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International Genetic Testing and Counseling Practices for Parkinson's Disease

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Abstract

Background: There is growing clinical and research utilization of genetic testing in Parkinson's Disease (PD), including direct-to-consumer testing.

Objectives: To determine the international landscape of genetic testing in PD to inform future worldwide recommendations.

Methods: A web-based survey assessing current practices, concerns, and barriers to genetic testing and counseling was administered to the International Parkinson and Movement Disorders Society membership.

Results: Common hurdles across sites included cost and access to genetic testing, and counseling, as well as education on genetic counseling. Region-dependent differences in access to and availability of testing and counseling were most notable in Africa. High-income countries also demonstrated heterogeneity, with European nations more likely to have genetic testing covered through insurance than Pan-American and Asian countries.

Conclusions: This survey highlights not only diversity of barriers in different regions, but the shared and highly actionable needs for improved education and access to genetic counseling and testing for PD worldwide.

Introduction

Precision medicine based on genetic risk categories holds promise for personalized medical care for Parkinson's disease (PD).[1–4] However, it has been noted that precision medicine could also "potentially widen racial and ethnic disparities if access to them is unequal and if interest to use them differs across groups."[5] Despite suggestive data, genetic testing may not change the diagnosis or clinical management at present.[6–8] Testing may be expensive, demand significant resources, and genetic counseling is often difficult to obtain.[9,8,10] We are at a juncture where the demand for genetic testing will likely rise both because of potential therapies as well as patient choice.[7] There is a need to determine the worldwide landscape of genetic testing and practices for PD,[11,12] with particular focus on potentially surmountable access and barriers to testing across regions and practices.

We report results from a web-based survey designed to assess current practices, concerns, and barriers to PD genetic testing and counseling among International Parkinson and Movement Disorder Society (MDS) members and identify areas to improve access and education (Supplementary Table 1).

Methods

The 52-item, multiple-choice survey was developed by the MDS Genetic Task Force[11] with six major sections (1) demographics and practice features, (2) individual and regional practices of genetic testing, (2) availability and type of genetic counseling, (4) regional policies and guidelines, (5) pre-symptomatic testing and counseling and (6) ethical issues and considerations. (Supplemental S1/S2). A non-personalized SurveyMonkey link was emailed to 8,744 MDS members 1/12/2021 (www.surveymonkey.com/mp/audience) followed by an email reminder; it closed 2/28/21.

Responses were grouped according to whether the respondent was a movement specialist, the four MDS geographic sections (Table 1A) and the respondent's country by the Human Development Index (HDI)[13], using a cut-score of <0.788 to separate between higher index of development ("developed") from lower index (termed, "developing").[24] The United Nations national HDI incorporates life expectancy, education, and gross national income per capita (https://hdr.undp.org/towards-hdr-2022), and is a standard measure from the UN carrying greater ability to discern additional factors in a country beyond economic wealth and GDP that bear on health status. We chose the HDI given the concern of the tremendous diversity of economic status of different countries within specific MDS regions, but also the need to include these other factors. The cut point is established by the UN (https://hdr.undp.org/reports-and-publications/2020-human-development-report/data-readers-guide).

Results

Respondent Characteristics:

568 (6.4%) of those emailed completed part or all of the survey: 11% were from the African Section, 25% Asian and Oceanic, 32% European, and 32% Pan-American, commensurate with the overall representative of membership distribution. The proportion of respondents from developing nations (those that met HDI criteria of <0.788) was greater in African and Asian/Oceanic section responses compared with Pan-American (38%) and European (5%). There was also greatest diversity of HDI, meaning that there was a greater mix from developed and developing nations, in the Asian/Oceanic and Pan-American sections. 52% were movement disorder specialists, and 31% general neurologists. Movement disorders specialists were less frequent in the African (13%) and Asian and Oceanic sections (32%) than in the Pan-American (72%) and European (62%) sections (Table 1).

Availability and practice of genetic testing: (see supplemental Table 2)

Genetic testing was available in >85% of centers in respondents' regions, except Africa (42%). HDI developed countries were more likely to have genetic testing available (96.4% vs. 70.9%).

