

## Research Article

# Experiences of Health Service Access and Use for People Living with Parkinson's Disease in Ireland: A National Survey

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**Background.** Despite the growing prevalence of Parkinson's disease (PD) and the need to plan for future health service provision, little is known in the Irish context about PD patients' experiences of service access/use. **Methods.** A cross-sectional survey, with multiple formats, i.e., online, pen-and-paper, and telephone. Data were collected from May 2020 to July 2021 using a multipronged recruitment strategy. The survey was completed by people with PD alone or with the support of a carer/support person. **Results.** A total of 1402 responses were included. Over half (53%) were male. Approx. 10% were diagnosed with young-onset PD. A minority (6%) reported attending only their GP to manage their PD, with the rest attending a generic or specialist outpatient clinic. Almost 1-in-5 reported it took more than 12 months to obtain the diagnosis. Most were diagnosed by neurologists (84%), followed by GPs (8%) and geriatricians (7%); 1% indicated "other." Of those diagnosed privately, 37% of these patients subsequently switched to the public system for ongoing management. The majority (97%) reported currently taking PD medications, but just 52% believed these were working effectively. Access to the range of health and social care professionals, including PD nurse specialists and clinical therapies is universally poor. **Conclusions.** A number of significant gaps in PD care are discussed, which require urgent attention. A reconfigured model of PD care is necessary to accommodate the growing need for specialist, integrated care at the population level. Specifically, more PD nurse specialists are needed within the public health system.

## 1. Introduction

Parkinson's disease (PD) is a neurodegenerative multisystem condition, characterised by cardinal motor symptoms including bradykinesia, rigidity and resting tremor, and postural instability, along with a wide range of nonmotor symptoms [1]. The current global estimate of PD prevalence is that there are six million people living with PD [2]. While there are no published prevalence studies in the Irish context, the Parkinson's Association of Ireland estimates there are approximately 12,000 people with PD in the Republic of Ireland. Life expectancy for this cohort is

heterogeneous, ranging from 6 to 20 years and is influenced by a range of factors, including age of onset [1].

The estimated total cost of PD care at European level is €13.9bn [3]. The high cost is unsurprising, given that recent studies from the UK, US, and Canada indicate that people with PD have more emergency department and in-patient admissions, increased lengths of hospital stay, and more admissions to skilled nursing/rehabilitation facilities [4–6] than those without PD.

There are no curative modalities for PD currently; however, there are effective pharmacological and non-pharmacological approaches to symptom management,

which can improve quality of life [7]. Despite this, people with PD often report high levels of unmet healthcare needs, especially in relation to information about the condition, prognosis, and treatment options; accessing nondrug therapies; and the management of nonmotor symptoms [8, 9].

In Ireland, like in many European countries, national policy aims to provide integrated, multidisciplinary PD care. There are considerable barriers to adopting same, including service underprovision, the absence of subspecialists across disciplines, and lack of personnel to coordinate such care [10, 11]. For context, the healthcare system in Ireland is publicly funded. It operates via a “two-tier” model, offering both public and private healthcare options. The public system is operated by the Health Service Executive (HSE). Through the HSE, people are entitled to free access to some aspects of primary care and all hospital care. There are fees associated with some other HSE-provided services, e.g., general practitioner visits (for those without a “medical card”) and specialist consultations. Private healthcare options are available for those who can afford it. Many Irish residents (45% of the population, according to 2019 Irish Central Statistics Office data) choose to purchase private health insurance to access speedier assessment, diagnosis, and treatment. This produces inequity between public and private patients, including people living with PD, in terms of timely access to appropriate services.

A large survey of people with PD ( $N=1775$ ) was conducted by Schrag et al. [12] across 11 European countries, relating to experiences of PD care. The authors indicate that data from Ireland were included in the analysis; however, Irish data were not presented in a way that is identifiable within the paper. The study included a large sample, but one key limitation was that respondents were recruited through national PD organizations; it is possible that this cohort has different experiences than those not linked in with support services and are not representative of the wider population.

Little research has been conducted in Ireland; however, a qualitative study by Fox et al. [13] explored PD patients’ and carers’ ( $N=31$ ) needs and healthcare experiences from a “holistic” perspective. The findings indicated several shortcomings, including lack of information about PD/available supports; infrequent interaction with care providers; and lack of focus on nonmotor symptoms. Such findings are not unique to the Irish context [9, 12, 14–18]. In addition, the “Treating Parkinson’s” survey ( $N=955$ ) was conducted by Stubbe et al. [19] amongst people with PD; though findings were only published as a conference abstract. Some key findings were that 17% needed to take their medication earlier than prescribed, owing to a return of motor symptoms; and just over half felt their movement difficulties were adequately treated.

