

Move for Change Part III: a European survey evaluating the impact of the EPDA Charter for People with Parkinson's Disease

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Background and purpose: Move for Change is an online pan-European patient survey based on the European Parkinson's Disease Association (EPDA) Charter for People with Parkinson's Disease (PD), which states that all PD patients have the right to: be referred to a doctor with a specialist interest in PD; receive an accurate diagnosis; have access to support services; receive continuous care; and take part in managing their illness.

Methods: This part of the survey focuses on the final two elements of the Charter. It was administered online through the EPDA website and through affiliated patient associations' websites. A total of 1591 questionnaires were received and 1546 were analysed (97.2%).

Results: Approximately half of the patients (53.0%) consulted a neurologist regularly (every 4–6 months). Consultations were usually arranged as part of a follow-up process (65.5%) and lasted for 15–30 min (63.2%), with 16.1% lasting <10 min and 17.9% lasting >30 min. Patients were largely satisfied with the attention they received (63.2%) but just 11.6% of patients were involved in treatment decisions, and 39.1% prepared a list of symptom changes for discussion. Two hundred caregivers also took part in the survey, and 71.4% felt included in the treatment plan by the doctor.

Conclusions: These results highlight that PD disease-management is driven by the clinician; he/she arranges consultations and makes the majority of management decisions, rather than patients being included in the process. This survey can be used to raise awareness for PD patients, encouraging greater involvement in the management of PD.

Introduction

It is estimated that ~1.2 million people in Europe have Parkinson's disease (PD) [1]. The neurodegenerative nature of the disease can lead to a greatly diminished quality of life [2–4]. PD has a high socioeconomic burden, estimated to be €13.9 billion across Europe and expected to worsen due to the increased risk of PD in our aging population [5–8].

The *Charter for People with Parkinson's Disease* was launched by the European Parkinson's Disease Association (EPDA), with the World Health Organization, in 1997 as part of its campaign against PD [9]. To understand the disease management approach for PD across Europe, and to evaluate the influence that

the Charter has had since it was introduced, the Move for Change campaign was launched in 2010; a series of three pan-European surveys were devised to identify the highs and lows of PD treatment and to evaluate the quality of disease management from the patients' perspective [10].

Part I of the survey focused on the first two statements of the Charter: all PD patients have the right to be referred to a doctor with a specialist interest in PD and to receive an accurate diagnosis. Over 2000 completed questionnaires from 35 European countries were summarized [11], and the results indicated that only 11.9% of respondents had received their initial diagnosis from a doctor specializing in PD, 43.8% of the respondents had not received a consultation from a doctor specializing in PD in the 2 years following diagnosis, and almost half of the respondents were dissatisfied with the manner in which their diagnosis had been delivered. Part II of the survey focused on

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access to support services, based on a comparable data set of 1752 questionnaires from 32 European countries [12]. These data identified that PD patients most commonly have access to general practitioners (GPs; 87.0%) and neurologists (90.0%), but less so to a doctor specializing in PD (68.0%). GPs were highlighted to be 'very helpful' by only 35.6% of patients, which was concerning considering they were one of the most accessible healthcare professionals (HCPs).

The European Parkinson's Disease Standards of Care Consensus Statement, Volume I [11], has been developed by the EPDA and a multidisciplinary team of HCPs, Parkinson's specialists, patients and their caregivers to demonstrate the standards of care that PD patients should receive throughout Europe. This document is used in conjunction with the Move for Change survey results to lobby for the standardization of Parkinson's care across Europe and was presented to Members of the European Parliament in November 2011.

This paper presents the findings of the final part of the Move for Change campaign, which was available for online completion in 2012, and which focuses on the final two parts of the Charter, i.e. 'all patients have the right to receive continuous care' and 'to take part in the management of their illness'. This survey asked participants to indicate how often they had consultations with various HCPs and how involved they had been in decisions regarding their disease management. Evidence suggests that patients who are actively involved in decisions regarding their disease management are more satisfied with the decided methods than those who are less involved in the decision [14]. Additionally, by involving patients in the decision-making process, better outcomes can be achieved at a reduced cost [15]. Interestingly, it is the involvement in the process rather than making the final decision which demonstrates the most benefit for patients [16]. Patients with PD are no exception, and a recent survey revealed a strong desire amongst patients to be involved in shared decision making [17].