The most ordered genetic tests were multigene panels (52.9%), followed by single-gene tests (41.0%), whole exome sequencing (29.7%) and whole genome sequencing (WGS) (14.9%) Glucocerebrosidase (*GBA1*) variants were included in testing for 40%−53% (general neurologist-movement specialists) of respondents, and copy number variants (e.g., *PRKN* deletions) for 32–43%. Of note, up to 19% of centers did not need to use an accredited laboratory suggesting that some testing (in particular WGS) may be done on a research basis.

Overall, major barriers and unmet needs in genetic testing included cost (79%), access (64%), and knowledge (60%). While cost was important in both developing/developed countries (Table 1C), the disparity between "costs covered by insurance" vs. those "presenting a high (financial) burden to patients" was markedly more pronounced in the African (covered by insurance (0%) vs. high burden to patient (78.9%), Asian and Oceanic (10.3% vs. 69.8%) and Pan-American (14% vs. 36.0%) sections compared with

the European (53.6% vs. 30.7%) section. While only 35% noted that clinician knowledge of genetic testing was low, 58% stated interest in resources that would help improve their knowledge of genetic counseling, and this was present across MDS regions.

Genetic counseling for Symptomatic Testing:

In the question regarding availability of genetic counseling, 59% reported that there was "low" or "no" access to genetic counseling for 59% of clinicians, *vs. 41% who reported "medium" or "high" availability.*This varied by region, with limited access in 87% of African, 58% of Asian and Oceanic, 62.9% of Pan-American, and 48% of European section participants. For 17% of participants, there was no regional standard for providing genetic counseling, with African (24%) and Pan-American (22%) sections more likely to lack a standard than European (14%) and Asian and Oceanic (11%) sections. Results of genetic testing were more commonly returned by a physician (74%) vs. a genetic counselor (21%). Genetic counseling included pre-test counseling for 59% of participants and post-test counseling for 73% (positive and negative results: 49%, positive results only: 24%). Variants of uncertain significance (VUS) are reported to patients by 56% of clinicians, 15% do not report any VUS, and 14% have a process to revisit any VUS.

Research testing, ethical and regulatory concerns, and pre-symptomatic testing data are reported in Supplemental Tables 1 and 2. **"Write in" responses** (Supplemental Material 3) included concerns regarding the clinical utility of testing, the need for guidelines, and of potential discrimination based on testing.

Discussion:

Our survey of current practices of international genetic testing identified many differences in access to and availability of testing and counseling, as well as types of tests being ordered, with cost, availability, and access to genetic counseling comprising major barriers. These hurdles varied by region including whether the clinician was specialized in movement disorders or a general neurologist. Highly actionable from this survey is a lack of confidence of clinicians in performing testing and counseling, as well as that 60% noted that more education about testing is needed.

Availability of genetic counseling was identified as one major barrier. Overall, more than half of respondents had low or no access to counseling (see Table 2), and nearly half of the counseling is being performed by neurologists (Table 2, question 1). A future challenge for the MDS will be to provide practical guidelines for genetic counseling and testing for PD. Meanwhile, educational resources regarding genetics and genetic counseling can and should be developed and provided. In particular, attitudes to testing are likely to vary by cultural, religious, educational, socioeconomic, and other backgrounds.[5,16,17] This has been observed within regions and among different ethnic groups and should be considered and incorporated into non-directive genetic counseling as well as genetic testing paradigms.

Access to genetic testing is a challenge that is both worldwide and varies by region (Supplemental Material 4). Barriers were often attributed to cost.[9,10] The greatest disparity and reduced access was in Africa, as others have reported.[10] In order to determine whether

regional differences were solely attributed to differences in development indices of wealth, longevity and education (using the UN- Human Development Index (HDI) as a proxy for this), we performed multiple regression models focused on barriers and including and not including HDI as co-variates (Supplementary Material 5), suggesting that regional differences were not solely due to the country development index of the respondents. Even among and within developed countries, there was heterogeneity. Thus, education for the funders, whether governmental or private, regarding the cost and time demands of testing and counseling is needed. One initiative to improve access to genetic testing in the US in the Parkinson's Foundation sponsored PD-GENErations study. As this survey was completed prior to the pandemic, it is likely that resources may be even further strained than represented here.