While the above-mentioned studies by Fox et al. [13] and Stubbe et al. [19] provide important insights into the experience of living with PD in Ireland, the methods used limit the generalisability of the findings. To address this gap, this study aims to examine the healthcare experiences of people with PD across Ireland.

## 2. Methods

**2.1. Study Design.** This study employed a cross-sectional survey design. Survey development was informed by a literature review and in consultation with the Parkinson’s Association of Ireland (PAI), the project steering committee and a public and patient involvement (PPI) advisory group ( $N=10$  people with PD). The advisory group was diverse demographically (age, sex, and geographical location) and clinically (disease stage and symptomology). The survey was piloted amongst the PPI advisory group and modified accordingly before distribution. Changes focused on ensuring a logical structure, maximising clarity/readability, and minimising respondent time burden.

This anonymous survey collected data on the following: sociodemographic characteristics; experiences of health service access, diagnosis, and medical management; multidisciplinary input; and perspectives on improving PD care. Questions were mostly close-ended; however, open-text boxes were also provided to facilitate elaboration. The full survey is available for download in PDF format (see supplementary file 1).

**2.2. Recruitment and Sampling.** Respondents were aged  $\geq 18$  years, with a diagnosis of PD and ordinarily resident in Ireland. A multipronged recruitment strategy was used to reach a broad spectrum of people with PD. The survey was advertised on (i) local radio stations and newspapers/magazines, (ii) social media (Facebook/Instagram), (iii) through the PAI mailing list, magazine, and electronic newsletter, (iv) the Move4Parkinson’s (voluntary advocacy group) mailing list, and at (v) outreach events/conferences. In addition, random samples of care homes and General Practitioner (GP) clinics, and all movement disorder specialists nationwide were sent recruitment posters for display in clinics.

**2.3. Data Collection.** Data were collected over a 14-month period (May 2020–July 2021). A 6-month data collection period was planned; however, the COVID-19 pandemic created barriers to reaching people with PD, many of whom “cocooned” for extended periods.

The survey was completed by respondents through one of the following three formats: online, postal, and telephone. The online version was hosted on Google Forms. Respondents were primarily people with PD. However, those who required support completing the survey could nominate a respondent; this facilitated those with more advanced PD to share their experiences. It took approximately 20 minutes to complete.

**2.4. Data Analysis.** Data were analysed using SPSS-V28. Descriptive statistics are presented, including frequencies and valid percentages. Independent samples chi-square tests, Mann–Whitney  $U$  tests, and Kruskal–Wallis tests were used to determine group differences, as appropriate (significance set at  $p < 0.05$ ).

Qualitative data from the open-text boxes were analysed using inductive content analysis [20].

**2.5. Ethics.** Approval was granted for this study by the Clinical Research Ethics Committee of the Cork Teaching Hospitals (ref: ECM 4 (m) 10/03/2020). A participant information page was provided for review, before participants gave informed consent (tick-box, to ensure anonymity).

### 3. Results

Respondent ( $N = 1402$ ) characteristics are depicted in Table 1. Approximately, two-thirds (61.2%) of the responses were from people with PD (alone), while a further 12.0% were submitted by people with PD with a support person present; the final 26.8% were completed by a carer/support person, on behalf of the person with PD. The age distribution of those with PD is reported separately in Figure 1. The majority were diagnosed with PD after the age of 50 (89.9%,  $n = 1099$ ), with the remaining 10.1% ( $n = 123$ ) diagnosed with early-onset PD (i.e., defined as <50 years).

The time since PD diagnosis was reported as “less than one year” for 6.7% ( $n = 89$ ), “1–5 years” for 36.7% ( $n = 485$ ), and “6–10 years” for 27.5% ( $n = 364$ ). An additional 17.0% ( $n = 225$ ) reported a duration of “11–15 years” and 12.0% ( $n = 159$ ) selected “more than 15 years.”

Under half of respondents (42.6%,  $n = 566$ ) reported needing one or more walking aids. Over half (56.5%,  $n = 752$ ) reported having an informal care partner (primarily female (74.3%,  $n = 550$ )). Most primary care partners were “spousal” (78.3%,  $n = 578$ ); the remainder were “adult children” (13.4%,  $n = 99$ ), “paid/formal carers” (5.8%,  $n = 43$ ), and “other (e.g., friend, neighbour, and other relative)” (2.4%,  $n = 18$ ). Of those that did not have a carer ( $n = 580$ ), 20.7% ( $n = 120$ ) indicated they need more day-to-day support.