Now that the Move for Change campaign is complete, the data from all three surveys will be used by the EPDA to demonstrate the unmet need in PD across Europe and to lobby for change, highlighting the areas of disease management that must be altered in order to ensure that the rights of the Charter are met across Europe. In addition, the complete survey data set will allow for intra-country analyses and help PD organizations and HCPs in different countries to lobby for change based on the benefits shown in other countries.

Methods

The Move for Change Part III survey was launched online on 12 April 2012 in conjunction with the European Parkinson's Action Day and ran until 31 December 2012. Measures taken to aid promotion of this survey included: translated website banners; advertisements in quarterly Member Organizations' (MOs') national journals and external journals; emails from MOs to their members; and promotion by the EPDA.

The survey complied with the Code of Conduct for pharmaceutical market research of the European Pharmaceutical Market Research Association and no adverse events were reported. Approval from the Clinical Research Ethics Committee or Independent Review Board was not required because drug therapy was not addressed. The methods used for Part III of this survey have been published previously [11].

The survey

The survey consisted of 19 questions covering: patient demographics; regularity of PD patient consultations with various HCPs; duration that PD patients have to wait to arrange a consultation; the involvement of PD patients in treatment and management decisions; and the level of PD patient preparation before a consultation. Translated into 24 languages by the local PD organizations, the survey was completed in local language. The complete questionnaire is included as an online supplement to this manuscript of volume II [12].

Results

Assimilation of questionnaire information

A total of 1591 forms were received from patients in 30 different countries, and 1546 (97.2%) were analysed. This is comparable to Part I of the survey (2149 received, 96.2% analysed [11]) and to Part II (1786 received, 98.1% analysed [12]). The remaining 45 questionnaires were rejected largely due to unanswered questions. Although results from countries with less than eight respondents (i.e. $\leq 0.5\%$ of the total survey sample) were included in regional- and European-level analyses, data from these countries were not analysed at an individual country level. A full analysis report can be accessed on the EPDA website at <http://www.epda.eu.com/en/projects/move-for-change/part-3/> [18] which demonstrates a considerable variation across Europe. It is important to note that data reported at a European level are not representative of the current situation in individual countries.

Demographics

Of the 1546 questionnaires analysed: 50.7% were from men; the most common age group was 60–69 years (35.9%); and the age of respondents ranged from <30 years (0.4%) to ≥80 years (4.5%). Only 1.1% of patients were diagnosed before 1986, whilst 77.6% were diagnosed from 2006 to 2012; the median disease duration was 3 years (2006–2012). Table 1 shows the regional distribution and demographic data for respondents.

HCP consultation details

Figure 1 demonstrates the regularity with which patients consult various clinical and allied health services, 53.0% of patients indicating they attended consultations with a neurologist and 40.9% consulting their GP on a 4- to 6-monthly basis. Unfortunately it is not known whether these patients went on to have a follow-up appointment with a neurologist as this question was not raised within the survey. Additional data have been provided in Fig. S1 in Volume I [11] to show the frequency of consultations compared with duration of disease; patients with shorter disease duration consulted HCPs on a more regular basis than those with longer duration. For patients with the most advanced PD (diagnosis before 1980) the neurologist and GP are still the most frequently consulted HCPs, with at least 4-monthly consultations indicated by 37.5%.

Other clinical HCPs visited every 4–6 months were a neurologist specializing in PD (25.1%), a hospital doctor (19.5%) and a PD specialist nurse (14.2%). For the allied services, the physiotherapist was consulted on a weekly or monthly basis by 40.1% of

patients; this was three-fold more than the percentage of patients consulting a neurologist at the same regularity. The time taken to arrange a consultation with a GP (69.5%) or physiotherapist (38.7%) was less than 2 weeks.