In the regions surveyed, testing is most commonly done using gene panels, which is consistent with a previous report,[18] although a minority of sites obtain whole-exome sequencing. As such, there is great variability in genes tested and types of variants that can be detected, including VUS, which may make interpretation of results a challenge.[19–21] Importantly, only about half of movement disorder specialists noted that *GBA1* variant testing was available, further highlighting the need to improve access to testing, since *GBA1* variants comprise the most common genetic risk of PD worldwide and several trials focused on *GBA1* variant carriers are underway.[3,22,23]

"Write-in" responses from the survey also provided valuable insights. Respondents saw the lack of actionability as a rationale to not perform testing. If precision-medicine initiatives are eventually successful, respondents may be more likely to perform testing in the future. Others were concerned about potential discrimination based on testing results and the need for policies to protect vulnerable populations. Drawbacks to this survey include the low response rate and that it was administered solely in English, thus potentially limiting its applicability to MDS members who did not respond. We suspect participation bias toward physician MDS members who are more inclined to be interested in PD genetics and comfortable arranging testing. Our study most likely underestimates the number of clinicians performing testing in both the larger MDS community and among general neurologists. Further, while many noted that their patients utilize direct-to-consumer (DTC) genetic testing, it is not known how many patients this represents. Thus, future surveys should include perspectives on PD DTC genetic testing for patients and their family members.

In summary, this global survey provides important information that will inform future recommendations for PD genetic testing and counseling, including short and long-term goals and strategies.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Table 1:
Survey Demographics, Testing Practice and Barriers:

Table 1A: Survey Response Characteristics and 1B: Regional and practice-specific genetic testing; 1C: Barriers to knowledge of genetic testing

1A: Survey respondent demographics	Overall N=568	Movement Specialists N=295	MDS Section			
			African N=62	Asian/ Oceanic N=144	European N=183	Pan-American N=179
Responses, % of respondents		51.9%	10.9%	25.4%	32.2%	31.5%
Gender, N (%)						
Women	264 (46.5%)	141 (47.8%)	28 (45.2%)	60 (41.7%)	87 (47.5%)	89 (49.7%)
Men	303 (53.4%)	153 (51.9%)	34 (54.8%)	83 (57.6%)	96 (52.5%)	90 (50.3%)
Non-binary/diverse	1 (0.2%)	1 (0.3%)	0 (0)	1 (0.7%)	0 (0)	0 (0)
Age, N (%)						
<35	82 (14.4%)	26 (8.8%)	13 (21.0%)	26 (18.1%)	21 (11.5%)	22 (12.3%)
35–50	295 (51.9%)	154 (52.2%)	39 (62.9%)	71 (49.3%)	94 (51.4%)	91 (50.8%)
>50	191 (33.6%)	115 (39.0%)	10 (16.1%)	47 (32.6%)	68 (37.2%)	66 (36.9%)
Practice, N (%)						
Major medical center	399 (70.3%)	233 (79.0%)	41 (66.1%)	107 (74.3%)	136 (74.3%)	115 (64.3%)
Private clinic	92 (16.2%)	31 (10.5%)	8 (12.9%)	25 (17.4%)	26 (14.2%)	33 (18.4%)
Other	77 (13.6%)	31 (10.5%)	13 (21.0%)	12 (8.3%)	21 (11.5%)	31 (17.3%)
Profession, N (%)						
General neurologist	177 (31.2%)		32 (51.6%)	73 (50.7%)	48 (26.4%)	24 (13.4%)
Movement specialist	295 (51.9%)		8 (12.9%)	46 (31.9%)	112 (61.5%)	129 (72.1%)
Genetic counselor	1 (0.2%)		0 (0)	0 (0)	0 (0)	1 (0.6%)
Health profession (non-MD)	10 (5.1%)		10 (16.1%)	5 (3.5%)	4 (2.2%)	10 (5.6%)
Other	65 (11.5%)		12 (19.4%)	20 (13.9%)	18 (9.9%)	15 (8.4%)
Human development Index HDI (mean ± SD)	0.81 ± 0.12	0.86 ± 0.09	0.61 ± 0.09	0.76 ± 0.11	0.88 ± 0.05	0.85 ± 0.09
Respondents from Developing countries (below HDI 0.788), N (%)	226 (40.4%)	63 (21.8%)	61 (98.4%)	88 (63.8%)	9 (5.0%)	68 (38.2%)