**3.1. Time to Diagnosis.** Under half (46.2%;  $n = 603$ ) reported that it took  $\leq 3$  months from when they first sought help for their symptoms, to when they obtained their diagnosis. It took 4–7 months for 22.8% ( $n = 297$ ) and 8–12 months for 12.5% ( $n = 163$ ), while 18.4% ( $n = 240$ ) reported that it took 12+ months to obtain the diagnosis.

Those in the private healthcare system were more likely to be diagnosed within 3 months (76.9%,  $n = 412$ ), compared to public patients (23.1%,  $n = 124$ ),  $X^2(1, N = 1188) = 36.43$ ,  $p < 0.001$ . Those with early-onset PD were less likely to obtain a diagnosis within 3 months compared to later-onset,  $X^2(1, N = 1190) = 10.73$ ,  $p = 0.001$ . Delays in diagnosis were qualitatively attributed ( $n = 235$  open-text responses) to the following factors: GPs not recognising the symptoms or need for specialist referral (particularly in early-onset PD) and long public waitlists to see specialists and for brain imaging (and results of same).

**3.2. Diagnosing Speciality.** Most were diagnosed by neurologists (83.8%,  $n = 1104$ ), followed by geriatricians (7.4%,  $n = 98$ ) and GPs (7.4%,  $n = 98$ ), while 1.4% ( $n = 18$ ) indicated

TABLE 1: Sociodemographic characteristics of people with PD.

		Valid % (n)
Gender	Male	52.5% (732)
	Female	47.1% (657)
	Nonbinary/other	0.4% (6)
Ethnicity	White Irish	94.8% (1269)
	White (not Irish)	4.6% (61)
	Other	0.6% (9)
Province	Leinster	45.9% (609)
	Munster	27.6% (367)
	Connaught	19.1% (254)
	Ulster	7.4% (98)
Living arrangement	Own home (with spouse/family)	73.3% (979)
	Own home (alone)	19.2% (256)
	Relative's home	3.5% (47)
	Care home/other	4.0% (54)
First language	English	96.6% (1291)
Area type	Rural	37.3% (493)
	Village/town	37.1% (490)
	City	25.6% (338)
Relationship status	Married/partner	74.9% (992)
	Separated/divorced	4.5% (59)
	Single (never married)	6.2% (82)
	Widowed	14.4% (191)
Employment status	Retired	69.5% ( $n = 922$ )
	Unable to work due to disability	12.4% ( $n = 165$ )
	Employed/self-employed	12.2% ( $n = 162$ )
	Homemaker	5.1% ( $n = 67$ )
	Unemployed	0.8% ( $n = 10$ )

“other.” Those diagnosed by a neurologist were significantly more likely to be diagnosed in the private system (70.8%,  $n = 782$ ), compared to those diagnosed by a geriatrician (33.7%,  $n = 33$ ),  $X^2(1, N = 1202) = 56.89$ ,  $p < 0.001$ . Of those diagnosed privately ( $n = 815$ ), either by a neurologist or a geriatrician, 36.9% ( $n = 301$ ) subsequently switched to the public system for ongoing PD management. Some people with PD only under the care of a GP (i.e., 5.8%,  $n = 77$ ), indicated they were not aware that specialist outpatient clinics existed.

**3.3. Diagnostic Disclosure and Postdiagnostic Support.** The majority (78.3%,  $n = 1032$ ) indicated the diagnostic disclosure of PD was “acceptable.” There were no differences in disclosure acceptability between those diagnosed publicly, versus privately,  $X^2(1, N = 1193) = 1.56$ ,  $p = 0.212$ ; nor were there gender differences in acceptability,  $X^2(1, N = 1308) = 0.13$ ,  $p = 0.723$ . However, those diagnosed by geriatricians were more likely to report acceptable disclosure (91.8%,  $n = 90$ ), compared to those diagnosed by a neurologist (77.0%,  $n = 843$ ),  $X^2(1, N = 1193) = 11.64$ ,  $p < 0.001$ . Regression analysis demonstrated that the association remained significant ( $p = 0.04$ ) after controlling for age at diagnosis. Those with early-onset PD were less likely to report an acceptable disclosure (58.3%,  $n = 70$ ), compared to later-onset (80.8%,  $n = 877$ ),  $X^2(1, N = 1205) = 32.50$ ,  $p < 0.001$ . Qualitatively ( $n = 316$  open text responses), the key problems indicated regarding disclosure included: not being advised to bring a support person, excessive focus on

