times to see a neurologist (general and/or specialist). These differences in waiting times were seen within the same country as well as from country to country. In Denmark and Sweden, PwPs were seen quickly (usually within one month after referral). However this was not the case in other countries, in particular Ireland, the North West of England, Slovenia, Italy and Hungary. The long waiting times were often shocking for the participants from countries where there were no such delays.

"I was three years at general neurologist and then I decided to pay myself [to see a specialist neurologists] as the waiting times were too long. There the diagnosis was immediately made." (PwP, Slovenia)

"I read in a magazine for some people it takes them a year to see a specialist, I wonder how is that even possible?" (PwP, Denmark)

PwPs from Hungary talked favourably about what they termed 'Parkinson's school'. They found the school practical and useful, particularly so when healthcare professionals came and presented to them there.

"I am part of the Hungarian Delta Parkinson's Association and I take part in all the programmes organised by them. I also took part in Parkinson's School and I received lots of helpful information there." (PwP, Hungary)

Some of the PwPs expressed concern and questioned whether Parkinson's was genetic. Although at least one participant from most of the included countries questioned the genetic link, concern was most prominent in Ireland and Denmark.

"I'm mostly interested to read more, as it strikes me although they say Parkinson's is not inherited, we have so many cases in my family. It would be good to be informed whether there are methods, which could detect Parkinson's even when you are young." (PwP, Denmark)

The PwPs from Spain and Ireland talked about the benefits of attending their national association's support groups, as through these groups they were able to access services that they were not able to access through the health service. In Ireland they talked more about exercise classes, such as yoga (although speech therapy was mentioned also). However in Spain the services they could access through the Association were services that other countries offered through their health system, including physiotherapy and access to a psychologist.

"Those treatments are accessible, thanks to the association." (PwP, Spain)

Although in all countries, a few of the PwPs would comment on their fears for the future (especially if they live alone). Comments around the fears appeared more pronounced in France. The fear of being "a burden" was often stressed.

"I don't want to depend too much on people and I am not brave enough to kill myself. I found a place in Zurich where I could be assisted to die." (PwP, France)

4.2. Findings from the in-depth interviews - Carers

In total, in-depth interviews were conducted with 36 carers for this study. At least three carers were interviewed in each of the included eleven countries. All of the carers interviewed, with the exception of four of them, were either the husband or wife to the PwP. The others were carers to a parent (two daughters, one son and one neighbour). The average age of the carers was 63 years, with the youngest aged 29 and oldest aged 82 years. 67% were female. The average number of years since the PwPs was diagnosed was 11, with the number of years ranging between 2 years and 31 years. Further details of the carers who participated are given in Appendix I.

4.2.1. First signs and initial reactions

- **Initial symptom recognition**

Although some of the participants stated that they noticed the symptoms almost immediately, for most of the participants they did not realise that there was a problem straightaway. Instead it was more of an insidious process where they began to notice one symptom after another - predominantly movement restrictions.

"I first noticed my husband had a problem with walking and talking – it was like he was drunk, although he actually never drinks." (Carer, Italy)

"At first, I noticed his handwriting was getting smaller and then, after a while I noticed his right hand dangled down in an unusual way." (Carer, UK)

"If you spend time with someone all day long, you sometimes don't notice. You need to first be made aware that something is wrong." (Carer, Germany)

Some of the carers reported that they were often the ones who noticed that something was wrong, before the PwPs did. Of interest, the symptoms were often noticed more pronouncedly when the PwPs started to (often unconsciously) make changes to the way they did everyday tasks.

"I started to notice he would always use his left hand to hold the car keys and do some tasks. I don't think he even realised he was doing it." (Carer, Ireland)

"We were sitting opposite each other, talking, and I noticed his hand moved. I asked him 'Didn't you notice that?', but all he said was that there was nothing wrong." (Carer, Hungary)

Often, as with the PwPs, the carers did not think there was anything seriously wrong, and contributed the symptoms to "a trapped nerve", "stress" or "tiredness". When they did think that something was seriously wrong, a few thought that the PwPs had suffered a minor stroke.

"Even before diagnosis he had motor deficiencies, he dragged the leg behind him and had a motionless arm. We thought it was a minor stroke, because this is what runs in the family." (Carer, Slovenia)

"I thought he just needed a rest." (Carer, Spain)

For some of the carers, they feared that the symptoms were caused by Parkinson's. This was usually when they had known someone with Parkinson's, often a close family member, such as a parent or grandparent.

"My father had Parkinson's and I first noticed my husband shaking, especially when he was concentrating he was shaking a lot. I told him he needed to see a doctor but he wouldn't believe me." (Carer, Denmark)

A few of the carers reported that they had not noticed any symptoms at all, with a couple feeling the PwPs was "overreacting".

"No, no I noticed absolutely nothing. The symptoms [partner's name] has was a pain in the shoulder." (Carer, Ireland)

"I didn't notice, I didn't know she had the disease. Her writing got smaller and smaller but I didn't expect her diagnosis. I thought it was just overworking." (Carer, Denmark)

A few of the carers postulated that the Parkinson's had been bought on by a traumatic event which had occurred.

"We had a small fire, and even though it was a small one and we were not hurt, the whole house had to been cleaned and redecorated. It was during all the work that was going on and the insurance company had moved us into a hotel that the symptoms started to show." (Carer, UK)

"His father had Parkinson's. Now whether this is inherited or not, I don't know, but I know that his father's death was a trauma for him, and that he started shuffling after that." (Carer, Hungary)

Overall, before the diagnosis had been made for most of the carers, the symptoms did not cause them any undue concern. Interestingly, even those who feared it was something more serious than a trapped nerve, for example a minor stroke, did not remember feeling overly anxious.

"My feelings at that point...that is difficult to recall. I did not want to think too negatively." (Carer, Netherlands)

• **Help-seeking behaviour**

Many of the carers reported that it was them that in fact encouraged their partner to seek help (more if the person with Parkinson's was male). Nearly all first went to their GP/family doctor.

"I had had enough of his symptoms, being that we went everywhere together [...] and all I heard was his shuffling his feet. And I told him one morning that I've had enough, it's time to go and see the doctor." (Carer, Hungary)

At this initial appointment, the experiences were mixed. For some, the GP quickly referred them on to a neurologist as the GP suspected that it could be Parkinson's. However, for others the GP simply told them there was nothing wrong, which caused great frustration. In these cases it was often reported that the PwPs and carer had to go back numerous times before the referral was made.

"First we went to the GP, who eventually gave us the referral to the neurologist – although he first said that everything seems to be fine, but we demanded the referral paper for the neurologist..." (Carer, Slovenia)

Around half of the carers attended the initial appointment with the PwP. The other carers usually did not attend the first appointment as either they did not think anything was "serious wrong" or that their partner (usually the men or where the carer was the PwP's child) would not appreciate them attending, due to their independent personalities.

"He didn't want me to go with him [to the doctors], it's just only recently I started to go with him." (Carer, Denmark)

"I asked him, 'Do you want me to come in with you?' and he said 'No'. He has always been like that, a very private person. So I respected his wishes and went to get a coffee nearby." (Carer, Italy)

Where another condition was suspected by the GP, this often delayed the PwP being referred.

"I think we all [including the GP] thought it might be a stroke. This turned out to be a bit of a red herring as we ended up seeing the GP four times before being referred to the neurologist." (Carer, UK)

"We went to see a number of doctors where various suggestions were made including RSI or strains in her neck. This went on for a few years and I became more and more concerned." (Carer, Sweden)

- **Reaction to the diagnosis**

As with the PwPs, the main reaction was shock. However many of the carers talked about remaining strong and moving on from the diagnosis as quickly as they could as they believed this was the best way to support the PwP.

"Hearing the diagnosis we felt sad, but as we are a big family, happy family, we needed to continue. We were 'we have to move on' and we joked a lot as humour is a great part of our family." (Carer, Denmark)

"I felt like there was a brick in my chest [when told the diagnosis]. I was unable to cry, but I wanted to....I just assumed it was arthritis, so it was a great shock." (Carer, UK)

"When the diagnosis was given, the whole family was present – first you just stand, and can't really realise it. Then you read a bit and calm down. You know it's not a deathly disease and it's developing slowly." (Carer, Slovenia)

Again, similar to the PwPs, where a life threatening and shortening condition was expected (usually a brain tumour), although the diagnosis of Parkinson's was a shock, at first there was a sense of relief that the PwPs did not have only a short time to live.

"They thought he may have a brain tumour. I have to say we were very unlucky with our neurologist. He sent us the diagnosis per fax...can you imagine? He did not even bother to call him in for a conversation. But we were relieved we were not told, 'you have less than three months to live and there is nothing we can do.' " (Carer, Germany)

- **Previous knowledge of Parkinson's disease**

As mentioned previously, a small number of the participants had a degree of knowledge about Parkinson's disease prior to the diagnosis. This was mainly due to their having a family member who had Parkinson's. All these family members had now passed away, however the carers remembered clearly how the disease had impacted on the PwP and their whole family. In addition to this, often the family member had Parkinson's 30 or more years ago when there were not the range of treatments currently available, so the carers who had seen this were often very anxious and negative about what the future held for them and the PwP.

"My grandmother had Parkinson's. I remember it clearly. It was very bad then, there was nothing they [the doctors] could give her. I remember her just shuffling around, unable to help herself at all in the end." (Carer, Sweden)

"I had known a bit about it as when I was a young girl I worked at a home and I remember a man with Parkinson's." (Carer, Ireland)

However, most of the respondents did not know anything about Parkinson's or just knew about the tremor symptom, frequently due to a celebrity having the disease.

"None of my other family members have PD, it is not running in our family so I never suspected it. Sure, at first a bit of a shock, but I have never seen Parkinson's as a threat, look at Michael J Fox, he is still alive and kicking." (Carer, Germany)

“You could see she got tired very quickly. And she always used to be very conscientious with housework, but then it got worse. We noticed together, but we had no idea a thing such as Parkinson's disease existed at all.” (Carer, Slovenia)

Nearly all of the carers valued the information that the neurologist gave verbally during the appointment where the diagnosis was given. However the information varied and not all neurologists gave information to either the PwPs and/or the carer. When given little information during the appointment, or if the carer was not present at the appointment, then the Internet was often used to gain further information. However, this could cause great anxiety due to some of the information available online.

“The first neurologist was good, but he didn't talk much about the disease, didn't explain much.” (Carer, Italy)

“There was a lack of sensitivity by the neurologist when the diagnosis was given and no information was provided.” (Carer, France)

“I was away from home when I got to know the news and my world just crashed down. In the beginning when I didn't know the disease and just went looking on the Internet. I thought, OK this is over, here it says you get the disease you die of it. Then I spoke to one of my friends who was studying medicine and she told me things can be done and it made me feel a bit better.” (Carer, Slovenia)

“I had no idea what it was, I immediately googled. Will my wife die? Does it progress quickly? But I was not shocked like other people.” (Carer, Germany)

4.2.2. Role as a carer

- **Involvement with healthcare professionals**

After the initial consultation, nearly all of the carers attended subsequent appointments with the PwP. When they did not attend the appointments, this was in line with the PwP's wishes, as opposed to their own desires.