1B: Regional and practice-specific genetic testing;	Overall N=568	Movement Specialists N=295	MDS Section			
			African N=62	Asian/ Oceanic N=144	European N=183	Pan-American N=179
Source of regional genetic testing:						
An outside center	191 (40.6%)	95 (37.0%)	57 (38.0%)	63 (54.3%)	53 (34.6%)	57 (38.0%)
My center	143 (30.4%)	106 (41.3%)	6 (11.5%)	27 (23.3%)	58 (37.9%)	52 (34.7%)

1A: Survey respondent demographics	Overall N=568	Movement Specialists N=295	MDS Section			
			African N=62	Asian/ Oceanic N=144	European N=183	Pan-American N=179
Another dept at my center	60 (12.7%)	36 (14.0%)	21 (14.0%)	11 (9.5%)	28 (18.3%)	21 (14.0%)
Do not refer for testing	56 (11.9%)	17 (6.6%)	11 (7.3%)	10 (8.6%)	12 (7.8%)	11 (7.3%)
Do not know	21 (4.5%)	3 (1.2%)	9 (6.0%)	5 (4.3%)	2 (1.3%)	9 (6.0%)
Describe genetic testing in your area:						
Restricted to select centers	256 (54.4%)	146 (56.8%)	18 (34.6%)	61 (52.6%)	80 (52.3%)	97 (64.7%)
Accessible to general neurology	149 (31.6%)	99 (38.5%)	4 (7.7%)	36 (31.0%)	64 (41.8%)	45 (30.0%)
Not available in my country	66 (14.0%)	12 (4.7%)	30 (57.7%)	19 (16.4%)	9 (5.9%)	8 (5.3%)
Frequency of clinical testing sent by an MD at your center:						
Common (≥1 per month)	90 (19.1%)	68 (24.5%)	2 (3.9%)	19 (16.4%)	42 (27.5%)	27 (18.0%)
Infrequent (<1 per month)	164 (34.8%)	108 (42.0%)	7 (13.5%)	41 (35.3%)	55 (36.0%)	61 (40.7%)
Rare (<1 per 6 months)	142 (30.2%)	61 (23.7%)	19 (36.5%)	40 (34.5%)	38 (24.8%)	45 (30.0%)
Never	75 (15.9%)	20 (7.8%)	24 (46.2%)	16 (13.8%)	18 (11.8%)	17 (11.3%)
Regional frequency: providers sending clinical testing:						
Common (≥1 per month)	28 (5.9%)	19 (7.4%)	2 (3.9%)	7 (6.0%)	16 (10.5%)	3 (2.0%)
Infrequent (<1 per month)	109 (23.1%)	76 (29.6%)	3 (5.8%)	28 (24.1%)	37 (24.2%)	41 (27.3%)
Rare (< 1 per 6 months)	233 (49.5%)	126 (49.0%)	19 (36.5%)	56 (48.3%)	79 (51.6%)	79 (52.7%)
Never	101 (21.4%)	36 (14.0%)	28 (53.9%)	25 (21.6%)	21 (13.7%)	27 (18.0%)
Testing sent from your center (may include >1)						
Panel	249 (52.9%)	79 (69.6%)	6 (11.5%)	46 (39.7%)	105 (68.6%)	92 (61.3%)
Specific single genes	193 (41.0%)	135 (52.5%)	7 (13.5%)	44 (37.9%)	77 (50.3%)	65 (43.3%)
WES	140 (29.7%)	99 (38.5%)	6 (11.5%)	36 (31.0%)	49 (32.0%)	49 (32.7%)
WGS	70 (14.9%)	48 (18.7%)	3 (5.8%)	17 (14.7%)	29 (19.0%)	21 (14.0%)
None	59 (12.5%)	19 (7.4%)	21 (40.4%)	10 (8.6%)	10 (6.5%)	18 (12.0%)
N/A	76 (16.1%)	16 (6.2%)	22 (42.3%)	21 (18.1%)	15 (9.8%)	18 (12.0%)
Certified laboratory required for clinical testing?						
Yes	279 (59.2%)	174 (67.7%)	19 (36.5%)	67 (57.8%)	103 (67.3%)	90 (60.0%)
No	73 (15.5%)	39 (15.2%)	10 (19.2%)	19 (16.4%)	10 (19.2%)	18 (12.0%)
Do not know	119 (25.3%)	44 (17.1%)	23 (44.2%)	30 (25.9%)	24 (15.7%)	42 (28.0%)