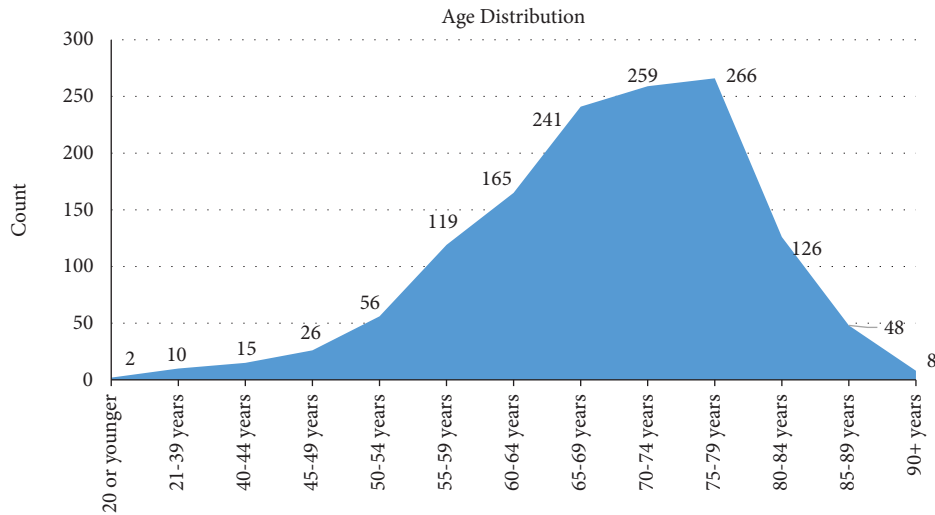


FIGURE 1: Distribution of age categories.

degeneration and loss and insufficient focus on available management strategies, not being given ample time to discuss information or support needs/services, not being given take-home written information, lack of clinician empathy, and lack of privacy (particularly amongst hospital in-patients).

Participants were asked whether, in the weeks following diagnosis, a healthcare professional checked in with them; the majority (76.1%,  $n = 999$ ) indicated “no.” Approximately half of respondents (48.1%,  $n = 623$ ) indicated they do not have a main point of contact for PD-related queries.

**3.4. Outpatient Clinics.** Of those attending an outpatient clinic for their PD ( $n = 1245$ ), 56.2% reported being in the public system and 43.8% in the private system. The mean distance travelled each way to attend an outpatient clinic was 45.9 km (SD = 49.7, range: 1–300 kms), with a median distance of 30 km (IQR = 53.5). A Mann–Whitney  $U$  test showed a significant difference in distance travelled each way to clinic, between those living in self-reported “urban” (mdn = 20, IQR = 44) versus “rural” (mdn = 45, IQR = 60) areas, ( $U = 94920.5$ ,  $p > 0.0001$ ). Qualitative responses ( $n = 147$ ) indicated that travelling long distances was fatiguing and costly (travel, subsistence, and overnight accommodation (if attending a morning appointment)).

Over half (57.3%,  $n = 718$ ) reported attending an outpatient clinic at least every 6 months, while the remaining 42.7% reported attending annually or less frequently. Private patients were more likely to attend clinic every 6 months, compared to public patients,  $X^2(1, N = 1232) = 41.34$ ,  $p < 0.001$ . Over half (53.6%,  $n = 665$ ) stated that they would like more frequent outpatient clinic visits. Unsurprisingly, public patients were more likely to want more frequent visits (65.9%,  $n = 457$ ) than private patients (36.7%,  $n = 194$ ),  $X^2(1, N = 1222) = 102.1$ ,  $p < 0.001$ . For private patients, the cost per clinic visit was a contributing factor. Qualitative responses ( $n = 97$ ) additionally highlighted the poor availability of urgent review slots at outpatient PD clinics.

**3.5. Perceived Quality of Care.** The perceived quality of care was also explored: 72.9% ( $n = 913$ ) reported having enough time with their doctor; 71.1% ( $n = 873$ ) felt involved in decision-making about their care; 70.8% ( $n = 865$ ) indicated they feel listened to during clinic visits, while 61.6% ( $n = 758$ ) felt that their PD symptoms are adequately assessed. Qualitative responses ( $n = 159$ ) emphasized that nonmotor symptoms, especially psychological symptoms (e.g., anxiety, depression, and apathy), are not well probed.