“I always travel with my husband to the appointments, but I just sit outside when he goes in to see the doctor. I feel my husband is very independent and would probably prefer to go in by himself.” (Carer, UK)

“He does not want us to go to appointments with him. He wants to keep it to himself, because he does not want to cause any unrest. He only tells us that the neurologist is very positive about the situation.” (Carer, Netherlands)

The experiences with neurologists were varied. Unlike the PwPs who reported that, whilst neurologists often lacked “personal skills” but were trusted clinically, the carers were less positive about the neurologists' clinical decisions. A few felt that the PwP had been over medicated, or they had been given conflicting information on what was clinically available for the PwPs.

“He was sent home with a prescription and the Consultant told him they would make him feel better but we were not told about the side effects. First week was grand as it was a low dose, the second week was a nightmare cause of his blood pressure...one night I thought he was going to die in the bed on me. I can honestly say, in those initial years, he was over medicated.” (Carer, Ireland)

“It is necessary for the neurologist to take more time and explain the [side effects] more carefully and with more consideration.” (Carer, France)

Many of the carers felt that they needed to be present at all appointments in case they needed to fight the PwP's corner.

"I feel I have to go [to the appointments] as he [PwP] will never make a fuss, he will just sit there and say everything is fine. One time we went and my husband, he was explaining that eating was becoming more of a problem for him and the neurologist just said 'well don't order the soup when you go out for a meal.' I wish he was joking, but he was not!" (Carer, UK)

"She [the neurologist] gave my husband a minimal amount of medication, but I noticed that the medication wasn't really helping. His state worsened. So I asked another neurologist at a second hospital to see my husband. I took my husband's scans to her and she said it was definitely Parkinson's. She also gave him medication, the same as what the previous doctor had given him, but double the dose. Then I asked her [the Consultant] to refer him to a physiotherapist." (Carer, Hungary)

"My part of the care, because [partner's name] was never sick, I had to go and fight his corner to get his meds reviewed." (Carer, Ireland)

The relationship with GPs varied greatly. Usually the GP was also the PwP's GP, therefore this often helped the carer as the GP understood the pressures they were under. When they had a good relationship with their GP they found their support immensely helpful, personally as well as in relation to concerns and questions they might have in relation to the PwP.

"Our GP, although he is lovely and will admit, as he only has two Parkinson's patients on his books, so he will admit he doesn't know much about it, and has to ring the nurse specialist. However he is always there to help if I do have a question and when I see him for my own issues, he understand all I deal with." (Carer, Ireland)

- **Impact on day-to-day life**

For some of the carers, their day-to-day life had been greatly affected, sometimes having to give up work. However for others, the PwP was still living a relatively independent life and therefore, their day-to-day activities had not been greatly affected.

"I would like to go back to work, but I'm more concerned of leaving him [PwP] now." (Carer, Ireland)

"Parkinson's is lived with the close relatives. They have the burden. The government needs to do more to support them." (Carer, France)

"At the moment, it is fine. My husband is happy, still active and takes our dogs for walks. His quality of life is still high." (Carer, UK)

However the unpredictable nature of the disease made planning every day activities difficult for many of the carers.

"One thing which is difficult with Parkinson's is that it is so unpredictable. It varies so much from day to day, hour to hour so you just have to take every day as it comes." (Carer, Ireland)

Many of the carers had to remind the PwP to take their medication at the correct times. When the PwP did not manage their medication effectively, the carers would often feel frustrated. A few also talked about changing the food they cooked for the whole family, so the PwP would be able to eat with everyone still without feeling self-conscious.

"I care for my elderly mother also. And when I have to leave [PwP name] for the day, I am very conscious of leaving him some lunch so that he can eat. I cannot do anything with bread anymore." (Carer, UK)

“Once, I got very angry, because he had not properly arranged his medication before the holidays it is impossible not to take your medication when you have Parkinson’s.” (Carer, Netherlands)

A lot of the carers, although still trying to encourage the PwP to lead an active life, were also anxious when leaving the PwP alone and started to feel as though they could not go out as often by themselves. This anxiety often resulted in carers feeling more isolated as the PwP’s condition deteriorated. A few of the carers gave examples of the increasing isolation, for example, not being about to go and eat out with friends any more.

“He never wants to go out for a meal any more, or eat in front of people. We are OK when we go to a little café near where we live as they know him, and just bring him a mug instead of a china cup. They do it with no fuss and never say anything. They are great in there. But around there, the streets are all cobles so he has fallen before.” (Carer, UK)

The isolation was particularly prominent in those who lived in rural areas and had always been dependent on the PwP to do the driving.

“For me it has changed my life totally. The first couple of months were not too bad as we could still get out and about freely but as the years have gone on...He will no longer drive and I have never driven so we are severely housebound.” (Carer, Ireland)

A few of the carers said that, although it was often easier for them to just do everything, - dress and wash the PwP, cook all the food, do all the shopping, and so on - they felt it was very important that the PwP remained independent for as long as possible and therefore, they would often not help them and still give them jobs to do around the house and garden.

“I think many caregivers are helpless in the beginning and do not know where to turn for information, that is what I experience. People ask me, especially when young patients get sick, I tell them – do your own thing and don’t protect the person with Parkinson’s, don’t disable them completely, don’t take away their decision making.” (Carer, Germany)

“You sometimes think, oh I will just do it [the job] as it’s quicker, but you have to help them to help themselves.” (Carer, Sweden)

4.2.3. Support needs

- Informational needs**

The need for information was highlighted by nearly all of the carers, although, as with the PwPs, they felt that too much information about events that might or might not happen in the future was not useful and in fact could just cause greater anxiety.

“Yes, we are members of the Parkinson’s Association, but we have asked them not to send their magazine to us, because there were a lot of stories in it where we were not yet ready for. We thought, oh no, we do not want to read this, because we have not yet come to such an advanced stage of the disease. Otherwise, your vision is already completely outlined for you.” (Carer, Netherlands)

“We, as carers and people who have to understand patients, need to be as informed of this disease as the patients, so that we can help them appropriately...that is why I go to the school [Parkinson’s school].” (Carer, Hungary)

More than anything, the carers appreciated the Parkinson’s disease specialist nurses as, on the whole, they felt they were very approachable and had time to talk to you. However, carers in Ireland and Slovenia stressed the need for more specialist nurses.

“When we visit the Parkinson’s centre, I like to talk to the nurse there to ask questions about whether what I observe in my husband is a ‘normal’ reaction to aging or is it indicative of a progression of his Parkinson’s.” (Carer, UK)

“He [PD nurse] is an absolute godsend. It is great, as a carer, to be able to pick up the phone and get advice.” (Carer, Ireland)

“The Parkinson’s nurse should be more as a home care nurse – as you don’t get to see the neurologist very often and when you do, it’s only for 15-20 minutes, and she has lots of experience and we would need a couple of nurses like her to go around the patient’s homes.” (Carer, Slovenia)

It was stressed by some of the carers that their informational needs differed from that of the PwPs; however healthcare professionals did not always understand this. Carers felt, first and most importantly, that they needed information about how to manage the medication (as mentioned previous, this was often their role). They wanted to be told about the side effects and what they should do/who they should contact if there are problems with the medication.

“If it’s just a matter of introducing a new medicine, no, but if it is making me aware of possible serious side effects or discussing the necessity of my involvement, then yes, I do think it’s very useful for me to accompany my mother to her appointments in the future.” (Carer, Germany)

“Carers should know they have different needs and different questions about Parkinson’s. Health care professionals should not only focus on the patient but also on those things.” (Carer, Netherlands)

The carers also wanted information on how to deal with certain symptoms, in particular the non-motor symptoms, such as the behavioural issues and mental health problems that can occur.

“We should get information or training on how to behave with the patient, because I tell you, sometimes I run out of patience – because he doesn’t listen, he’s stubborn, wants to work at inappropriate times, once he worked until 3am. We had some problems with that and you don’t know who to turn to.” (Carer, Slovenia)

• **Accessing financial support**

Difficulties in accessing financial support were mentioned consistently by carers across many of the included countries. The carers talked about the difficulties in accessing support, and often only managed to have financial support once the PwP was in the later stages of the disease.

“I get carer allowance now, but not until 2102 [around 8 years after diagnosis].” (Carer, Ireland)

“I don’t have any financial help from the government but if there was any possibility that would be nice.... He is a 100% classified as disabled. I have to be with him 24 hours a day. I stopped working three years ago and I’m the only person to take care of him.” (Carer, Italy)

One carer talked about when her husband was sent from Ireland to the UK to receive Deep Brain Stimulation. The carer was exasperated by the lack of the support the state provided, as although they paid the medical bill and flights over, they would not pay for accommodation for the carer whilst in the UK nor would they even pay for a suitcase to be taken on the aeroplane. While it was only one carer who talked about this issue (due to none of the other participants from Ireland having received DBS), it is important to highlight this issue as affects PwPs and their carers in countries where the advanced treatments are outsourced.

“They won’t give you compensation for trains or taxis, just flights. They won’t even cover you, of course I had to bring a suitcase as we were going to be there maybe three weeks they said, and they wouldn’t

even cover the bag...for the surgery, I had to stay for 14 days which cost me well over £1,000 just for the hotel room.” (Carer, Ireland)

- **The need for ‘me’ time**

Many of the carers, particularly those who cared for a PwP in the later stages of the disease, talked about the need for more support, including time to themselves, even if it was just for a few hours a week to go to the shops, or sit in a café and read a book. The lack of support infringed on their ability to care for the PwP.

“Two kinds of support could be done to support carers. First getting help with someone else to take care of him, so I even have some free hours to myself. And the other some kind of that would help me how to understand certain situations. For instance he can’t eat, and for every meal there is a fight between us.” (Carer, Italy)

“Without doubt the carers need help. They spend all the time helping the person with Parkinson’s.... How can we keep on helping when no one helps us?” (Carer, Spain)

Sometimes friends or family members would visit them and look after the PwP whilst the carer had some time alone. This was greatly appreciated. They also mentioned that, on the whole, if they asked for help, people would help them, but they felt often other carers were too ashamed to ask.

“People often offer that if you need something, that you then just have to say it, but many Parkinson’s patients and carers dare not ask them for help because they do not want to bother them. But if you ask for it, you notice that people are quite willing to do things with or for you.” (Carer, Netherlands)

- **Benefits of attending support groups**

Many of the carers talked about attending support groups, however the reviews were mixed. Whilst some of the carers gained great support from the groups, others went mainly to gain information.

“Access to more information is useful and we are in the association and go to group meetings to get that.” (Carer, Ireland)

“The doctor never gave me any specific information for my role as a carer, but I learnt through experience and from meetings with organised self-help groups for carers.” (Carer, Italy)

“Many of the carers do not know much about Parkinson’s so it is helpful [to attain more information], then you can help with the decisions.” (Carer, Spain)

At the support groups, some of the carers felt that they were not able to express their concerns and opinions freely, especially if they would be seen as a criticism of the PwP that they cared for. However, many of the carers felt they needed someone to talk to.