Figure 2 shows that most consultations were arranged as part of a routine follow-up process (65.5%), with only 12.9% indicating that a consultation was arranged because medication was ineffective or because of a change in symptoms (11.9%). The trend in clinical consultation duration across Europe is 15–30 min (63.2%); 79.3% of these patients indicated they had received adequate attention, whilst 17.2% felt rushed. An additional 17.9% of patients stated that clinical consultations with a doctor (GP, hospital doctor or neurologist) lasted more than 30 min, and 92.8% of these felt that the time was adequate for their requirements.

When asked how they prepared for their HCP consultations, 62.4% prepared a list of questions to take to the consultations and only 39.1% wrote a list of symptom changes to discuss with the HCP. Just 10.7% took notes when discussing points during the consultation.

Disease management decisions

Figure 3 shows that only 11.6% of patients made treatment-related decisions on their own, with most (50.6%) making the decision with the HCP. However, 34.2% were uninvolved with decisions relating to their treatment. Decisions relating to further disease management, however, showed 37.5% made a collaborative decision with the HCP, compared with 28.4% who were uninvolved in the decisions and 14.4% who

Table 1 Geographical region distribution of respondents

	Mean gender ^a		Mean age (years)	Mean years since diagnosis (years)	Forms analysed (N)	Percentage of total forms analysed (%)
	Men (%)	Women (%)				
Global region						
Eastern Europe Bosnia and Herzegovina ^b , Czech Republic, Hungary, Poland ^b , Russia ^b , Romania ^b , Ukraine	42.9	56.1	58.7	8.8	98	6.3
Northern Europe Denmark, Finland, Ireland, Norway, Sweden, UK	45.9	53.7	61.4	6.5	492	31.8
Southern Europe Croatia ^b , Cyprus ^b , Greece, Israel, Italy, Malta, Portugal ^b , Slovenia, Spain, Turkey ^b	56.5	43.3	64.4	8.2	561	36.3
Western Europe Austria, Belgium, France, Germany, Luxembourg, The Netherlands, Switzerland	50.3	49.7	61.5	6.5	384	24.8
Not stated	54.5	45.5	65.5	8.0	11	0.7
Total ^a	50.7	49.0	62.4	7.3	1546	100.0

^a0.3% of respondents did not state gender; ^bincluded in regional analysis; national sample too small to analyse individually.

