#### 1. Introduction

This survey is part of My PD Journey, a multi-stakeholder project by the European Parkinson's Disease Association (EPDA).

6%

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 care 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.

We would be most grateful if you would share your experiences of receiving a diagnosis, treatment and care for Parkinson's. This will help us understand how well healthcare systems are currently meeting the needs of people with Parkinson's and their families across Europe.

This survey should be completed by a person with Parkinson's disease, or by a family member / carer / healthcare professional on behalf of the person with Parkinson's. Any information you provide will be completely anonymous and treated in confidence.

The survey should take no more than 20 minutes. It is very important each person with Parkinson's completes the survey only once. This survey closes on 31 December 2014. If you have any questions about the survey, please email us at <a href="mailto:merrittrk@googlemail.com">merrittrk@googlemail.com</a>.

Thank you very much in advance for your time and help in completing this survey.

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2. About you			
			12%
1. In what year were yo	ou diagnosed with	Parkinson's disease?	
Are you male or female.	ale?		
Male			
Female			
3. How would you desc	ribe the area that	you live in?	
Rural			
Town			
City			
4. Which country do yo	u currently live in?		
Denmark	$\circ$	Ireland	Spain
France		Italy	Sweden
Germany		Netherlands	United Kingdom
Hungary	0	Slovenia	
5. Are you currently em	ployed?		
Yes			
O No			
6. What is/was your occ	cupation?		

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3. About you	
	18%
7. How would you describe your current state of mobility?	
I have no problems in walking about	
I have some problems in walking about	
I am confined to bed	
8. How would you describe your current ability to care for yourself?	
I have no problems with self-care	
I have some problems washing or dressing myself	
I am unable to wash or dress myself	
9. How would you describe your current ability to perform everyday activities (e.g. v family or leisure)?	vork, study, housework,
I have no problems with performing everyday activities	
I have some problems with performing everyday activities	
I am unable to perform everyday activities	
10. How would you describe your current level of pain or discomfort?	
I have no pain or discomfort	
I have moderate pain or discomfort	
I have extreme pain or discomfort	
11. How would you describe your current level of anxiety or depression?	
I am not anxious or depressed	
I am moderately anxious or depressed	
I am extremely anxious or depressed	
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### 4. About you

	24%
12. Compared with your general level of health over the past 12 months, would you	say your health today is
O Better	
Much the same	
O Worse	
13. Which of the following statements best describes how you feel about your indep	endence?
I am able to do all chores without slowness, difficulty or impairment	
I am able to do all chores with some degree of slowness, difficulty and impairment, and am beginn	ning to be aware of difficulty
Chores take twice as long and I am conscious of difficulty and slowness	
Chores take three to four times as long and I spend a large part of the day doing these	
I can do most chores, but exceedingly slowly and requiring a lot of effort	
I need help with half the chores and have difficulty with everything	
I can assist with all the chores, but am only able to do a few on my own	
I can manage a few chores with some effort, but need a lot of help	
O I do nothing on my own, but can be a slight help with some chores	
I am totally dependent and helpless	
O I am bedridden	
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5. Getting a diagnosis of Parkinson's disease

		29%
14. How old were you Years	when you were first diagnosed with Pa	arkinson's?
15. How long has it be	een since you were first diagnosed with	n Parkinson's?
Less than 1 year		
At least 1 year but les	s than 2 years	
At least 2 years but le	ess than 3 years	
At least 3 years but le	ess than 5 years	
At least 5 years but le	ess than 10 years	
More than 10 years		
16. Which country wer	re you living in when you were first dia	gnosed with Parkinson's?
O Denmark	O Ireland	O Spain
France	ltaly	Sweden
Germany	Netherlands	O United Kingdom
Hungary	Slovenia	
Other (please specify	)	
	Prev Ne	xt

6. (	Getting a	diagnosis	of Parkinson's	disease
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17. Before you were diagnosed with Parkinson's, what symptom(s) did you have that prompted you to seek
medical help, and estimate how long had you had these symptoms? (Please select ONE option in EACH row)