“For me it’s sometimes, when everything is piling up, really helpful to have a conversation with someone on the outside, even if we don’t talk about the problems at all. That means a lot.” (Carer, Slovenia)

“As a carer, everything is geared towards the person with Parkinson’s and it is hard to get support for you; you can’t always talk openly.” (Carer, Ireland)

“The government should create support centres just for the carers.” (Carer, France)

To try and address this issue, a few reportedly started attending non-specific support groups. However they usually left after a couple of sessions, as they were too general and again they did not feel as if people understood the problems they were facing. Or that they felt guilty for “moaning” when some of the people attending had far greater issues (for example, caring for a severely disabled child which was seen by the

carers interviewed as being far worst). Where the national Parkinson's associations ran carer specific groups, this was greatly appreciated by the carers.

"I went to a few group meetings, but no one else was there for Parkinson's and to be honest, I felt guilty – some carers have it a lot worse than I do. I have two healthy children, grown up, I have grandchildren now. I felt guilty for complaining about [PwP name]." (Carer, UK)

"We've joined the Parkinson's organisation's evening sessions, each joined a group for patients and a group for carers." (Carer, Denmark)

Carers often expressed frustration when the PwP did not want to attend the support groups, as they did not feel they could attend alone. More reluctance to join a group was reported by the female carers (in relationship to a male PwP), as the men did not always want to go.

"My husband refuses any support from self-group, it's not in his personality." (Carer, Italy)

• **Points of difference**

Although carers from all the countries commented on other people's reactions when they discussed their partner's condition (most of which were reportedly positive and supportive) and discussed the value of educating the general public about Parkinson's, carers in Slovenia explicitly mentioned the need to reduce the "stigma" attached to the disease. Raising awareness was particularly important in relation to certain symptoms (such as appearing drunk).

"People shouldn't look weirdly at someone on the road who is shaking or is standing at the cash register and not being able to move. I as well might have looked at someone weirdly before I knew about the disease – you just think the patient is drunk because they are shaking or have a weird walk." (Carer, Slovenia)

Slovenia and UK were the only countries where non-evidence based alternative therapies were mentioned.

"I once told the doctor when he asked me why we decided for alternative therapy which had bad outcomes: "If I knew now that there are some witches that cure the disease, I would just thank you for your help so far and leave you to go and seek that." (Carer, Slovenia)

"I believe in the Bach flower remedies ...I think that they can help although the neurologist probably would think I was mad to even suggest it. I am not saying they would ever replace the medicine, but you have to believe in something, and I believe strongly in that." (Carer, UK)

A few of the carers felt as if they had to take on the role of coordinator; with the support of the GP, they often felt as if they had to coordinate all the other healthcare professions. This could be stressful and could add to their anxiety. This was predominantly an issue for carers in the Netherlands.

Finally, in Denmark the carers often reported dissatisfaction with the GP. In other countries, only the minority of respondents reported dissatisfaction, however it was more consistent in Denmark. In addition to this, in Denmark a few of the carers also mentioned how they were in "denial" and thought their partner was "over reacting" at first. This denial was discussed by PwPs from other countries, but not by the carers.

"I just didn't want to accept there was a problem. I was trying to stay positive and thinking she overreacts." (Carer, Denmark)

"We went to the GP and he said my husband didn't have Parkinson's. I told him I wanted to go further and see a specialist. He was arrogant, he said: 'If madam wishes, then he will visit a specialist.'" (Carer, Denmark)

4.3. Findings from the in-depth interviews – Healthcare professionals

In total individual in-depth interviews were conducted with 98 healthcare professionals for this study. Table 9 details the type of healthcare professionals included in the study, and the number interviewed in each country. As many of the healthcare professionals were known to either the EPDA or the national Parkinson's disease associations, no further details are given to ensure full confidentiality.

Table 9. Healthcare professionals interviewed

Type of health care professional	Total numbered interviewed by profession	Country	Total interviewed by country level
Neurologist specialised in PD	23	Denmark	7
PD nurse specialist	17	France	7
Physiotherapist	13	Germany	10
Speech and language therapist	8	Hungary	7
Psychologist	7	Ireland	7
Nurse (non PD specific)	5	Italy	10
Art therapist/ Music therapist	2	Netherlands	10
Occupational therapist	8	Slovenia	8
Social worker	1	Spain	13
Nutritionist	3	Sweden	7
General neurologist	4	UK	12
General practitioner	3		
Geriatrician	4		

4.3.1. Improving pathways

- **Use of guidelines**

Nearly all of the healthcare professionals talked about guidelines, however the number of guidelines which a country had varied greatly. A few of the countries had various separate guidelines for different healthcare professionals, when other countries reportedly had just one main set of guidelines which some of the healthcare professionals felt were developed mainly for clinical staff (although the guidelines usually referred to treatment from other healthcare professionals also, for example the UK's guidelines).

“These guidelines are not used everywhere, the reason being that they are actually being collected, rewritten and standardised right now. This is a very long procedure, I mean there are hundreds of disease specific guidelines.” (HCP, Hungary)

In countries where there were a lot of different guidelines, a couple of the health professionals thought it was over kill and it would be more effective and coordinated (among the healthcare professionals) if there was just one.

“We are supposed to work as a multidisciplinary team and yet everyone wants to develop their own guidelines. Would not one be better and help with coordination?” (HCP, Denmark)

“I know other countries in Europe love to develop lots of different guidelines. I am not sure if anyone follows them, one is enough to contemplate!” (HCP, UK)

When it was reported that a country did not have their own, they usually used guidelines from another country (either officially or unofficially). For example, the healthcare professionals from Ireland reported that they used the UK's guidelines.

“We don't have proper guidelines in physiotherapy in Slovenia, when browsing the internet I found the Dutch guidelines and I'm sticking to them 90%.” (HCP, Slovenia)

When asked what impact the publishing of the guidelines had made, there was a mixed response. Although all of the healthcare professionals agreed that having guidelines to “set the standards and direction” was important, adoption was reportedly slow. Most felt unable to say how many of the professionals in their specialist areas (for example, neurology) complied with the guidelines.

To try and increase compliance in the Netherlands, if physiotherapists wanted to be part of ParkinsonNet, they had to comply with the guidelines.

“I think a particular strength in our country is ParkinsonNet where people can only become a member of ParkinsonNet if they follow thorough baseline training, which is in full accordance with the existing guidelines.” (HCP, Netherlands)

Professionals from other countries thought this was a good model but harder to achieve with the clinical professionals working within the state sector. Most of the health professionals who discussed this, felt that unless the national government said that they must be a member of a certain organisation, then there was no advantage for them of being so (for example, no extra pay). It was hypothesised that being a member of such an organisation might be beneficial for those working in the private sector as it might mean more business for them.

“I cannot see it working in the UK. Maybe for a private physiotherapists if it helped them find more clients, but not for an NHS doctor – what would the benefit be for them?” (HCP, UK)

Despite the introduction of guidelines, they were not always well received by the healthcare professionals. Whilst they were useful in understanding what treatments were scientifically proven to be effective, the way the guidelines set certain rules and standards that should be followed in each healthcare profession was criticised. In particular, healthcare professionals in Germany and Hungary stated that they did not want to standardise, or turn their patients “into statistics for progress reports”, and guidelines were regarded as having this effect. Health care professionals stressed that they do not aim to improve on statistics, but would rather help each individual patient according to their personal needs.

“The problem which guidelines have is that they offer guidelines on how to treat patients on average but they cannot help in the decision about individual treatment – not every patient is like another. It's helpful to know how to interpret and when to deviate from the guidelines individualised medicine in some ways juxtaposes the guidelines.” (HCP, Germany)

“I do not want guidelines to define what expectations I have towards a patient [...] I want to help patients express themselves in the best way possible. I would like them to gain confidence, to express their opinions.” (HCP, Hungary)

“The guidelines are limiting us in a way, but I do think the guidelines help with the everyday practice.” (HCP, Italy)

A couple of the older HCPs felt that the guidelines were not for them, and were more useful for the young professionals with less experience.

“Guidelines are understood as a support for the less experience, I believe my state of knowledge does not require guidelines. They should not be copied blindly.” (HCP, Germany)

Concern was also raised that guidelines became outdated very quickly.

“The guidelines were revised about two or three years ago, but by the time they were revised, they were already outdated.” (HCP, Netherlands)

“There is a lack of knowledge about the guidelines, and to be honest they are outdated already.” (HCP, UK)

“Because of new technologies it is necessary to modify the guidelines often” (HCP, Spain)

- **Referral pathway**

As with the findings from the PwP interviews, the referral pathway usually started with the GP. The GP was the “gate keeper” who then made the referral to the neurologist.

“GPs treat PD patients rarely and if they do, only for a short period. They have a limited budget and PD medication is not covered, so they have no interest in keeping PD patients because that would mean that they have no money left for other patients.” (HCP, Germany)

Waiting times then varied greatly, not just between countries, but between regions in the same country. PwPs were usually seen within one to three months, however even within the same country, the professionals did not always agree with each other. Therefore from the qualitative interviews it was not always clear what was actually happening. Waiting times to see a specialised neurologist were reportedly a lot longer than to see a general neurologist due to shortages of specialists.

“If you are prepared to take any general neurologist in town than probably you can get there within 2 weeks – if you want to see a movement disorder specialist it would be a matter of a month maybe more.” (HCP, Germany)

“There are some places in Denmark where patients wait too long for about a year, to see Parkinson’s specialists.” (HCP, Denmark)

The variations were not just reported in relation to neurologists, but also in access to PD nurse specialists and other therapists (for example, physiotherapists). While often the healthcare professionals stated that across the whole of their country PwPs could access a physiotherapist, for example, they were not knowledgeable about Parkinson’s disease (as they were general, community-based professionals, as opposed to specialised ones). This meant that the treatment the PwPs received was not always believed to be as effective as it could be.

“In theory, everyone has access [to a physiotherapist] wherever they live, even in the rural areas....but they might not be so good as they are community physios, so they do not see many patients with Parkinson’s.” (HCP, Sweden)

Often the neurologist then made the referral to the therapist and decided what extra therapy the PwPs needed. However in some countries (predominantly northern Europe), the PD nurse specialist was present in all the consultations and then acted as a coordinator. This was regarded as useful for all involved (including other healthcare professionals, PwPs and carers) as it was acknowledged that neurologists, due to their heavy case load, often had limited time to spend with their patients.

“This clinic has a great referral system, all thanks to the neurologist who works here. She immediately advises all patients to see us [Physiotherapist] as soon as possible.” (Hungary, HCP)

“Patients enjoy the professionals who make time for them.” (HCP, France)

“It’s side by side, in the same room actually; we participate in the consultations.” (HCP, Denmark)

Some of the healthcare professionals (including neurologists) also recognised that neurologists did not always have the “best bedside manners”.

“We [neurologists] are rather a pompous bunch!” (HCP, UK)

- **Working across other hospital departments**

Concerns were expressed by a few of the healthcare professionals (secondary care based ones predominantly), that outcomes for PwPs were poor if they were admitted into hospital. In particular if they ended up in another hospital department where the doctors and nurses knew little about Parkinson’s, for example orthopaedics.