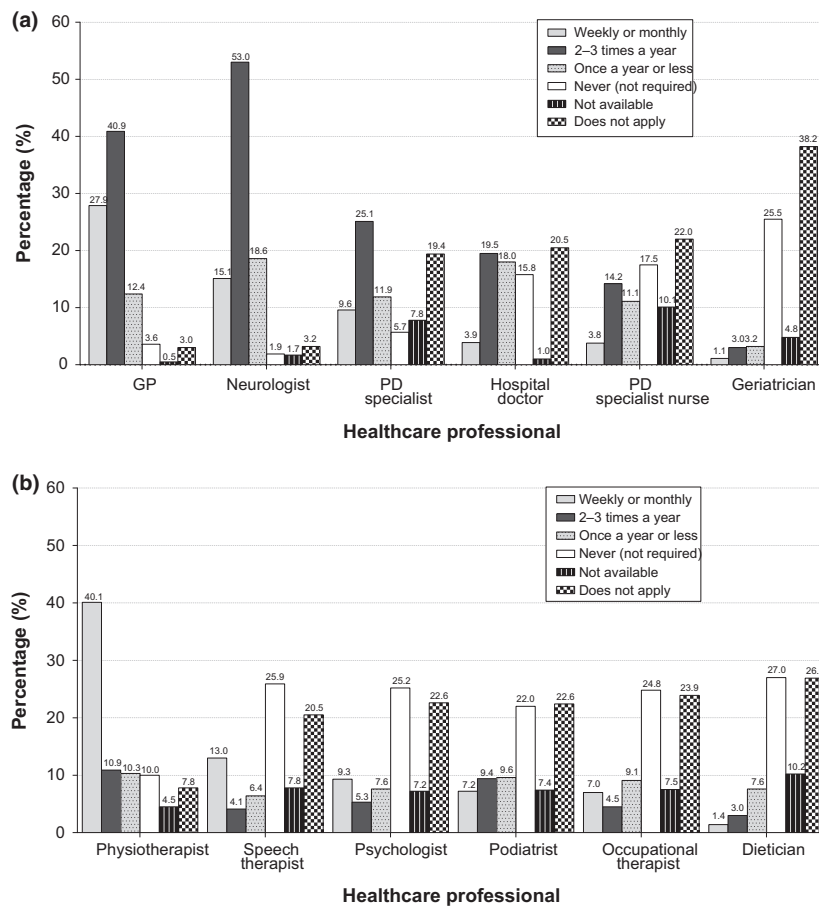


Figure 1 Percentage of total respondents indicating (a) the frequency that patients visit clinical HCPs ($n = 1546$) and (b) the frequency that patients visit allied health services ($n = 1546$).

made the decision alone. It should be noted that 19.7% did not answer this question.

Information sources and availability

Information on the treatment and management options was available from a variety of sources: PD organizations (64.1%); Internet searches (62.4%); friends (62.4%); and the GP (60.5%; Fig. 4). Table 2 shows the type of information available to patients during consultations, and how helpful this was. Most patients indicated that information on medication frequency (49.6%), medication type (43.5%) and symptoms (35.3%) was the most clearly explained and helpful. Information on fatigue (44.5%), appropriate diet (44.4%) and pain management (40.0%) was not available.

Caregivers of PD patients

A section for the caregivers and partners of the PD patients was included to provide their views on HCP consultations and the dedication towards both the

patient and the caregiver themselves. Only 200 responded to this section of the survey; 8.5% of these did not attend consultations with the patient, 59.0% helped the patient to prepare a list of questions, 46.5% helped with a list of symptom changes.

The majority of caregivers felt that a consultation of ≥ 30 min was enough time to talk about their own concerns (60.7%) and 71.4% felt that the doctor had tried to understand the symptoms and involve the caregiver in the treatment plan.

Discussion

The Move for Change survey was designed to identify the areas of PD care in Europe which are not meeting the standards indicated in clinical guidelines and the EPDA Charter [9,19–22], and is the largest European patient survey focused on this topic. Here, the final part of the survey is presented, which concentrated on the management of PD and continued treatment for patients. A large majority of consultations across Europe are arranged as part of a routine follow-up process, suggesting that treatment is driven by the

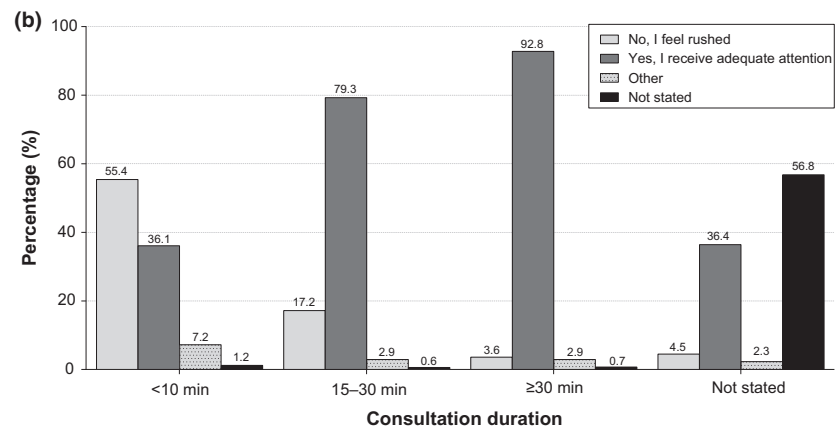
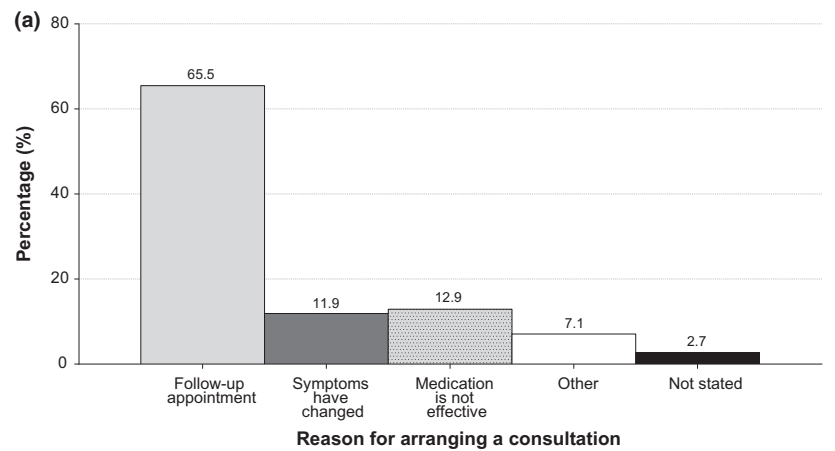