Table 2 depicts the results of chi-square analyses. Public patients were less likely to report having enough time with their doctor, being involved in decision-making, feeling listened to, and adequate symptom assessment. In addition, those with early-onset PD were less likely to report having enough time with their doctor, feeling listened to and adequate symptom assessment.

**3.6. Medication.** Most people with PD were taking anti-PD medications (96.7%,  $n = 1286$ ; 95% CI: 95.6–97.6%, see Figure 2). Just 52.2% ( $n = 663$ ) believed their current PD medications were working effectively (95% CI: 49.4–54.9%). For those not taking PD medications (i.e., 3.3%,  $n = 44$ ), the following factors influenced their decision, according to open-text responses: a perceived lack of need; concerns regarding side effects; having a medical contraindication (e.g., melanoma); trying to conceive; and preferences for complementary/alternative therapies.

**3.7. Multidisciplinary Team Access.** Just 20.7% ( $n = 290$ ) reported having any access to a PD nurse specialist (95% CI: 19.7–24.3%). The most common qualitative response ( $n = 618$ ) for service development was improved access to a PD nurse specialist for all patients. The involvement of other therapeutic disciplines is depicted in Figure 3.

Chi-square analyses demonstrated that public patients were more likely to report access to a PD nurse, a speech and language therapist, and an occupational therapist, than

TABLE 2: Differences in perceived quality of care.

	Quality indicator	Valid cases	$X^2$ ( $df=1$ )	Significance
Public versus private patients	Enough time with doctor	1233	27.11	$p < 0.001^{***}$
	Involved in decision-making	1210	23.71	$p < 0.001^{***}$
	Feel listened to	1204	22.27	$p < 0.001^{***}$
	Adequate symptom assessment	1215	12.57	$p < 0.001^{***}$
Early versus later onset patients	Enough time with doctor	1145	18.01	$p < 0.001^{***}$
	Involved in decision-making	1120	1.95	$p = 0.162$
	Feel listened to	1114	5.02	$p = 0.025^*$
	Adequate symptom assessment	1122	16.63	$p < 0.001^{***}$

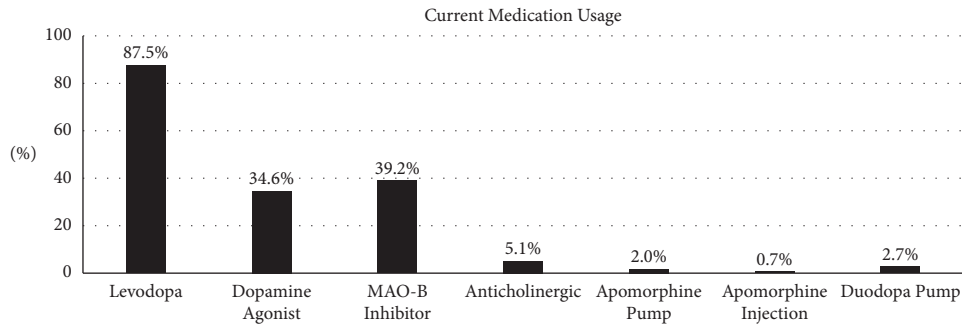


FIGURE 2: PD medications.

private patients (Table 3). Qualitative responses ( $n = 435$ ) suggest that access barriers include patients not being aware of the role/benefits of MDT disciplines, and services not being available locally. For private patients, cost was a significant access barrier. In addition, some who have had clinical therapy involvement noted a lack of PD-specific expertise amongst therapists, limiting the benefit.

#### 4. Discussion

This study examined the healthcare experiences of people living with PD in Ireland, through a national survey ( $N = 1402$ ). The findings demonstrate important patterns regarding healthcare access and perceptions of care acceptability and quality.

Almost one-fifth of the total respondents stated it took longer than 12 months to obtain a diagnosis, with public patients being diagnosed slower than private patients, and those with early-onset PD being diagnosed slower than those with later-onset PD. Delays were attributed to poor GP symptom recognition (especially amongst young-onset cohorts) and poor capacity in the public system, relating to specialist clinic provision, and wait times for specialised brain imaging.

The current findings show that most PD diagnoses (84%) are made by neurologists; this pattern is consistent with Stubbe et al.'s [19] findings in Ireland. Schrag et al. [12] also reported similar findings across 11 European countries (i.e., 87% diagnosed by a neurologist).

Almost one-quarter indicated the disclosure of their PD diagnosis was not acceptable. This reflects Schrag et al.'s [17] finding, where 22% of the sample were dissatisfied. Bloem et al. [21] measured PD patients' ( $N = 2068$ ) experiences of

diagnosis on a Likert scale and reported that just under half (45%) rated their experiences as "poor" or "very poor." The disparity in disclosure acceptability may relate to varying measurement approaches. Another influencing factor may be sample composition; Schrag et al. [17] recruited from across 11 European countries, while Bloem et al. [21] recruited from across 35 European countries, making it difficult to know if the findings are generalisable to any of the involved countries.