“1 in 10 are dying, which is much higher than you see from stroke. More people get home after having a stroke.” (HCP, Ireland)

“Having an outreach team is the most urgent thing still needed. When patients are being admitted, they end up staying longer in hospitals if they are admitted in wards where staff do not know anything about Parkinson’s.” (HCP, UK)

When there were sufficient numbers of PD nurse specialist available, these professionals often acted as coordinators with the other departments. The other hospital departments would telephone to inform them they had a PwP on their ward. The PD nurse specialist would then go and check the medications were being administered correctly. However in hospitals where there was only one or a few PD nurses specialists, it was not possible to offer 24 hour support (which was needed for services such as Accident and Emergency (a 27/7 service)).

“We would be able to spend more time with patients all over the hospital if there were more staff available. Nurses all work for 12 hour shifts.” (HCP, Hungary)

- **Delays in referrals to specialists**

It was recognised by nearly all of the healthcare professionals interviewed (even the GPs), that GPs were often slow to recognise the symptoms of Parkinson’s disease. This then prevented timely referrals to secondary care professionals. GPs often failed to notice someone’s symptoms as Parkinson’s disease as they rarely came in contact with anyone affected by the disease.

A few of the healthcare professionals also talked about the problems in relation to GPs managing the PwPs treatment (and not referring them on to secondary care). Referrals would only be made after a couple of years when the GP could no longer manage the symptoms effectively. However this was reportedly becoming less of a problem as it was mainly the older GPs who tried to manage the PwPs treatments themselves.

“They often manage the first year of care then refer them to us when thing deteriorate and they do not know what medication to use next.” (HCP, Ireland)

Most of the healthcare professionals felt that GPs could not be expected to know about Parkinson’s disease in any detail (as they could not be expected to be experts in every area). Training for GPs was not recognised as a solution since, unless they saw someone with Parkinson’s disease in the following weeks, it would be forgotten about. Although a couple of the healthcare professionals interviewed thought that training for GPs should still be offered as some GPs may work in areas of higher prevalence.

“I think the reason is that the GPs see only a few Parkinson’s patients in their lives. The early symptoms are difficult to identify. I’m not necessarily blaming the GPs; you can’t be an expert in all the diseases. And training the GP is something that I think it not going to be effective because you can give them a teaching course, but if you don’t see a patient next week, you tend to forget. So I think the education should go not towards the GP’s but maybe the patients. (HCP, Netherlands)

The GPs interviewed for this study all said that they found it useful to be able to contact their local PD nurse specialist if they had any concerns about the PwPs, and to ask for advice on what medications they were able to give for the side effects (as although the neurologists managed the medication for the Parkinson’s disease and often medication to reduce the side effects as well, frequently the PwPs would still see their GP to discuss the medication and the side effects).

“I have to be honest, I am not sure what I can add as I know very little about Parkinson’s. Of course I studied it when I was at medical school, but that was over 20 years ago and a lot will have changed. What I do know mainly comes from having one patient with the disease. But that is it. He comes to see me often, I think partly because he is lonely. When I am not sure how to answer his questions, I phone up his PD nurse.” (HCP, UK)

“The general practitioner will be kept informed, but basically if the patient is treated by the neurologist, we take care of everything related to the Parkinson’s disease. Only if a patient has additional symptoms such as swollen feet or a spot on the skin, we indicate that the patient should contact his/her doctor.” (HCP, Netherlands)

Instead of training the GPs, a couple of the professionals suggested up-skilling and empowering the PwPs instead. However not all of the professionals agreed this was a good idea; a few feared it would “pass the burden of responsibility” onto the PwPs, possibility contributing to their stress.

“When doctors are not doing their job properly and need to change, why should the patient have to be the one to make that happen? Shouldn’t doctors be doing it anyway as it is their job? Why pass the buck?” (HCP, UK)

When discussing referral delays, a few of the healthcare professionals also recognised that the delays often stemmed from general neurologists.

4.3.2. Access considerations

- **Access to care**

Many of the healthcare professionals, in all of the included countries, highlighted the inconsistencies across their country in relation to access to care.

“One of my greatest passions is to harmonise care. There is this tremendous variation of care in our country and the big challenge is two things: to raise the average quality of care and secondly, to reduce the variation in care...In terms of hospital care we have very good centres but there is still huge variation in care.” (HCP, Netherlands)

The exception was France, where they had tried to overcome this problem by establishing around 20³¹ specialist centres. However the healthcare professionals from France still recognised that more needed to be done as the specialist centres only saw the more “unusual” cases (for example, those diagnosed at a very young age with the disease).

³¹ Different HCPs gave different numbers, so it was unclear to the research team if it was 20 or 24 centres

“There are 20 national centres – a couple of years ago there was created a White book on PD, which led to a national plan for PD. That allowed identifying what they call expert centres, as a result there have been recourses dedicated to those centres...In general, the access to neurologist is easy as we have more than 10 times more neurologists in France compare to the UK.” (HCP, France)

The inconsistencies in access to care were not just regarded as a problem for clinical professionals, however it was reported to be an issue for all of the professionals.

“It is very different type of care you get as a PD patient, across Sweden, depending on where you live. There are very few neurologists that specialise in PD. But for the therapists too. The specialised ones tend to be grouped together either in Stockholm or the south attached to the university.” (HCP, Sweden)

• **Access to multidisciplinary teams**

In all of the countries, multidisciplinary teams operated. However in relation to the last point, access varied greatly within the countries, with the healthcare professionals reporting it was “down to luck” where you lived in the country, as to whether or not the PwPs would have access to such a team. Rural areas reportedly had worse access.

Most of the multidisciplinary teams included a Parkinson’s nurse specialist, speech and language therapist, physiotherapist and an occupational health therapist. A nutritionist was also sometimes part of the team, however this was less common. In the Netherlands, sex therapists were often included within the teams, although such specialists were not mentioned by professionals from outside of the Netherlands.

For most of the countries, the team member who the healthcare professionals felt was missing and was much needed was a psychologist or psychiatrist. A few of the healthcare professionals stated that they had, until recently, had access to psychological services. However due to budget cuts, these services had been stopped altogether, or reduced substantially. Budget cuts also reportedly affected other healthcare professionals’ standard of work also.

“Physiotherapy has got worse in Sweden, I feel in the last few years. They used to get 1:1 sessions, however these days they are told what to do and left to their own devices to exercise.” (HCP, Sweden)

“Until the summer we had a psychologists. However there is no money to have on any more.” (HCP, Ireland)

The need for more PD nurse specialists was also frequently mentioned (particularly by neurologists), although professionals in the UK, Demark, Sweden or the Netherlands did not mention this.

“It would be better if we had more nurses. There are not too many nurses in Hungary, so this is quite a vain hope.” (HCP, Hungary)

“A broad coverage with PD nurses would improve the quality of life for patients enormously because they would create capacity, especially psychologically to deal with serious cases.” (HCP, Germany)

Coordination within the multidisciplinary teams was criticised by a few of the healthcare professionals (more by the PD nurse specialists and therapists, as opposed to the doctors). It was postulated that the lack of coordination between the members of the multidisciplinary team meant that case reviews were not done effectively (as a whole team) and also it could place a further burden on the carer to coordinate everything.

“I believe that PD specialists do not put enough effort in to sit together and come up with an multidisciplinary care scheme ...The system itself is structured in such a way that it is more worthwhile for each neurologist to work for himself...I do not believe that two PD experts would get along well long-term. This can only work for a university clinic where there is one boss who manages all other specialists. In a practice where everyone wants to be their own boss.” (HCP, Germany)

"You could create a lot more overlap instead of everyone working on their own island. For example, a neuropsychologist could have a conversation with the caregiver while I am working with the patient. Other healthcare professionals sometimes feel as if their toes have been stepped on if you raise certain issues. They believe that that is 'their site'." (HCP, Netherlands)

- **Access to specialised nursing homes, home visits and palliative care**

It was unclear if any nursing homes exclusively for PwPs existed (in a couple of the countries there was disagreement among the healthcare professionals whether they had them or not).

Interviewer: "Are their specialised nursing homes for PwPs in Sweden?"

HCP 1: "Yes, I think there is one in Stockholm, but only that one."

HCP 2: "No, there are none."

However, general nursing homes were seen as an area where much training and education was needed. Nearly all of the healthcare professionals asked, felt that nursing home staff did not know enough about Parkinson's and this resulted in poor management of medication. In nearly all of the countries, healthcare professionals started to run training courses (often very informally) in nursing homes. However, the high turnover of staff caused issues as they felt it was a "never ending problem" which needed extra resources to resolve.

"I often try and run training courses, but the changing staff and the shift patterns often makes things difficult [to train everyone]." (HCP, Sweden)

When the PD nurse specialist acted as a coordinator, if one of their PwPs was in a particular home, they would try and visit that home and explain what medication dosages were needed at what times. Again, the constant staff changes made this a time consuming task.

In relation to palliative care, the overwhelming feeling was that it was too cancer focused at the moment as it followed the cancer model.

"Palliative care in general used to be a disaster in Ireland, but it's getting better." (HCP, Ireland)

"It's not very good and it's not very easy to get in a hospice. That's why this project with home visits why set up and is growing, because of the need in the community and to try to get better in the palliative care." (HCP, Denmark)

"It's mainly for cancer patients and not as well organised for Parkinson's disease... There is a lot to be done on that." (HCP, France)

Some of the healthcare professionals would offer home visits (although this was less frequent in secondary care and more often in relation to therapists working at a community level).

"Patients only have access to GP's home visits. It's the GP's decision to visit the patient or the patients to visit them in the surgery." (HCP, Italy)

The healthcare professionals recognised the value of home visits to both the PwPs and their carer. Although it was acknowledged that home visits were time consuming and not always feasible with the workload. To compensate, often the healthcare professionals talked about giving out their phone number so that the PwPs and their carers would feel that they could be contacted if needed.

"They all have a number they can reach me on. But when they get to know is, they become reliant on you." (HCP, Ireland)

4.3.3. Carer involvement

- **Carer involvement and support**

On the whole, carers were actively encouraged to be involved and were welcomed at the consultations. However this was only if the PwPs wanted the carer to be present and involved.

"I always ask the carers' questions. I don't consult with carers alone, or very rarely, but if the carer is here [with the patient] I do pose questions so as to have an external opinion, not just what the patients tells me. But this is not compulsory. Support from the family is important. I always ask patients about their family. A supportive environment is very important." (HCP, Hungary)

"Caregivers, yes that is a must. We could not do it without them. If you do not get to see the caregiver, you will miss a part of the patient. I believe that if I would see no more caregivers, then I would no longer be able to deliver good care." (HCP, Netherlands)

"Carers need to understand Parkinson's as much as the person with Parkinson's does. They should be encouraged to be fully involved." (HCP, UK)

"Parkinson's is to be lived with the family and the carer, therefore the participation of the carers in the decisions is positive." (HCP, Spain)

Some of the healthcare professionals felt that, although the carers were present during consultations, they were not actively involved in the decision-making.

"Carers are not involved in any structural way in clinical decisions at the moment and I think this is a huge gap for health care. I think carers should be much more intensively involved in the decisions, but I can't say this is structural thing in the Netherlands in anyway." (HCP, Netherlands)

A few of the healthcare professionals felt that carers needed to be educated about their role and supported more effectively. It was acknowledged that the healthcare professionals focused predominantly on the PwPs, which could result in the carers needs being neglected.