1C Barriers to genetic testing and knowledge of genetic testing	Overall N=568	Movement Specialists N=295	MDS Section			
			African N=62	Asian/ Oceanic N=144	European N=183	Pan-American N=179

1A: Survey respondent demographics	Overall N=568	Movement Specialists N=295	MDS Section			
			African N=62	Asian/ Oceanic N=144	European N=183	Pan-American N=179
Major unmet needs: obtaining testing for your patients?[SÂ]						
Cost	305 (78.6%)	330 (78.6%)	33 (91.7%)	78 (82.1%)	81 (62.3%)	113 (89.0%)
Access	247 (63.7%)	271 (64.5%)	30 (83.3%)	54 (56.8%)	71 (54.6%)	92 (72.4%)
Knowledge	232 (59.8%)	254 (60.5%)	20 (55.6%)	58 (61.1%)	90 (69.2%)	64 (50.4%)
Cost Burden						
Insurance/govt	115 (24.4%)	78 (30.4%)	0 (0)	12 (10.3%)	82 (53.6%)	21 (14.0%)
High burden to patient	223 (47.4%)	92 (25.8%)	41 (78.9%)	81 (69.8%)	47 (30.7%)	54 (36.0%)
Low burden to patient	46 (9.8%)	26 (10.1%)	4 (7.7%)	16 (13.8%)	12 (7.8%)	14 (9.3%)
Variable burden to patient	87 (18.5%)	61 (23.7%)	7 (13.5%)	7 (6.0%)	12 (7.8%)	61 (40.7%)
Barriers for Neurologists						
Patient cost	308 (71.1%)	163 (71.2%)	37 (74.0%)	86 (76.8%)	63 (48.8%)	122 (85.9%)
Knowledge	202 (46.7%)	99 (43.2%)	27 (54.0%)	59 (52.7%)	68 (52.7%)	48 (33.8%)
Access to GC	160 (37.0%)	69 (30.1%)	28 (56.0%)	40 (35.7%)	44 (34.1%)	48 (33.8%)
Access to testing	142 (32.8%)	60 (26.2%)	32 (64.0%)	42 (37.5%)	32 (24.8%)	36 (25.4%)
None	29 (6.7%)	24 (10.5%)	1 (2.0%)	4 (3.6%)	21 (16.3%)	3 (2.1%)
Other	29 (6.7%)	17 (7.4%)	2 (4.0%)	5 (4.5%)	8 (6.2%)	14 (9.9%)
Barriers for MD Specialist (may include more than one)						
Patient cost	NA	151 (69.6%)	3 (60.0%)	29 (76.3%)	34 (47.2%)	85 (83.3%)
Knowledge		26 (12.0%)	1 (20.0%)	4 (10.5%)	11 (15.3%)	10 (9.8%)
Availability		91 (41.9%)	4 (80.0%)	14 (36.8%)	27 (37.5%)	46 (45.1%)
Testing time		54 (24.9%)	0 (0)	12 (31.6%)	21 (29.2%)	21 (20.6%)
Counseling time		46 (21.2%)	1 (20.0%)	10 (26.3%)	15 (20.8%)	20 (19.6%)
None		32 (14.7%)	0 (0)	5 (13.2%)	21 (29.2%)	6 (5.9%)
Other/NA		40 (18.4%)	3 (60.0%)	3 (7.9%)	16 (22.2%)	20 (19.6%)
Patient Genetics knowledge						
Low	318 (80.9%)	173 (72.7%)	35 (97.2%)	80 (83.3%)	101 (76.5%)	102 (79.1%)
Medium	66 (16.8%)	56 (23.5%)	1 (2.8%)	13 (13.5%)	26 (19.7%)	26 (20.2%)
High	9 (2.3%)	9 (3.8%)	0 (0)	3 (3.1%)	5 (3.8%)	1 (0.8%)
Physician Genetic testing knowledge level						
Low	147 (34.5%)	38 (16.0%)	22 (48.9%)	50 (49.0%)	36 (25.9%)	39 (27.9%)
Medium	196 (46.0%)	126 (52.9%)	19 (42.2%)	35 (34.3%)	69 (49.6%)	73 (52.1%)
High	83 (19.5%)	74 (31.1%)	4 (8.9%)	17 (16.7%)	34 (24.5%)	28 (20.0%)