Between-group differences were found in disclosure acceptability; those diagnosed by a geriatrician were more likely to report an acceptable delivery than those diagnosed by a neurologist; and those diagnosed before age 50 were less likely to report an acceptable disclosure. Notably, after controlling for the effect of age, being diagnosed by a geriatrician remained independently associated with a more acceptable disclosure. It is possible that given the expertise that geriatricians have in working with patients with multiple morbidities, they might have a more holistic approach to assessment and disclosure, that is experienced as more person-centred than diagnoses disclosed by neurologists. This finding might also be impacted upon by a restriction of range in the data, given that the majority of respondents were diagnosed by a neurologist. This finding requires further investigation in future research.

Schrag et al. [17] reported that nearly half of respondents had not received information on nondrug treatment options at diagnosis. In Peek's [22] qualitative study, dissatisfied patients indicated physicians did not understand the emotional impact of the diagnosis for patients. Other studies, including the present study, support these findings [21, 23]. Postdiagnostic support was poor also, with over three-

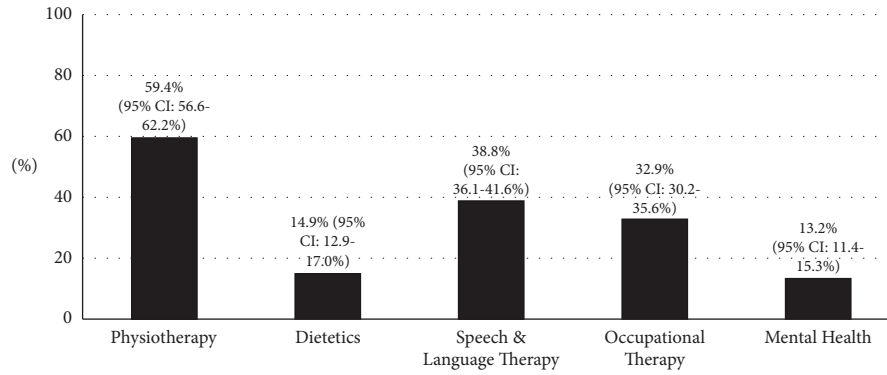


FIGURE 3: Clinical therapy involvement.

TABLE 3: Differences in access to clinical therapies.

Discipline access	Valid cases	% Public	% Private	<i>p</i> value
<i>Public versus private PD patients</i>				
PD nurse specialist	1168	32.0% (231/722)	10.0% (54/540)	<i>p</i> < 0.001***
Physiotherapy	1164	60.7% (405/667)	57.5% (286/497)	<i>p</i> = 0.275
Mental health	1150	13.5% (89/660)	12.4% (61/490)	<i>p</i> = 0.606
Speech and language therapy	1169	43.7% (293/670)	31.9% (159/499)	<i>p</i> < 0.001***
Occupational therapy	1152	38.2% (252/659)	26.4% (130/493)	<i>p</i> < 0.001***
Dietician	1150	16.5% (110/665)	12.8% (62/485)	<i>p</i> = 0.078

quarters of respondents stating that no healthcare professional checked-in with them postdiagnosis, which we know is a particularly vulnerable time.

Most (57%) attend an outpatient clinic at least every 6 months, and the remainder (43%) attend annually, or less frequently. Riggare et al. [24] reported this exact pattern amongst 346 people with PD in Sweden, with 57% of their survey respondents also attending for follow-up at least every 6 months. Similarly, both Schrag et al. [12] and Stubbe et al. [19] found that approximately half of patients were seen for review every 6 months.

Over half of respondents would like more frequent routine outpatient clinic visits; this is line with the Schrag et al.'s [12] finding that 48% were not satisfied with review frequency. Unsurprisingly, we found that private patients were more likely to have follow-up visits every six months. The qualitative data on this topic support the above-mentioned findings, while also highlighting high costs for private patients and the absence of rapid review slots across clinics (e.g., for urgent medication review).