"Mostly. I mean they come together with caregivers, seldom they come alone. You get a better picture of the patient's situation, the carers also need support, important that they get attention." (HCP, Germany)

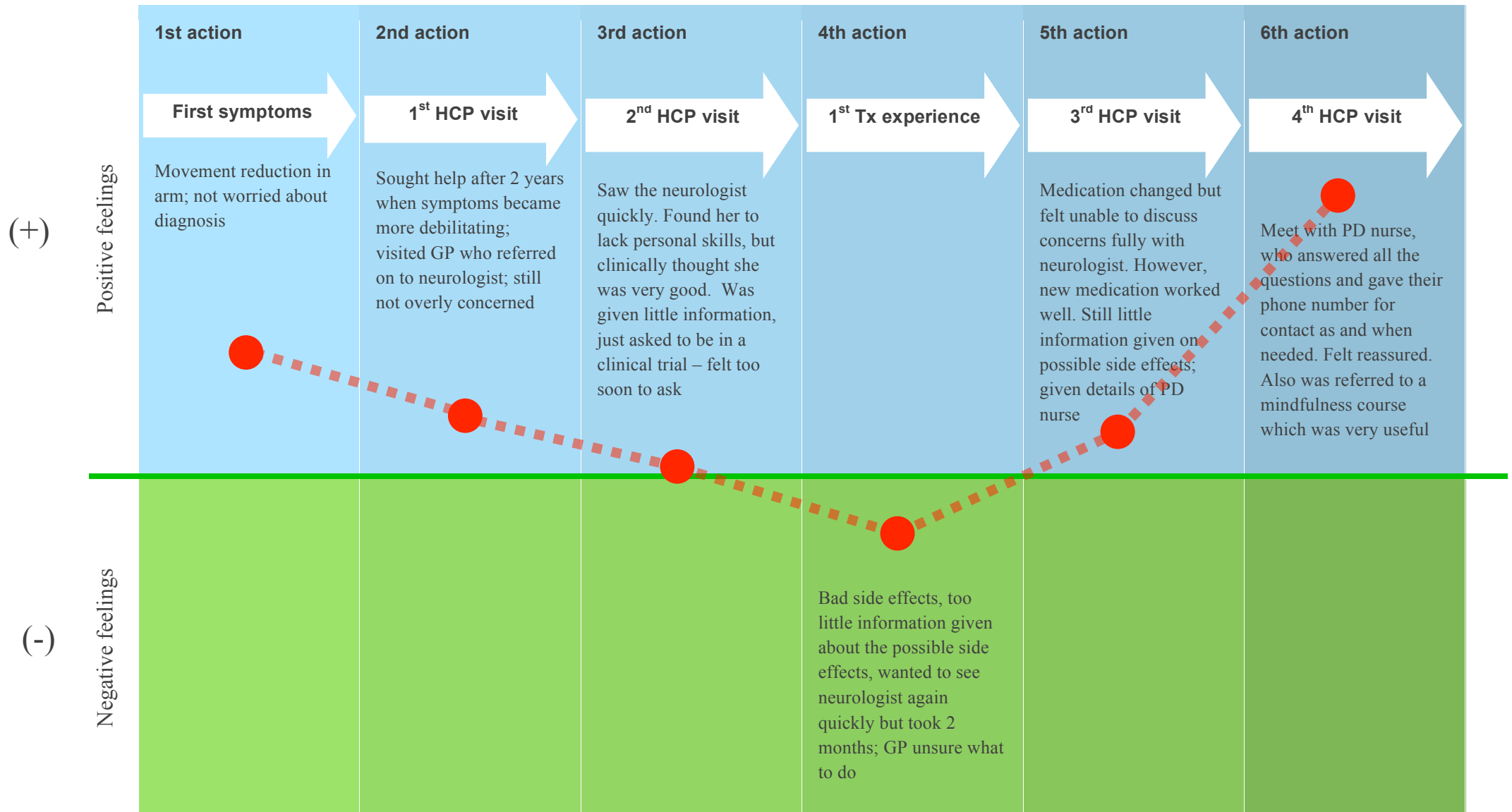
"It would be nice if something could be organised for the patient and the caregiver at the same time, because the caregiver cannot leave the patient alone. I also think that, in the future, volunteers and health care professionals should visit Parkinson's patients more often at home, so that the caregiver can take a break. Over the years of illness, the caregiver is also increasingly homebound." (HCP, Netherlands)

5. JOURNEY MAPPING

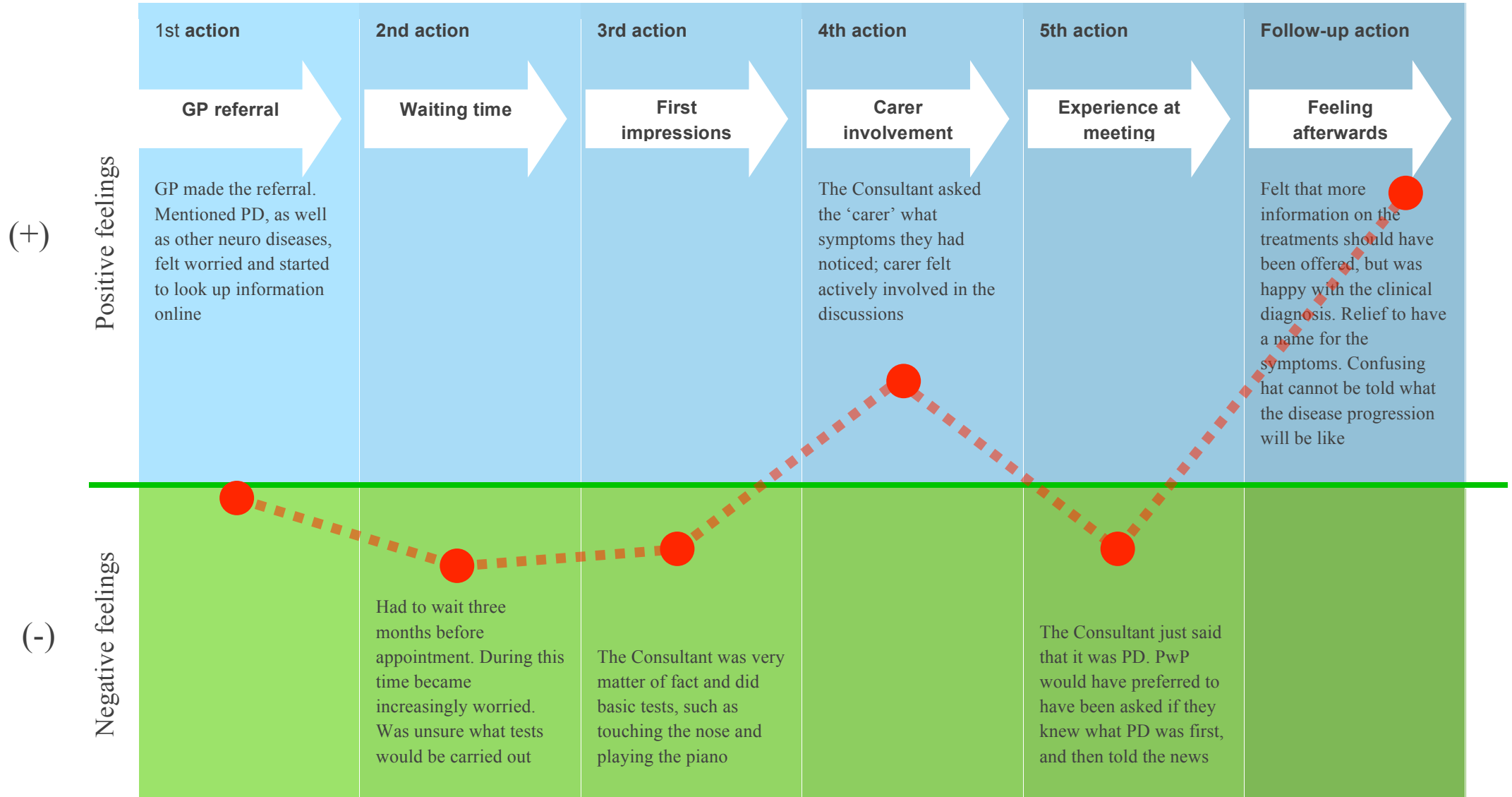
‘Journey mapping’ is a tool adapted from commercial marketing and is frequently used by the British National Health Service to understand a user’s experience of a service or product. For example, the a journey map might be developed to describe all the experiences a user has with a service or a number of services and the emotional responses they provoke – from their first impression of the building, to speaking to staff or receiving information. Journey mapping is a way to see a service from the user’s perspective in order to make recommendations for improvement that are customer-, or patient-, centred.

For this project, four journey maps have been developed, based on the findings from the qualitative interviews with PwPs. The experiences selected are common across the 11 countries. The journey maps allow for a visualisation of the experiences (which have already been described in Section Four).

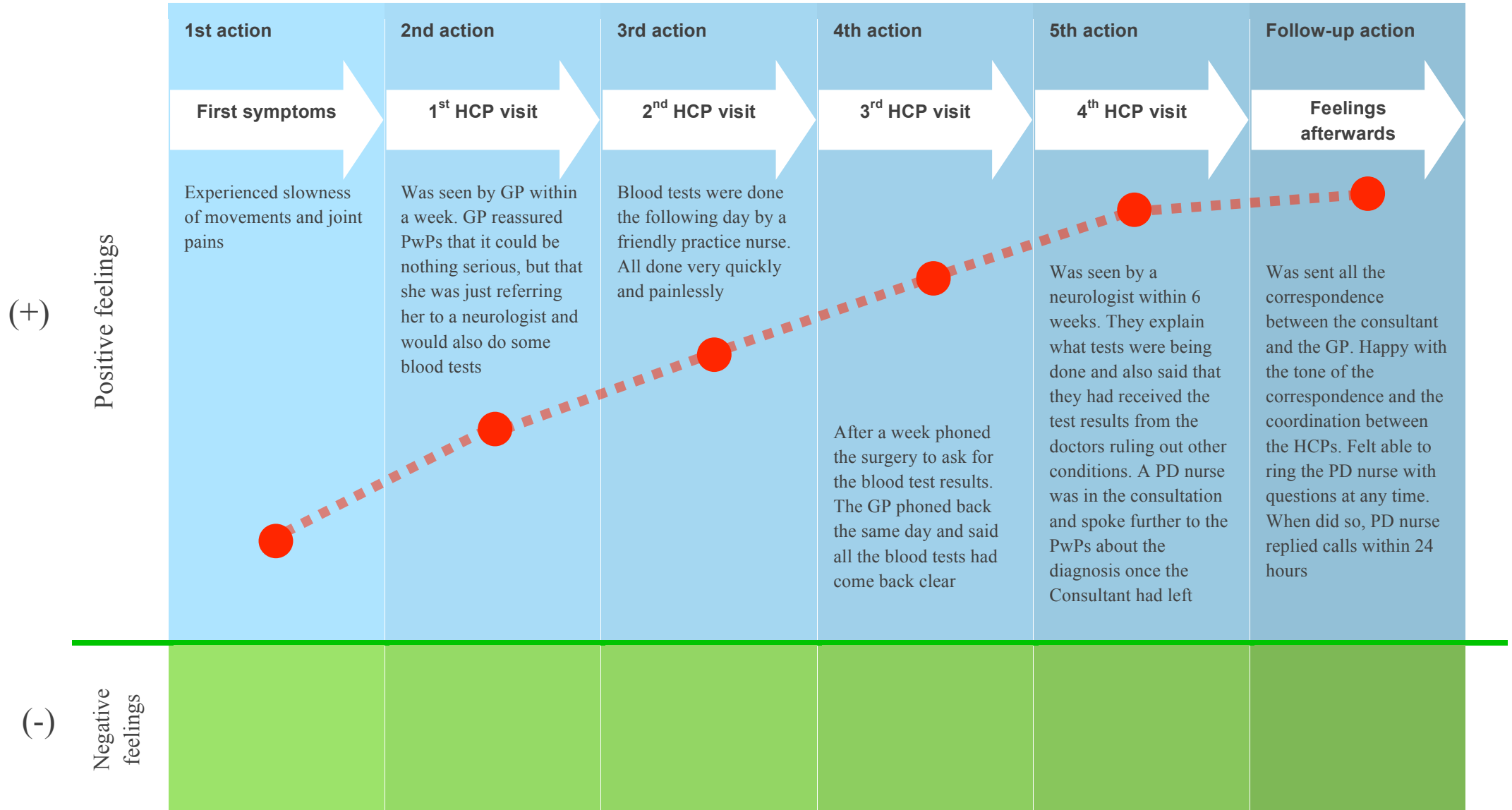
PwP journey map #1: From noticing first symptoms to receiving