Figure 2 Percentage of total respondents indicating their reasons for arranging a consultation with their doctor, the duration of the appointment, and patient satisfaction ($n = 1546$).

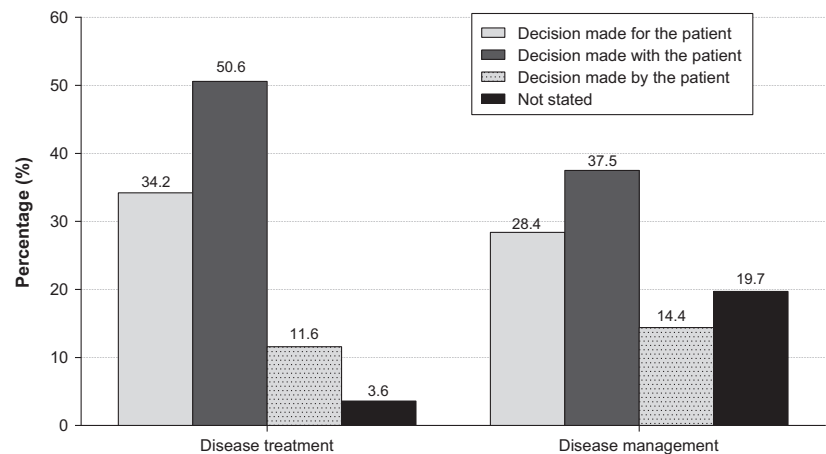


Figure 3 Percentage of total respondents indicating how disease treatment and management decisions have been made ($n = 1546$).

HCP and not by patient needs. Most patients feel they receive adequate attention from the HCP during the consultations, which commonly last between 15 and 30 min. Satisfaction levels increased with longer durations of the consultation. It is important to note that these data may not be an accurate representation of clinical consultation satisfaction; more dissatisfied patients are likely to be those with a poor relationship

with their clinician or Parkinson's support networks and may not have been aware of the survey in order to respond. Frequent and prolonged physiotherapy treatment was common, suggesting chronic treatment. Evidence to support the effectiveness of this type of lengthy treatment with high referral rates is limited [23] and guidelines state that treatment should ideally consist of short-lived interventions [24].

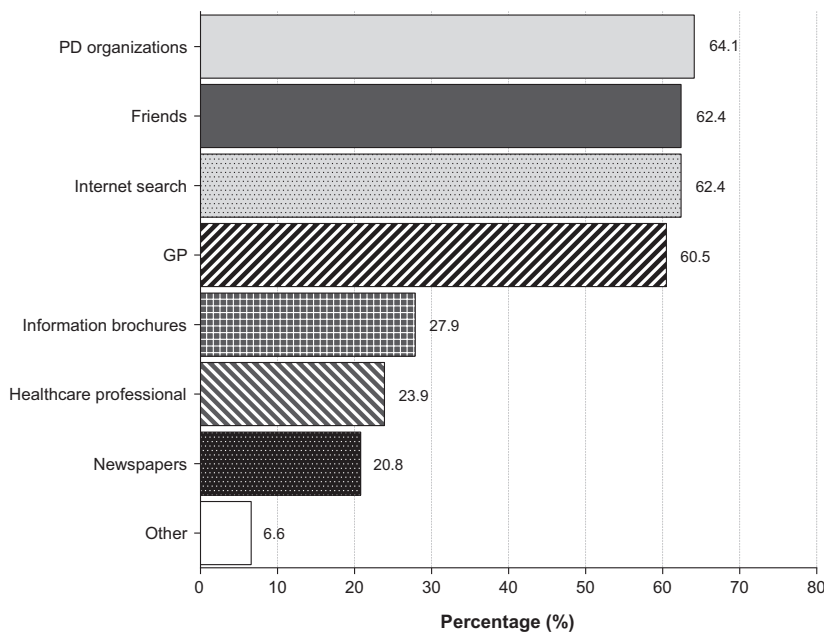


Figure 4 Percentage of total respondents indicating the sources of information used by patients to help them make decisions regarding management ($n = 1546$).