Trends regarding perceived care quality were largely positive. The majority reported having enough time with their doctor, feeling involved in decision-making, and feeling listened to during consultations. A US survey of people with PD ( $N = 726$ ) by Dorsey et al. [25] found that 61% of respondents were satisfied with the time spent with their doctor, while Riggare et al. [24] noted 35% did not have sufficient time with their doctor (i.e., neurologists specifically). Schrag et al. [24] found that just 63% were satisfied with their involvement in decision-making processes. The present findings therefore compare favourably with international and European data. Of note, respondents were least satisfied with symptom assessment. The qualitative data indicated that respondents were

typically referring to poor nonmotor symptom assessment, especially for psychological health. Other studies have highlighted this issue also [13, 26, 27]. Mathur et al. [28] reported that 24% of PD patients do not fully communicate the range of nonmotor symptoms experienced, partially because of perceived lack of clinician interest.

There were significant differences in perceived care quality, depending on (i) whether patients were public or private and (ii) whether patients had early versus later PD onset. Specifically, public patients were less likely to report having enough time with their doctor, being involved in decision-making, feeling listened to, and having thorough symptom assessment. Those with early-onset PD were less likely to report having enough time with their doctor, feeling listened to, and adequate symptom assessment.

Most respondents (97%) reported taking PD medications. This is consistent with Stubbe et al.'s [19] finding (98%). The most common classes were levodopa (88%), MAO-B inhibitors (39%), and dopamine agonists (35%). Similar findings were reported by Stubbe et al. [19] regarding levodopa (87%); however, more people reported taking MAO-B inhibitors (47%) and dopamine agonists (40%) in Stubbe et al.'s [19] study, perhaps owing to their slightly younger age profile.

An unexpected finding was that over half (52%) believed their medications were "not working as they should be," e.g., wearing off sooner than expected. It should be noted here, however, that some respondents clarified in the open-text box that they were not sure how to make that determination. This indicates that this specific finding may have low reliability and should be interpreted with caution. It might also indicate that patients are not always given the appropriate information about this when they are prescribed PD



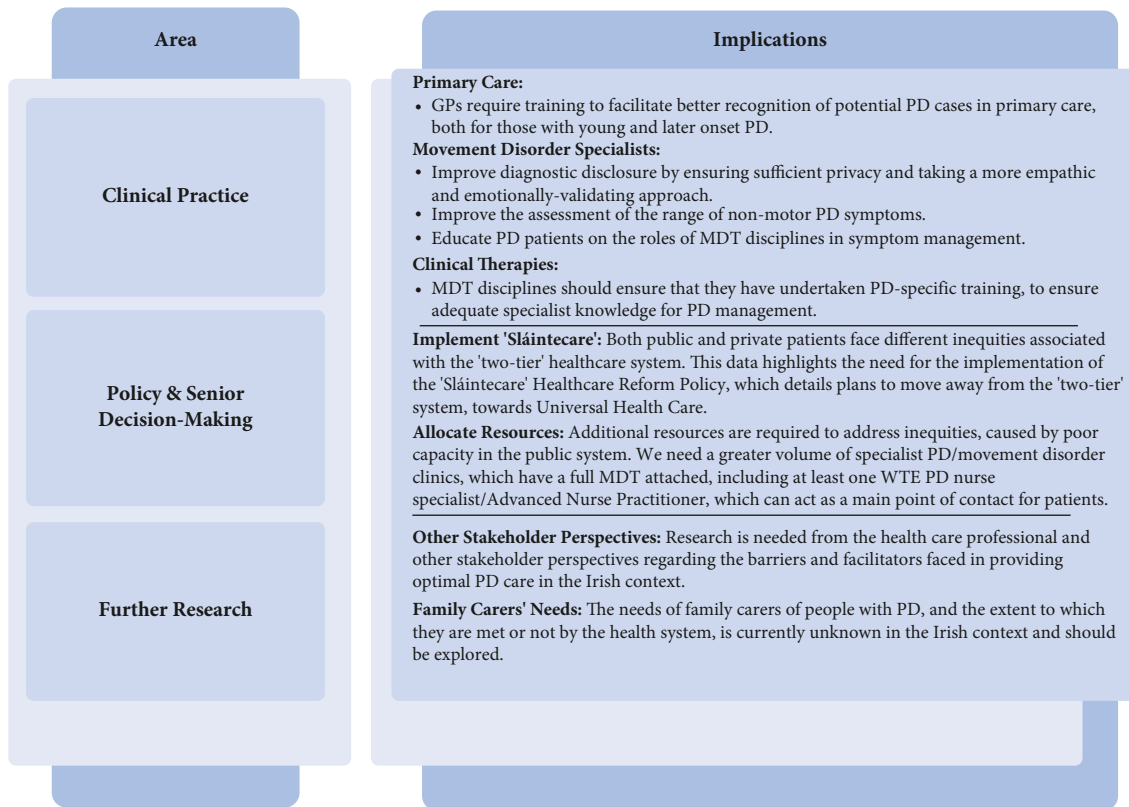


FIGURE 4: Implications of key findings.

medications, and that clinicians should place more emphasis on this in their communications with patients.