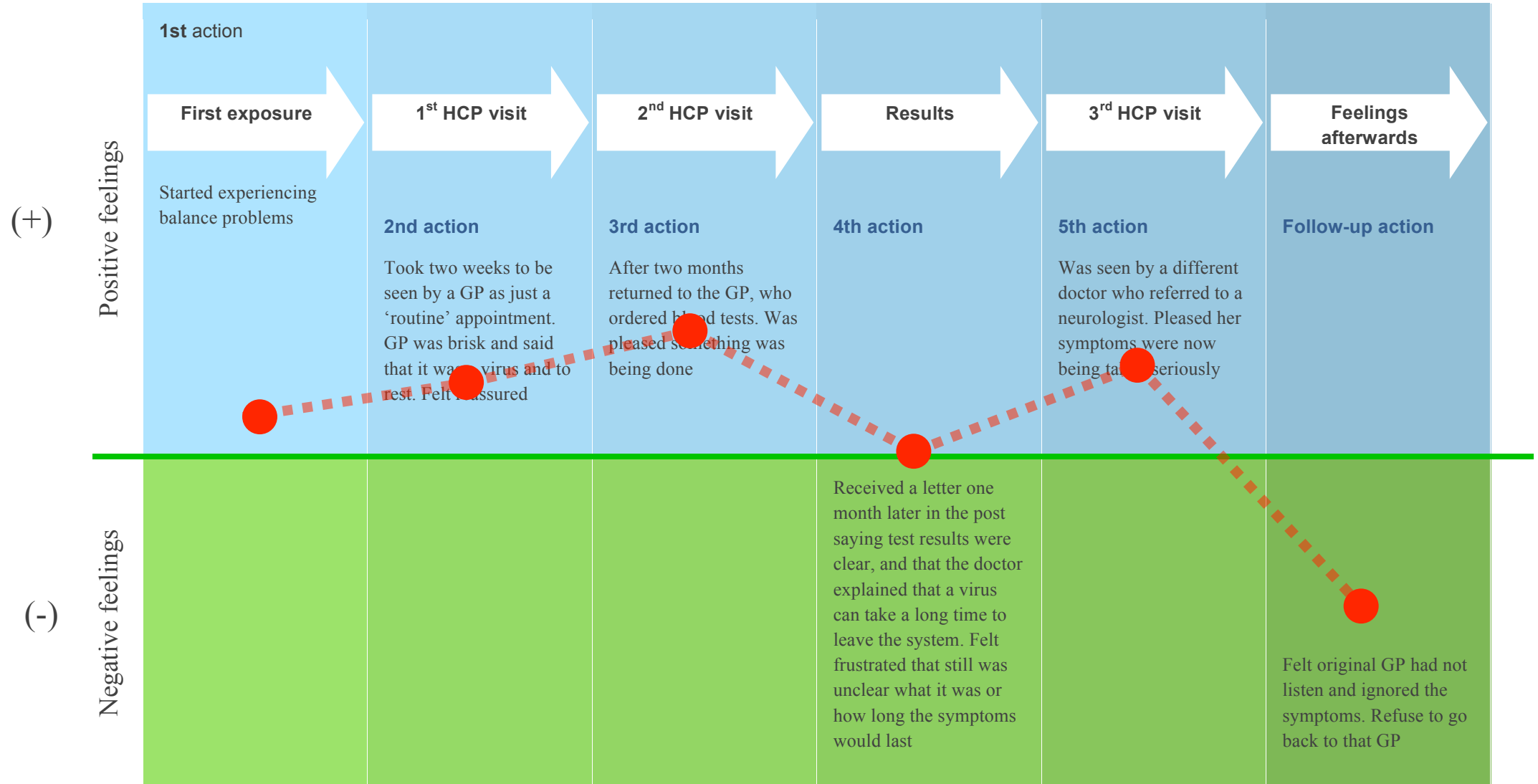
PwPs Journey Map #2: First appointment with neurologist



PwPs Journey Map #3: GP experience (positive)



PwPs Journey Map #4: GP experience (negative)



6. CASE STUDIES

Four short case studies have been identified for illustrative purposes. The case studies detail the experiences of PwPs. These experiences are similar for all of the eleven countries included in the study.

62, diagnosed at 59, works part-time at a university

"I had a dizzy spell at work...that was the first sign something was wrong. I booked an appointment with my GP almost immediately. I have been with the same GP for years and I think him to be excellent. He arranged for me to have some blood tests, to check for the basics such as glucose levels, that kind of thing. But he also referred me to see a neurologist. He explained that the waiting times in my area were sometimes up to six months, therefore he suggested that, if I could afford to do so, I went privately. I decided to take his advice and saw a Consultant within four weeks.

The neurologist took a full case history and was very thorough and arranged for me to have a brain scan. The first brain scan came back showing an anomaly. At this point I was petrified as I thought, this is it, I have cancer or some awful tumour and they are going to tell me I have three months to live. By the time you get to my age, it has happened to some of your friends. However when they investigated further, it was a small non-cancerous growth that was not affecting me in any way, so it was kind of a red herring.

It was arranged for me to see the neurologist again. It was then that he diagnosed me with Parkinson's. By this time my hand writing had deteriorated and I started to appear as if I was drunk sometimes, even though I rarely drink. My initial reaction was mixed. I had been for three brain scans at the specialist cancer clinic so I was prepared for a worse diagnosis. I was just relieved it was not cancer and he said I was not going to die from the Parkinson's. He said I would die with it, but not from it. So, as crazy as it sounds, in many ways it was a huge relief!

I can't really remember if I was given any information at diagnosis, except for the fact it had been diagnosed and that the neurologist said he can't predict how the PD would progress. He said my symptoms could become more pronounced but then they might not. Although I am the type of person who like lots of information, I'm fairly strict with myself on an issue such as this as I think too much information can be dangerous. So, although I do go on the Internet, I think we all do these days, I just look at official sites, such as the MAYO clinic's site. I avoid the discussion boards.

The neurologist is not easy to talk to, he is considered to be the best in the region. I am usually good at talking to people, but I did feel a bit intimidated to be honest. I feel as if I'm talking to someone who is heading up a research project...I joke to my family that I feel like a giant lab rat! I was referred for six sessions of physiotherapy and I found it helped a lot. Luckily my speech has not been affected.

I told my immediate family straight away. I debated about telling people at work. I decided to in the end; when one of my colleagues was diagnosed with Parkinson's, he didn't tell anyone and it became difficult for all of us. I worried about what people might think, if they started to think I could not do my job anymore, but sometimes I seem as if I am drunk so I would rather that they knew.

I think my GP is excellent...my appointments take 25 minutes; the other patients must hate me, as I think there is a great battle to see him! He always answers my questions and though he is not an expert on Parkinson's he has tried to learn more about it since he now has a few patients with it. However he leaves the medication up to my neurologist to prescribe. He will give me medication for the side effects though, he is the person who treats them."

47, housewife, diagnosed at 38

"I was diagnosed when I was 38. With hindsight, I had been experiencing symptoms for three years before I was actually told I had Parkinson's disease. The first symptom was a slight loss of power in my right arm, and then my right leg. I thought I must have just twisted it or something like that, however when it did not get any better, I went to see my GP. The GP thought I had a virus and told me just to rest. However, my right arm and leg became weaker so the GP referred me to physiotherapist. When that did not work, I finally changed GPs. By this time I had started to drool a bit also.

So after three years I went to see my new GP and he said, 'have you ever seen a neurologist?' And I said, 'no'. And he said, 'well you are going to see one now'. Within six weeks I was in a neurologist's office and she said she thought I had early Parkinson's'. However as I was young she wanted to send me for more tests, brain scans and different things but they all came back clear.

At first it was a relief that I had a name for it, after years of not knowing what was wrong with me, I now knew and when you know you can deal with it. Of course we went through all the emotions. Our three children were only young at the time and we did not know how we were going to cope. My husband and I had no idea what Parkinson's was, except for the tremor and I have never had that symptom. We went home and started to educate ourselves, mainly from information on the national Parkinson's association website.

My neurologist had been telling me how rare Parkinson's was, and maybe it is compared with other diseases that she might deal with, but I have met so many people now who are affected by the disease or have a family member who is. It makes me worry that Parkinson's is hereditary. However no one can really answer me when I ask if this is the case. I am of course worried for my children. I do not want them to have to experience this.

The neurologist is very cold; she is not a people's person at all! However I have been with the same one since my diagnosis and to be honest, things are a little better now. She does give me and my husband the opportunity to ask questions and explains why she has selected a particular medication and the possible side effects. I see her every six months now, although I saw her every three months for a year when I was having problems with the medication.

I have had a lot of physiotherapy which I have found helpful and I have a number that I can ring in case I have further problems and they will make an appointment for me to see the therapists again. I have also seen a dietician and I found her excellent. I think in time it would be useful for me to see an Occupational Therapist, however I am OK for now and the neurologist has told me that it is difficult to arrange an appointment with one due to the recent budget cuts.

I attend a local support group run by the national Parkinson's Association. They often have speakers; the other month they had a speech therapist and that was really interesting. The group is growing all the time and there are younger people coming to it now as well. I think it is important to remain active, that is one of the reasons why I attend the group; it gets me out of the house. Plus there is the social aspect to it. My husband attends the group with me as he gains a lot of information from going. He also goes to all of my appointments with the neurologist.