Table 2 Percentage of total respondents indicating the level and type of information available to them during consultations with an HCP

	It does not apply	Not comfortable raising this	No information available	Printed information available	Briefly mentioned	Explanation clear and helpful	Did not understand
Symptoms	1.9	1.2	15.5	11.1	23.0	35.3	1.2
Medication	2.1	0.6	8.9	8.0	25.0	43.5	1.5
Medication frequency	1.7	0.1	3.2	13.4	19.8	49.6	1.1
Side effects	2.9	1.3	24.4	8.2	25.4	21.0	1.7
Treating advanced Parkinson's	20.2	1.5	29.9	3.8	12.5	16.4	0.6
If medication has not been taken	8.3	0.8	32.4	4.6	19.5	19.0	0.5
Other medications	6.5	0.6	39.5	4.7	17.3	13.2	1.0
Foods	6.7	0.5	44.4	3.8	16.0	11.6	0.4
Health issues	4.7	1.3	39.3	3.3	21.2	12.2	0.6
Fatigue	5.4	1.1	44.5	2.8	15.5	11.1	1.0
Sleeping better	8.4	0.6	40.9	2.8	16.2	12.9	0.3
Coping with pain	13.8	0.6	40.0	2.5	12.8	9.4	0.5
Bowel and bladder issues	10.5	1.6	36.9	3.1	16.9	10.9	0.3
Exercise	1.4	0.2	13.8	6.4	25.2	33.9	0.5
Changes in mood	10.5	0.8	39.9	2.5	14.4	10.0	0.3
Assistance at home	17.7	0.6	39.2	2.5	9.6	7.7	0.5
Financial help	14.7	1.4	48.8	2.3	5.3	5.0	0.2
Support organizations	6.9	1.2	35.9	8.1	15.7	9.8	0.5
Help with daily living	4.3	0.3	25.0	5.6	23.2	19.8	0.5

The survey population is comparable to those seen in Parts I and II [11,12] as well as the general European PD population; other studies have shown comparable demographics [25,26].

The HCPs who were consulted most frequently and who had the shortest access time were the GPs and the neurologists. Yet, only half of the patients had regular scheduled appointments with their neurologist (53.0%), suggesting that there could be under-treatment in the remaining patients. Indeed, neurologist care is

associated with a reduction in hospitalization for psychosis and traumatic injury, and an increased frequency of neurologist consultations is associated with improved outcomes; Willis *et al.* [27] indicated that five or more outpatient visits with a neurologist over a period of 4 years was associated with a decrease in hospitalizations. These investigators suggest that the lower risks of hospitalization associated with neurologist care could indicate an improved ability of these HCPs to recognize and treat PD symptoms and complications.

This underscores the need for a broader implementation and easier access to neurologist care for Parkinson patients across Europe, and in particular to neurologists with expertise in movement disorders.

The results relating to PD specialist nurses concur with the data from Part II of the survey, highlighting that they do not have access but as a service they are very helpful [11]. PD nurse specialists are widely felt to be a critical part of the multidisciplinary team approach of PD patients, but there is little evidence to support this impression [28,29]. There are some recent data to suggest that PD patients cared for by a specialist nurse are more satisfied with their treatment and care than those consulting a general neurologist [30]. PD specialist nurses can improve the well-being of patients without impacting on healthcare costs through medication and symptom management support [30,31]. Moreover, clinical practice guidelines recommend regular consultations with a PD nurse specialist [22,32]. These presented data highlight poor accessibility to PD nurse specialists, reducing the realization of these potential benefits.