Most responses were from movement disorder specialists (n=295, 52.0%) and general neurologists (177, 31.2%), although this varied by region. As delineated in the table, participants, regardless of specialty, were from the following regions: African (62), Asian/Oceanic (144), European (183),

and Pan-American (179). 83.7% (394/471) of participants responded that a center in their region provided genetic testing, although ordering genetic testing was uncommon for physicians across all MDS regions. When genetic testing is ordered, a variety of genetic tests are utilized: multigene panels (52.9% overall), single gene tests (41.0%), whole exome sequencing (29.7%) and whole-genome sequencing (14.9%). Major unmet needs in genetic testing included the cost of testing (78.6%), as well as access to genetic testing (63.7%) and knowledge about genetic testing (59.8%). Patient cost was seen as a significant barrier to genetic testing for the general neurologist (71.1%), as well as knowledge (46.7%), access to testing (32.8%), and access to counseling (37%). 58% of participants said they were interested in resources that would help improve their knowledge of genetic counseling. Complete summary provided in supplemental material. SA: select all that apply; ^limited to patient facing participants. 400/568 respondents completed all 52 questions.

Table 2:

Standards of symptomatic and pre-symptomatic genetic counseling

I. Standards of symptomatic genetic counseling for patients						
		Movement	MDS Section			
	Overall N=568	Specialists N=295	African N=62	Asian/ Oceanic N=144	European N=183	Pan-American N=179
Regional standard of practice: who performs genetic counseling?[SA]						
Geneticist (MD)	203 (47.7%)	121 (50.8%)	14 (31.1%)	39 (38.2%)	82 (59.0%)	68 (48.6%)
Neurologist	196 (46.0%)	123 (51.7%)	17 (37.8%)	51 (50.0%)	64 (46.0%)	64 (45.7%)
Genetic counselor (MS)	121 (28.4%)	72 (30.3%)	14 (31.1%)	34 (33.3%)	32 (23.0%)	41 (29.3%)
No standard	73 (17.1%)	45 (18.9%)	11 (24.4%)	11 (10.8%)	20 (14.4%)	31 (22.1%)
Genetic counselor (Non-MS)	42 (9.9%)	24 (10.1%)	2 (4.4%)	14 (13.7%)	10 (7.2%)	16 (11.4%)
None is performed	41 (9.6%)	15 (6.3%)	11 (24.4%)	11 (10.8%)	6 (4.3%)	13 (9.3%)
Refer outside	40 (9.4%)	19 (8.0%)	5 (11.1%)	7 (6.9%)	15 (10.8%)	13 (9.3%)
Other	11 (2.6%)	7 (2.9%)	0 (0)	1 (1.0%)	3 (2.2%)	7 (5.0%)
Nurse	9 (2.1%)	0 (0)	1 (2.2%)	3. (2.9%)	3 (2.2%)	2 (1.4%)
What is the availability of genetic counseling?						
Low	201 (47.2%)	97 (40.8%)	28 (62.2%)	45 (44.1%)	59 (42.5%)	69 (49.3%)
Medium	108 (25.4%)	73 (30.7%)	4 (8.9%)	26 (25.5%)	43 (30.9%)	35 (25.0%)
High	66 (15.5%)	47 (19.8%)	2 (4.4%)	17 (16.7%)	30 (21.6%)	17 (12.1%)
None	51 (12.0%)	21 (8.8%)	11 (24.4%)	14 (13.7%)	7 (5.0%)	19 (13.6%)
Are you comfortable performing counseling? ^						
Yes	226 (57.5%)	90 (47.9%)	15 (41.7%)	59 (61.5%)	73 (55.3%)	79 (61.2%)
No	167 (42.5%)	98 (52.1%)	21 (58.3%)	37 (38.5%)	59 (44.7%)	50 (38.8%)
Is pre-test counseling included?						
Yes	251 (58.9%)	160 (67.2%)	20 (44.4%)	60 (58.8%)	85 (61.2%)	86 (61.4%)
Do not know	77 (18.1%)	29 (12.2%)	8 (17.8%)	26 (25.5%)	21 (15.1%)	22 (15.7%)
No	54 (12.7%)	27 (11.3%)	2 (4.4%)	10 (9.8%)	20 (14.4%)	22 (15.7%)
No counseling offered	44 (10.3%)	22 (9.2%)	15 (33.3%)	6 (5.9%)	13 (9.4%)	10 (7.1%)
Is post-test counseling included?						
Positive and negative results	208 (48.8%)	63 (26.5%)	16 (35.6%)	55 (53.9%)	65 (46.8%)	72 (51.4%)
Only positive results	102 (23.9%)	63 (26.5%)	102 (23.9%)	18 (17.7%)	44 (31.7%)	30 (21.4%)
Do not know	78 (18.3%)	26 (10.9%)	11 (24.4%)	23 (22.6%)	23 (16.6%)	21 (15.0%)
No	38 (8.9%)	22 (9.2%)	8 (17.8%)	6 (5.9%)	7 (5.0%)	17 (12.1%)
Who returns genetic results to patients?						