35%

	Less than 1 year	1 to 2 years	3 to 4 years	5 years or more	Does not apply
Anxiety	0	0	0	0	$\circ$
Apathy	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	
Bladder and bowel problems	0	0	0	$\circ$	$\circ$
Changes in the way you move (including the way you walk, dragging a leg, not swinging your arm etc)	0	0	0	0	0
Depression	$\circ$	0	$\circ$	$\circ$	0
Difficulty eating and/or swallowing	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\circ$	$\circ$
Eye problems	0	0	0	0	0
Falls (balance problems)	$\bigcirc$		$\bigcirc$	$\bigcirc$	
Fatigue	$\circ$	$\circ$	$\circ$	$\circ$	0
Freezing	$\bigcirc$		$\bigcirc$	$\bigcirc$	
Loss of smell or taste	$\circ$	0	$\circ$	$\circ$	0
Low blood pressure or dizziness	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\circ$
Muscle cramps	$\circ$	0	0	$\circ$	0
Pain	$\bigcirc$	$\bigcirc$	$\bigcirc$		
Rigidity (stiffness)	0	0	0	0	0
Skin and/or sweating problems	$\bigcirc$	$\circ$	$\circ$	$\circ$	$\bigcirc$
Sleep problems	0	0	0	0	0
Slowness of movement	0			0	

	Less than 1 year	1 to 2 years	3 to 4 years	5 years or more	Does not apply
Speech and communication problems (including small handwriting and reduced facial movements)	0	0	0	0	0
Stress	0	$\bigcirc$	$\circ$	$\bigcirc$	$\bigcirc$
Thinking or memory problems	0	0	0	$\circ$	0
Tremor (shaking)	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$
Other symptoms					
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Explained that you may have another disease / condition

Other (please specify)

, , , , , , , , , , , , , , , , , , , ,			
7. Getting a diagnosi	s of Parkinson's disea	ase	
			41%
18. How long was it be	efore you sought medica	l help after you first noticed your sy	mptoms?
Less than 1 month			
At least 1 month but le	ess than 3 months		
At least 3 months but	less than 6 months		
At least 6 months but	less than 12 months		
12 months or more			
Cannot remember			
19. What happened duapply)	uring your first appointm	ent with a healthcare professional?	(Please select ALL that
Discussed your gener	ral medical history		
Carried out a physical	I examination		
Observed your symptom	om(s)		
Referred you to a spe	cialist, or another doctor / hea	althcare professional	
Said nothing was wro	ng		
Said it was too early to	o tell if anything was wrong		
Said something was v	wrong, but not sure what		
Prescribed medication	n to relieve your symptom(s)		
Explained that you ma	ay have Parkinson's		

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M	y PD Journey que	stionnaire						
8.	8. Getting a diagnosis of Parkinson's disease							
						47	7%	
						1		
	<ol> <li>If you were referre Please select ONE or</li> </ol>		-	ofessional, h	ow long did	it take before	e you saw th	em?
			At least 1	At least 2 months but	At least 3 months but			
		Within 1 month	less than 2 months	less than 3	less than 4	4 months or more	Cannot remember	Does not apply
	General neurologist	O	O	O	O	O	O	О
	Neurologist who is a specialist in Parkinson's	0	0	0	0	0	0	0
	Care of the elderly doctor (geriatrician)	0	0	0	0	0	0	0
	Parkinson's disease nurse specialist	$\circ$	$\bigcirc$	$\circ$	$\circ$	$\bigcirc$	$\circ$	$\bigcirc$
	Physiotherapist	0	0	0	0	0	0	0
	Occupational therapist	0	0	0	0	0	0	0
	Speech and language therapist	0	0	$\circ$	0	0	0	0
2	What examination	e or toste word	carried out	to confirm if	you had Pai	rkinson's2 (P	Dassa salact	All that
	pply)	3 OF ICSIS WEIC	carried out	to commit ii	you nad r ai	1KIII30113: (1	icase select	ALL that
	General medical histo	ory						
	Physical examination							
	Observation of your s	ymptoms						
	Blood or urine tests							
	Brain scan (e.g. CT, N	MRI, DaTSCAN)						
	Genetic testing							
	Other (please specify	)						