The present findings showed that access to multidisciplinary input is universally low. We must clarify that we asked patients if they had “seen” this list of health professionals. Therefore, this might be an overestimate of access, which may include patients indicating that they have “seen” a professional but in the context of a group talk/education session. Even so, these findings compare unfavourably to Bloem et al.’s [29] survey findings, in which access to the following was superior: physiotherapy (68%), PD nurse specialist (45%), dietetics (28%), and counselling (38%). Some patients reporting access to one or more clinical therapies clarified that some therapists do not have PD-specific expertise; something echoed in Nijkraak et al.’s [30] work.

Between-group differences were found in MDT access, i.e., those in the public system were more likely to report access to a PD nurse, speech and language therapy, and occupational therapy. Qualitative responses indicated that while private patients have speedier diagnosis and more frequent clinic visits, they have poorer access to multidisciplinary input. This is consistent with how 37% of those diagnosed privately subsequently switched to the public system for ongoing management. Many further indicated that they were not aware that the listed disciplines could be beneficial for PD management. While private care is sometimes considered better quality, these findings show how, for PD, there are distinct disadvantages associated with both the public and private systems, just at different stages of

the condition. The implications of the above key findings are outlined in Figure 4.

**4.1. Strengths and Limitations.** This is the largest representative survey of people with PD in Ireland to date. Given the study design, causality cannot be assumed. It was also retrospective, and participants self-selected into the study, which can lead to recall and sampling biases, respectively. This survey was completed by three groups, i.e., people with PD alone, together with a carer, or a carer on behalf of a person with PD. While we asked respondents to report the perspectives of the person with PD, we cannot be sure that all carers’ responses reflect this. Ethnic minorities were underrepresented in these data (0.6% versus approximately 8% in the population); future research in Ireland should focus on the service access and use experiences of ethnic minorities living with PD. A strength of this study was having multiple routes of survey completion, i.e., pen-and-paper, online, and phone, which increases generalisability. This is evidenced by how just 68% of our respondents were PAI members, compared to other similar studies where 89–100% of respondents were members of national PD organisations [12, 21].

## 5. Conclusion

PD care in Ireland is substantially underresourced, with poor accessibility and flexibility, and lacks the necessary coordination and integration across MDT disciplines. Thus,

the current approach is neither holistic nor person-centred. The greatest gap in current care is the lack of access to PD nurse specialists and clinical therapists. Experiences of care varied considerably between respondents, on indices including geography, patient status (public/private), and age of onset (early versus later). In Ireland, in addition to the typical barriers to optimal PD care, the two-tier structure of the health system drives further inequality and disadvantages both public and private PD patients, but at different stages of the condition. The implications for practice, policy, and research outlined in Figure 4 should be heeded, given that population ageing will lead to an increased demand for PD services in the coming years. Senior decision-makers within the Department of Health and the HSE must place the resourcing of publicly provided, integrated, and specialist PD care higher on the policy and funding agenda.

### Data Availability

The dataset generated and/or analysed during the current study are not publicly available for confidentiality reasons, relating to the qualitative, open-text responses offered by participants within the survey. Data can be made available from the corresponding author upon reasonable request.

### Ethical Approval

Approval was granted for this study by the Clinical Research Ethics Committee of the Cork Teaching Hospitals (ref: ECM 4 (m) 10/03/2020). The study was performed in accordance with the guidance from the local ethics committee and the Declaration of Helsinki.

### Disclosure

A published abstract [31] from this research was presented at the British Geriatrics Society 2022 meeting: [https://academic.oup.com/ageing/article-abstract/51/Supplement\\_2/afac125.001/6607994](https://academic.oup.com/ageing/article-abstract/51/Supplement_2/afac125.001/6607994). The funding body did not have a role in any of the following processes: study design; data collection, analysis, or interpretation; or writing the manuscript.

### Conflicts of Interest

The authors declare that they have no competing interests.

### Authors' Contributions

EoS and AR collected the data. TW supported recruitment. EoS analysed and interpreted the data, with support from KB. EoS and ST drafted the manuscript. All authors reviewed and gave feedback on the manuscript.

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### Supplementary Materials

The survey developed for use in this study is attached as supplementary file 1. (*Supplementary Materials*)

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