The Move for Change Part II data highlighted the neurologist and GP to be the most accessible HCPs, but suggested an increased understanding of PD and its symptoms would be necessary to treat a patient appropriately, in particular for GPs [12]. The EPDA Charter stipulates that a PD patient should be referred to a doctor specializing in PD in order to receive an accurate diagnosis but does not specify which professional should be primarily responsible for continued care. Our feelings are that the complex and progressive nature of PD justifies periodic consultations with an expert in PD, interleaved with consultations with generically active professionals. These Part III data suggest a high frequency of consultations with GPs and neurologists, although this appeared to be driven by the clinicians and not by the actual needs of the patients. It is crucial that collaboration between patients and HCPs takes place to ensure that consultations are arranged at an appropriate time in order to achieve the best possible clinical outcomes. It is recommended that patients or their caregivers should be leading the timing of the consultations, so that they are held at a stage when the patient has poignant points to discuss. Observations in patients with inflammatory bowel disease suggest that such a patient-driven arrangement of consultations could result in a reduction in consultation frequency and also a reduction of costly 'no shows' [33]. Objective measures of disease progression or markers of vital complications such as falls will help in delivering a more individually tailored follow-up system, without the risk of losing patients who fail to report to their

physician despite clear indications to do so. The use of automated follow-up (e.g. ambulatory sensing) could assist with this [34].

The economic burden of disease with regard to patient-driven medicine must also be considered; care and services available will vary in different countries according to their healthcare system. Previous studies have shown that adherence to medication is improved if there is better collaboration between patients and clinicians [35], and compliance with medication in PD has been shown to reduce healthcare costs [36]. Involving patients in medical decisions, e.g. using shared decision approaches, can also help to reduce costs [37,38]. Additionally, better care, professionalized networks and an active role for patients can be implemented without changing the reimbursement system [39]. Future work will examine whether patient healthcare status affects the intensity of medical consumption, e.g. patients who utilize private health insurance systems may have more dedicated options. The act of being involved in disease-management decisions is thought to lead to patient satisfaction; the level of information the patients consider they have received regarding treatment discussion is a predictor of their satisfaction, rather than the actual involvement [14]. Evidence suggests 40–80% of medical information provided by the HCP is forgotten immediately [40], and only 10.7% of patients in this survey indicated that they took notes during a consultation. This could suggest a link between patients being truly involved in the decision-making process and those who are less engaged during the consultation. Most patients felt that the level of information in several areas of PD was limited, particularly in areas of fatigue, pain management, and advanced PD care. This could lead to a lower number of patients being able to make an informed decision regarding their disease management. There is also evidence to suggest that the transition into palliative/advanced care is poorly understood [41,42]. HCPs should provide patients with certified sources of information to avoid any bias and potential dangers of uncertified information; online portals can be useful resources for patients and, if the community is large enough, a self-correcting and improving element is likely to exist. In the Netherlands, for example, patients can use a web application to create an online encyclopaedia of relevant and useful information about coping with everyday challenges of PD [39].

Most patients in the Move for Change survey made collaborative decisions regarding disease and treatment with their GP, which would suggest that they were content with the outcomes. However, it can rightly be questioned whether these decisions were

truly made as part of a shared decision process, where patients have full access to all medical information and can weigh the importance of each element of the decision process [43,44]. Furthermore, the low percentage of consultations arranged due to dissatisfaction with medication (12.9%) could be correlated with the percentage of those who are not involved in treatment (34.2%) and disease management (28.4%) decisions. This is clinician-driven treatment rather than patient-driven care, and indicates that consultations are not being held when they should be in order to optimally treat the patient. Patients with a lower educational background are more likely to change treatment [45], so an improvement could lead to better-informed patients with regard to their disease and treatments available. Subsequently, they will be less likely to change their treatment, and a decision will be focused on necessity and benefit rather than concern and misunderstanding. It has been demonstrated that good patient–clinician collaboration can improve medication adherence in chronic conditions [35], which is important to achieve treatment outcomes and quality-of-life for the patient [46]. It is possible that a lack of patient involvement in the decision process partially explains the disappointing treatment compliance in patients with PD [47,48].