I try to walk as much as I can. After having Parkinson's for over a decade, attending the support group and hearing other people's stories and reading about the disease, the only thing I think that works for definite is exercise!"

57, part-time civil servant, diagnosed at 51

"My left hand started to look limp and I thought it must be a problem with the nerve. Then I went to stay with a friend and he told me that my left arm was not swinging when I walked and that I was dragging my left foot also. After that I went to see the local GP and whilst she is sometimes not the most helpful person, she referred me to see a neurologist immediately. The GP did mention Parkinson's, but she also mentioned MS. The Consultant was a nice man and very thorough. He sent me for some tests as he said the symptoms could be attached to a number of conditions. However, after ruling out other conditions, he diagnosed Parkinson's.

It was a complete shock as I was not expecting it at all; I thought only old people had Parkinson's. In hindsight I had been experiencing problems for over two years before I saw a doctor. I was the type of person who was never ill; I would maybe take an aspirin once every two years and I never needed antibiotics. I had also lost quite a bit of weight which on reflection was bought on by the condition.

The consultant told me that I should not go onto the internet and also not to tell people immediately as some people did not always react in a positive way. So I told my immediate family only. I did not tell my employer until I needed to reduce my hours which I ended up doing so within a year of diagnosis. I have to say the managers all reacted with kindness and consideration. They reassured me about the length of time I could work for.

The day I was diagnosed I was sent home with a prescription for medication. I had not been warned about the possible side effects. The first week was fine as I was on a lower dose, but the second week was horrific. I live by myself and I thought I was going to die as the medication started to affect my blood pressure dramatically. I was then put on a range of other medications, none of which worked. I would definitely say I was over medicated and medicated too quickly. I also came to the conclusion that it is all guess work, and that there is not one medication that works for everyone with the disease.

After three or four years of them experimenting with different medications, I was admitted to hospital and taken off everything. At that time I was also referred to a more experienced neurologist who specialises in Parkinson's. He said he would try one more drug and if that didn't work then he would consider Deep Brain Stimulation. I did not like the sound of that, but I trusted the new neurologist and my movement had been deteriorating – I started to just freeze a lot.

Eighteen months ago I had the operation. I was in hospital for about two weeks. I am happy with the results, although I think my sister thought I would be back to normal, all Parkinson's symptoms gone. However this is sadly not the case.

I have managed to attend a couple of speech therapy sessions which has also been very helpful. It has taught me how to project my voice more, add volume to my speech.

I still manage to go out with friends, although I am starting to feel more isolated as I do not like eating in public. I am also worried about what the future holds for me. As I never married and have no children, what will happen if I deteriorate further? I am thinking of moving to the capital city as that is where my sister lives and there seems to be much better provisions for people with Parkinson's there. It's rather hit and miss in my little town. Travelling by bus will also be easier there, as we only a few buses here and I cannot drive any more.

I thought about joining a self-help group, but I imagine only old people go who are a lot further down the line with their Parkinson's than I. I think it would be rather depressing."

74, retired; diagnosed at 72

"In 2012, we had a small house fire and after that I started to notice something was wrong. My wife did also. My walking seemed slower and less certain. I also felt that I was more inclined to slobber. However, at first we just thought it was the stress of all the builders coming into the house each day and having to deal with the insurance companies. We then thought that it might have been a minor stroke. I visited the doctor and he tested my blood ruling out a stroke. We then attributed the symptoms to arthritis which has affected other members of my family.

However, we then noted that my handwriting had become very small and my hands were very swollen and red. I also was having difficulty doing some everyday things, such as doing up buttons. My family encouraged me to go and see my GP again. I had to wait a week before I managed to get an appointment and the doctor told me that I had to make allowances for the aging process. However he decided to refer me to a neurologist at the local hospital for a second opinion.

It was about 8 weeks until I saw the consultant. Within five minutes he told me that I had what he described as a mild case of Parkinson's. I found the consultant most reassuring; he told me that the condition was not life threatening nor life shortening.

At that initial appointment I was told of the range of medical treatments available. I was also warned that most drugs lose their effectiveness over time. I saw the GP shortly thereafter and discussed the options. I asked what the side effects were for the suggested drug. The GP consulted the screen and read off a list of horrifying proportions. This included a possible impact on my mental faculties. Since my father had suffered from Alzheimer's disease, this caused me much concern. I decided not to start medication straight away first as I wanted to prolong the efficacy of the drug and secondly, I feared the possible side-effects. However after a further three months or so, I started on the medication because I felt that my gait was deteriorating. I was lucky and the drug did not seem to have bad side effects for me.

My life style has not been much affected. I continue to be active walking our dogs each day for an hour or so. Visits to contribute to grandchild care have not been lessened and I still do some consultancy work to keep my brain active. I am conscious that I have slowed down and this is often the cause of frustration. I do find it difficult to eat out with friends since I eat even more slowly than I used to do. I do not broadcast my problem but on the whole people are very tolerant whether they know or not. Although there are inevitably periods when I curse Parkinson's, it could be so much worse."

7. CONCLUSION AND RECOMMENDATIONS

By combining both quantitative and qualitative research methods within this study, it has been possible to identify many of gaps that are existing in Parkinson's care and management across Europe. The findings allow us to paint a more complete picture of what is happening, variability within the countries involved as well as differences between the countries, and obtain some understanding into *why* such gaps exist. Our findings also provide some insights to the clinical and emotional impact on both the PwP and their carer (described in their own words).

Additionally, by employing different data collection methods, together with collecting data from different sources (from PwPs, carers and healthcare professionals), we have been able to triangulate the findings adding greater validity to the results detailed in this report.

7.1. Key insights

A number of key insights were identified by this study. The insights detailed below were consistent across the eleven included counties.

1. *Informational needs*

Although PwPs and carers wanted to know the basic prognosis (*i.e.* 'Will I die from Parkinson's or will it shorten my life? What will be the probable effect on me physically?' etc) and were eager for possible side effects of their medication to be clearly explained, in-depth information about what could possibly happen in the future was inadequate. When the diagnosis is given, most people reported being in shock, and subsequently could not often remember what information they had been given during their initial appointment.

At that moment in time, it is important to reassure PwPs and their carers that Parkinson's is not a terminal illness. However, unless specially asked, further information about treatment options and self-help should be given at the next appointment (which should be within two weeks – ideally the following day - to avoid anxiety for the PwPs and their family or carer). A Parkinson's disease nurse specialists could lead the follow-up appointment.

Most patients would prefer for a follow-up appointment to be arranged (within a week) to discuss all the medication options and possible side effects, in addition to symptom management.

The information that is given out by healthcare professionals should also be patient and carer-led (with the acknowledgement that PwPs and their carers may want different types and/or amounts of information so this needs to be handled sensitively). The healthcare professionals should start by asking the PwPs what they currently know about the disease, and what type of information would be useful for them at that time point. This recommendation is in line with the UK's NICE guidelines which state that PwPs should have the opportunity to make informed decisions about their care and treatment and that evidence-based information should be offered in a form that is tailored to the needs of the individual patient (further details of the NICE guidelines are provided in the secondary review report)³².

2. *The role of Parkinson's disease nurse specialists (PDNS)*

The highest satisfaction rating was indicated where a PDNS acted as a disease coordinator. PwPs appreciated the PDNS fulfilling such a role as they often found the nurse easier to talk to, and were more available than neurologists to take their calls.

By increasing the number of PDNSs, this should increase the number of home visits and support that can be given to PwPs and their carers living in the more rural areas/areas where there is reduced access to

³² Accessed March 2015: National Institute for Health and Care Excellence - www.nice.org.uk/guidance/cg035

health services. However, it is acknowledged that shortages in therapists working in those areas, which specialise in Parkinson's, will still remain.

Parkinson's nurse specialist should attend consultations between the PwPs and the neurologist and then act as the main coordinator or bridge between the neurologist and PwP, ensuring that the PwP's medication is reviewed when necessary and that they have access to the therapy they need. The PDNS could also be responsible for communications between the different healthcare professionals (both in primary and secondary care/private and public sectors). However, in order to fulfil this role, greater administrative support would be needed.

The PDNS could utilise the tools used by the Netherland's Parkinson Centre, Nijmegen (or similar tools). At Nijmegen they routinely invite their patients to prioritise their own 'top five' complaints. Because this prioritisation is done before the actual visit to their centre, they can adjust the composition of the team according to the unique needs of each patient. This client-centred approach can be used to reduce the amount of time spent on redundant issues and focus on the priorities at that time point.

Specific PDNSs could also be the official link to hospital wards where PwPs are most frequently admitted, for example, orthopaedics, as well as nursing homes where it is known that they have a PwPs. In countries where there are few PDNSs, training and recruitment campaigns are needed to ensure that the workload is manageable for the nurses. Another possibility is that the nurse specialists act as a resource for more general nurses, or in countries where there are no PDNSs, the possibility of junior doctors fulfilling the same role could be explored.

3. ***Lack of communication between primary and secondary care***

A frequent cause of complaint was the lack of communication between the multidisciplinary team members, and communication between the primary and secondary care sectors.

France's National Plan for Neurodegenerative Disease 2014-2019³³ highlights the importance of improved coordination between healthcare professionals. A collaborative treatment programme is recommended in the Plan with the GP liaising regularly with the neurologist.

Related to this, a number of countries have developed interventions to enhance self-management. There is a strong evidence base to support self-management, and past studies have shown that empowering patients to self-manage improves self-efficacy, quality of life, treatment compliance and satisfaction³⁴. Whilst the PDNS can act as a 'link' to the various hospital departments (which this research found is already being done effectively in certain hospitals across Europe), PwPs can also be empowered to keep their own health records or records of their on-going treatment. Therefore if they are admitted to another department or centre, they can take the records with them.

In Russia for example, as soon as a PwP receives a diagnosis, a *Patient Card* is opened. The card contains all the data from the initial appointment where diagnosis was made, with detailed information indicating disease/symptom severity, duration, and rate of progression. If treatment is received, the card is updated to include detail of prescribed medication, dosage, when these must be taken, duration of treatment, and effectiveness of the treatment.

³³ Accessed March 2015: www.social-sante.gouv.fr/actualite-presse,42/communiqués,2322/une-nouvelle-dynamique-engagée-en,17511.html

³⁴ van der Marck, M. A., & Bloem, B. R. (2014). How to organize multispeciality care for patients with Parkinson's disease. *Parkinsonism and Related Disorders*, 20S1, S167-173.

4. ***Benefits of support groups and learning self-help techniques***

Support groups were seen as a wonderful social outlet for many of the PwPs who attended them; for the carers, the groups were more about gaining information. It is interesting to note that although many of the carers enjoyed attending the groups, they also felt there was no place where they could express their own frustrations and concerns, or speak freely during the meetings because the specific Parkinson's groups focused predominantly on the PwPs' needs. However, both the carers and PwPs found the advice provided by the support groups very helpful in relation to developing their own self-help techniques.

5. ***Lack of knowledge in relation to Parkinson's symptoms***

General practitioners did not always suspect Parkinson's when a patient displayed a tremor or other motor symptom. Additionally, if the person affected was young and/or did not have a tremor, they often delayed asking for help.