I. Standards of symptomatic genetic counseling for patients						
		Movement	MDS Section			
	Overall N=568	Specialists N=295	African N=62	Asian/ Oceanic N=144	European N=183	Pan-American N=179
Physician	315 (73.9%)	181 (76.1%)	32 (71.1%)	79 (77.5%)	93 (66.9%)	111 (79.3%)
Genetic counselor	88 (20.7%)	48 (20.2%)	8 (17.8%)	12 (11.8%)	41 (29.5%)	27 (19.3%)
Nurse/other staff	23 (5.4%)	9 (3.8%)	5 (11.1%)	11 (10.8%)	5 (3.6%)	2 (1.4%)
How do you report and follow through with VUS? SA^						
Report to patient	218 (55.5%)	136 (57.1%)	13 (36.1%)	55 (57.3%)	72 (54.5%)	78 (60.5%)
Do not perform WES/WGS	96 (24.4%)	56 (23.5%)	14 (38.9%)	21 (21.9%)	26 (19.7%)	35 (27.1%)
Do not report to patient	59 (15.0%)	38 (16.0%)	5 (13.9%)	12 (12.5%)	30 (22.7%)	12 (9.3%)
Process to revisit	56 (14.2%)	32 (13.4%)	5 (13.9%)	18 (18.8%)	17 (12.9%)	16 (12.4%)
Is genetic counseling required for PD genetic testing?						
Yes	236 (55.4%)	124 (52.1%)	26 (57.8%)	77 (75.5%)	75 (54.0%)	58 (41.4%)
No	111 (26.1%)	86 (36.1%)	7 (15.6%)	10 (9.8%)	39 (28.1%)	55 (39.3%)
Do not know	79 (18.5%)	28 (11.8%)	12 (26.7%)	15 (14.7%)	25 (18.0%)	27 (19.3%)

Regarding standards of symptomatic genetic counseling, there was no availability of counseling for 12% of participants, including in 24.4% of African, 13.7% of Asian and Oceanic, 13.6% of Pan-American, and 5% of European section participants. Among patient-facing individuals, 57.5% said they were comfortable performing genetic counseling. Results of genetic testing were most commonly returned by a physician (73.9%) or a genetic counselor (20.7%). Genetic counseling includes pre-test counseling according to 58.9% of participants and post-test counseling according to 72.7% (positive and negative results: 48.8%, positive results only: 23.9%). Pre-symptomatic genetic testing is available in 43.9% of participants' sites overall and in 57.7% of sites among movement disorder specialists. Participants from the African (13.6%) and Asian and Oceanic (36.1%) sections were less likely to have site-access to pre-symptomatic testing compared with participants from European (51.9%) and Pan-American (52%) sections. Pre-symptomatic counseling was included with testing according to 47.1% of participants and not included according to 14% of participants. The availability of genetic counseling for pre-symptomatic testing was most likely to be considered "low" (47.2%) compared with "medium" (25.4%) or "high" (15.5%), and counseling is most likely to be performed by a neurologist (30.1%), a medical geneticist (19.1%), or a genetic counselor (21.3%). Most participants were not aware of a country-wide policy that addresses PD pre-symptomatic genetic testing (60.7%) compared with those that were aware (11.7%). ^ limited to patient facing participants.