A diagnosis of PD also has a great impact on the caregivers (partner, family and friends of the patient) [49,50]. Both the motor and non-motor aspects of PD can result in a high burden and strain, particularly with more advanced disease [51]. Dedicated support for the caregiver is essential, to improve their quality-of-life and also help minimize rising healthcare costs [52,53]. Informal caregivers have the potential to significantly reduce the cost and care burdens of PD that would ordinarily fall on the health services [54], with evidence in the UK suggesting that this could be up to £119 billion annually [55]. This survey included a section for informal caregivers to indicate their involvement with preparation for consultations and during the appointment. Only 13% of the analysed forms included responses from the caregiver, hence the results must be interpreted very cautiously. However, this small group responded very consistently with a high percentage (91.5%) stating that they attended the consultation. The survey only superficially touched upon the many issues that are relevant for caregivers and more work is required here e.g. using the Parkinson's Disease Questionnaire – Carer (PDQ-Carer), allowing informal caregivers to highlight their specific areas of concern [56]. The EPDA is very supportive of informal caregivers and is in the process of developing a second Consensus Statement for Carers [57]; this will be a sister publication to the

Consensus Statement for People with Parkinson's Disease [13] and will focus on raising awareness of the informal caregivers' needs.

This study has several limitations, most of which have been previously highlighted in Parts I and II of the survey [11,12]. The most important to note is the possibility of response bias due to the methods by which it was promoted and completed. As the survey was only available online, participation was limited to those with Internet access who are likely to be well informed about their disease, may consult with their clinician more frequently and have a more favourable view on the quality of their consultations than patients who are less well informed. It is important to note that there may be under- or over-representation of participating countries, and the level of response is not necessarily indicative of the national PD population.

To conclude, the Move for Change survey has demonstrated that the EPDA Charter has been adapted only partially throughout Europe, and various unmet needs have been identified. Although PD patients are seen regularly by a physician, there is a lack of consultations with a PD specialist [11]. There is also a need for greater adoption of multidisciplinary care across Europe to provide the benefits PD patients need [12]. This final part of the survey has identified that, although on a regular basis, consultations were largely routine and not arranged by the patient based on their needs. The use of a multidisciplinary team and additional support services in the treatment and care of PD has been shown to be beneficial and encouraged across Europe, but access to some services such as PD specialist nursing is limited. Additionally, although most patients felt they had been involved in decisions regarding their disease management, true shared decision making is presumably still rare, and there are several vexing problems of PD (e.g. constipation) for which information was not adequately provided. It has been demonstrated that 'participatory medicine', where patients act as partners in their care with their HCPs, results in improved care and can also contain costs [58]. Therefore, it is important that the dialogue between patients and HCPs is improved so that patients become empowered enough to discuss changes in their condition and understand their treatment regimen, whilst the HCPs maintain the power to ensure the treatment plan is appropriate for the patient.

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Disclosure of conflicts of interest

Professor B. Bloem is a current associate editor for the *Journal of Parkinson's Disease*; is a current member of the editorial board of *Physiotherapy Canada*; and a previous member of the editorial board for *Movement Disorders*. He has served on the scientific advisory boards and received honoraria from Glaxo-SmithKline, Novartis, Boehringer Ingelheim and Teva-Lundbeck, and he has received scientific research contributions from the Stichting Internationaal Parkinson Fonds, Alkemade-Keuls Fonds, the Michael J Fox Foundation, the Netherlands Organization for Scientific Research and the Prinses Beatrix Fonds.

Professor F. Stocchi is at present an associate editor for the *Journal of Parkinson's Disease* and an editorial board member of *Movement Disorders*. He has received research funding from the Italian Research Council, and consulting fees and honoraria from the following: Merck Serono, Merck Sharp, Impax, Newron, Orion, Novartis, Teva-Lundbeck, Glaxo-SmithKline and Boehringer Ingelheim.

Supporting Information

Additional Supporting Information may be found in the online version of this article:

Figure S1. Percentage of total respondents indicating the frequency of consultation by the HCP, listed by duration of disease ($n = 1546$).

Data S1. Original questionnaire used for the Move for Change Part III survey.

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