6. ***Role of general practitioners***

The general practitioners interviewed freely admitted that, due to the limited number of PwPs attending their surgeries, they were not experts in the disease. However, this reinforced the view of other, more specialised, healthcare professionals who did not feel that it would be a good use of resources to train general practitioners in Parkinson's, as they did not see sufficient numbers of PwPs for this training to be productive. It was suggested that more education should be focused at the PwPs and carers themselves so that they become more informed and better able to articulate the symptoms and side effects more effectively.

7. ***Support for professionals working in nursing homes and general hospital wards***

Many healthcare professionals highlighted that huge improvements are needed in the way PwPs' medications are administered in both nursing homes and hospital wards. Although training to address this issue was on-going in many of the included countries, more work was reportedly necessary.

8. ***Regional variability***

From the qualitative interviews, it was reported that access to care and support outside of the main cities was greatly reduced. Even in countries where healthcare professionals considered Parkinson's facilities to be some of the best in the world, there were still issues with patients accessing specialised healthcare practitioners (including clinical professionals and therapists).

9. ***Patient satisfaction and quality of life:***

The survey revealed that the more frequently people with Parkinson's had their medication reviewed, the greater their satisfaction became. However, it should be noted that although respondents may report high levels of satisfaction with care, this does not necessarily equate to improved quality of life.

10. ***Using new technology to monitor health and support the management of the condition:***

During this study, many of the health professionals stated that Parkinson's is a chronic disease and therefore lessons can be learnt by reviewing interventions from other chronic diseases where there has been more research and investment due to the higher number of people affected.

This study found that PwPs, when experiencing side effects caused by their medication (which could sometimes result in poor adherence rates), often had to wait more than a month in order to be able to see their consultant and discuss the problems they were experiencing. That is one of the reasons why the PwPs and their carers valued PDNSs as they felt they were very approachable and that they were able to contact them to discuss any concerns or if the symptoms/side effects from the medication worsen. However, at the same time, there was also concern expressed in relation to the communication and coordination between the different healthcare professionals.

New technologies have been used in the case of other chronic diseases to help address similar problems. For example, for the management of bipolar disorder, the University of Oxford developed an intervention called TrueColours. The technology enables people to monitor their health by texting or emailing answers to simple health-related questions. Answers are recorded on a display that may be viewed online and printed out both by participants and all members of their care team. The system is sensitive enough to help identify even small changes in health and wellbeing for a wide range of different conditions, from post-operative quality-of-life to long-term mood disorders. This then enables the consultants and HCPs to determine if more regular appointments are needed, and also where an appointment is urgently needed.³⁵

Similar to TrueColours, an intervention funded by the European Commission is currently in the development and trial phase, to support the management of patients with Parkinson's disease. As well as continued monitoring of the disease and patient adherence to treatments, the electronic tool will support self-help techniques, for example, by allowing PwPs to try game-based physiotherapy at home and provide personalised suggestions for an optimal Parkinson's management plan³⁶.

The use of such technology could also support consultants and HCPs, when they are reviewing the diagnosis, which is a recommendation of the NICE guidelines from the UK³⁷.

Some interventions have already been developed and are currently being piloted or have been piloted recently. For example, Italian researchers have carried out studies to determine if home-based training with Nintendo Wii Fit and balance board could be an effective self-management tool for people living with Parkinson's. And in the UK, "myHealthPal" has been designed to help people manage their Parkinson's. Key features include the 'CareCircle' that is similar to Facebook in that users develop their own profile. CareCircle friends only see the specific information you allow them to see. Medication, tests, exercise, and sleep to be automatically captured, logged, analysed and shared among members of your CareCircle.

Of course, PwPs are not a homogenous group and therefore different tools and interventions will appeal more to different subsets. However by being able to offer PwPs a suite of tools/interventions and taking the time to discuss the options with the PwP, this will help to encourage and empower them to take action. Involving carers and encouraging them to use the tools and interventions will also help to sustain the behaviour change.

7.2. Recommendations

The recommendations below follow analysis of the European inventory findings as carried out by the My PD Journey multi-stakeholder coalition in addressing the key insights from the findings. The recommendations can be applied within a national or regional setting to effect improvements in the management of Parkinson's and, at the same time, offer potential socio-and health economic benefits to healthcare systems, Parkinson's care pathways, people with Parkinson's, their families and carers.

1. People with Parkinson's should receive a **personalised approach to treatment and care** – one that is tailored to individual needs and preferences.
2. **People with Parkinson's should have access to – and be referred within six months to – appropriate healthcare professionals with a specialty in Parkinson's.** This should apply both to the diagnosis (by a neurologist or doctor with a special interest in Parkinson's) as well as the continued management and review of the disease (by a multidisciplinary team of experts).

³⁵ Accessed January 2015: <http://oxtext.psych.ox.ac.uk/true-colours>

³⁶ <http://www.parkinson-manager.eu> Accessed: March 2015

³⁷ Accessed March 2015: National Institute for Health and Care Excellence - www.nice.org.uk/guidance/cg035

3. **People with Parkinson's and their carers should have access to a Parkinson's disease healthcare professional who is trained to monitor and manage the disease progression**, be a continuing point of contact for support (including home visits) when appropriate, and provide a reliable source of information about clinical and social issues.
4. It is essential that **coordination and communication between primary and secondary healthcare professionals is significantly improved and monitoring methods be developed**. This will ensure people with Parkinson's care plans remain consistent, regular and cohesive, resulting in their individual needs and preferences being met;
5. **Improved training about Parkinson's for professionals** working in nursing homes and general hospital wards is essential.
6. People with Parkinson's and their carers should have the **opportunity to ask for – and receive – all relevant information concerning the management and treatment of their disease**, enabling them to make informed decisions. In particular, patients should be able to request:
 - an appointment with a healthcare professional within two week of their initial diagnosis (if possible)
 - information on relevant support organisations and services.

In relation to the recommendations, the following considerations are noted:

1. It is acknowledged that different health systems exist across Europe and treatments for Parkinson's patients is funded in different ways (for example, state funded, insurance, private etc.); therefore these recommendations should be adapted and refined to fit the national healthcare environment.
2. The shortage of neurologists specialising in Parkinson's across Europe and further afield, is well documented. As a consequence, patients can wait up to six months before seeing a neurologist and consultations may occur less often than is recommended. However, the current economic climate and austerity measures facing most countries in Europe, added to a skills shortfall, a recommendation to increase the number of neurologists specialising in Parkinson's is considered to be unrealistic in the short term.
3. During this study, the research team were informed about a number of training programmes that are currently operating in many of the European countries involved in the study. These training programmes are working specifically with physiotherapists, although work is also been done with other therapists, such as speech and language.

This study found that keeping physically and mentally active was considered an effective 'treatment' (as perceived by the PwPs and often also their carers) and this finding is supported by various guidelines; for example, the national guidelines for Italy recommend exercise to improve quality of life³⁸. Therefore tools and interventions to help motivate people to stay active and build it into their daily routine so it becomes a habit are needed. In light of the work that is already being done, rather than be a recommendation in its own right, we would advocate that the national associations, in collaboration with the healthcare professionals, carry out additional work to promote self-help interventions.

4. Many of the recommendations favour enhancing the role of the Parkinson's nurse specialist. Although there is strong evidence to support recommendations to use Parkinson's nurse specialists, and it is well documented by other studies, the status of the Parkinson's nurse specialist is not recognised in many countries across Europe and the role remains inconsistent. It has been questioned whether using specialist nurses is part of the solution or part of the problem due to the shortages of nurses which is being experienced across Europe³⁹. However, studies have shown that those PwPs who are cared for by a nurse specialist have an improved subjective outcome, without any negative impact on clinical outcomes⁴⁰. In addition to this, our study shows that PwPs and their carers value the support given by Parkinson's nurse specialists, as long as they feel the nurse is working closely with the neurologist (as they may trust the clinical judgment of the neurologist, despite not being able often to talk openly to them).
5. Examples of good practices, identified through the review of the secondary evidence¹, have also been used to support some of the recommendations.
6. Cultural considerations need be taken into account and therefore any recommendations should be adapted to take this into consideration.
7. Finally, although a few of these recommendations might appear to be 'common sense' to those professionals who have dedicated their career to supporting PwPs, this study shows that the level of care and consideration for the patients' wellbeing varies greatly and that a more patient-centred approach to care and information giving is needed.

³⁸ Accessed March 2015: www.snlg-iss.it/cms/files/LGParkinson-web-agosto2013_0.pdf

³⁹ Kale, R & Menken M. Who should look after people with Parkinson's disease? BMJ. Jan 10, 2004; 328(7431): 62–63.

⁴⁰ Jarman B, Hurwitz B, Cook A, Bajekal M, Lee A. Effects of community based nurses specialising in Parkinson's disease on health outcome and costs: randomised controlled trial. BMJ 2002;324: 1072.

7.1. Research limitations

As with all research studies, there were limitations that should be noted.

In relation to the primary research survey, a number of limitations should be highlighted:

- The sample was self-selecting, potentially resulting in sample-bias
- Whilst internet-based recruitment provides access to a targeted sample in an effective way, Internet users may be limited to people who are possibly better educated and proactive. They may also be younger population, which might account for the young age of the sample in this study.
- Although the survey was only for PwPs, where the PwP was unable to complete the survey by themselves, their carers were encouraged to do this with them. However, within this study, the actual numbers of PwP who completed the survey with the help of carer is unknown.
- During the qualitative in-depth interviews, participants were encouraged to discuss other Parkinson's related health problems they were experiencing but the survey did not ask about other issues, for example diabetes, hypertension, etc. which might have affected their quality of life score.
- The survey questions often required respondents to think back over a long period of time, to when they were first diagnosed, etc. Whereas for some PwP this was a relatively recent, for others this event occurred more than 10 years ago. The findings in relation to such questions therefore may not be an accurate portrayal of events. This also applies to a number of the questions asked in the qualitative interviews.

In relation to the sampling for the in-depth qualitative interviews, as with the survey, the participants were self-selecting and often actively involved in their national Parkinson's Association. This can again potentially introduce bias in the sample. However, wherever feasible, the research team made great effort to try and recruit participants who were not actively involved in their national Parkinson's association, and healthcare professionals who were not known to the EPDA or the national body. Reassuringly, the findings for the PwP and carer interviews were consistent, whether they had been recruited through the national Parkinson's association or through another channel.

Initially, interviews with policy makers, senior civil servants/ministers, and funders were proposed. Whilst carrying out such interviews would have added strength to the project findings, budget constraints meant that this was not possible. However, it has been recognised as a potential area for future research as part of the overall programme of work for My PD Journey.

Finally, with Grounded Theory, the number of in-depth interviews to be conducted should not be pre-determined and that recruitment should continue until *data saturation* is reached (the point at which no new themes are identified and the emergent theory appears complete). However, due to the number of countries included in the project coupled with time constraints, for this study the number of research participants to be interviewed was agreed before the study commenced. Nevertheless, it was of particular note, and unusual given the number of countries included in the study, that many of the final themes were evident in the early stages of the interviewing process. Therefore data saturation was reached early and after the first wave of interviews, and further interviews were conducted to ensure the initial summation was accurate.