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## 9. Getting a diagnosis of Parkinson's disease 53% 22. Who gave you the diagnosis of Parkinson's? General practitioner or family doctor Hospital doctor General neurologist Neurologist who is a specialist in Parkinson's Care of the elderly doctor (geriatrician) Cannot remember Other (please specify) 23. How sensitively were you told you had Parkinson's? Very sensitively Quite sensitively Not very sensitively Not at all sensitively Cannot remember 24. How satisfied were you with the consultation when the initial diagnosis was given? Very satisfied Satisfied Dissatisfied Very dissatisfied Neutral Cannot remember

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My PD Journey questionnaire

10.	Getting	а	diagnosis	of	Par	kinson	's c	lisease
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25. When you were given your diagnosis, what information were you given? (Please select ONE option for
EACH row)

59%

	Leaflet/handouts/signposting to online information	Explained verbally	Both handout and verbal information	I did not want any information	No information was provided	Cannot remember
Symptoms, diagnosis and causes of Parkinson's	0	0	0	0	0	0
Medication	0			0	0	0
Surgical treatments	0	0	0	0	0	0
Non-drug treatments (e.g. physiotherapy, occupational therapy, complementary therapies etc.)	0	0	0	0	0	0
Maintaining physical well being (e.g. healthy eating, exercise etc.)	0	0	0	0	0	0
Maintaining emotional well being (e.g. anxiety, mood changes etc.)	0	0	0	0	0	0
Financial help available	0	0	0	0	0	0
Support organisations (e.g. patient associations)	0	0	0	0	$\circ$	0
Support for carers	0	0	0	0	0	0
Where to find more information on Parkinson's	0	0	0	0	0	0
Taking part in clinical trials	0	0	0	0	0	0

#### 26. If you were given information, how helpful was it?

Very helpful	Quite helpful	Not very helpful	Not helpful	Cannot remember	No information was provided
0	0	$\circ$	$\circ$	0	0
		Prev	Next		

11. Getting a diagnosis of Parkinson's disease

				65%
L				<u> </u>
27. When you were giv	ven your diagnosis of F	Parkinson's, wei	re you given time to as	k questions and discuss
Yes, I was given enou	igh time			
Yes, but I would have	liked more time			
No, I was not given ar	ny time			
I did not want to ask q	uestions at that time			
I did not feel able to as	sk questions or discuss cond	cerns at that time		
Cannot remember				
		Prev	rt	

#### 12. Your treatment

							71%
28. How soo	n after yo	ur diagnosis	did you rec	eive any i	medicatio	n or treatme	nt therapy?
This was o	liscussed b	ut I decided aga	ainst taking me	edication at	that time		
Immediate	ly						
Less than	1 month						
At least 1	month but le	ess than 3 mon	ths				
At least 3	months but	less than 6 mor	nths				
At least 6	months but	less than 12 mo	onths				
12 months	or more						
Cannot re	member						
				Prev	Next		

M	My PD Journey questionnaire								
1:	3. Your treatment								
							76%		
	29. Which of the followi apply in EACH row)	ng medicati	ons have	you taken a	and who pre	scribed the	m? (Please	select AL	L that
		General practitioner or family doctor	Hospital doctor	General neurologist	Neurologist who is a specialist in Parkinson's	Geriatrician	Parkinson's disease nurse specialist	Other	Does not apply
	Duodopa®								
	Madopar®								
	Sinemet®								
	Stalevo®								
	Entacapone (Comtan/Comtess®)								
	Tolcapone (Tasmar®)								
	Apomorphine (APO-go®)								
	Cabergoline (Cabaser®)								
	Pergolide (Celance®)								
	Pramipexole (MIRAPEXIN®/SIFROL®)								
	Ropinirole (REQUIP®)								
	Rotigotine (NEUPRO®)								
	Rasagiline (Azilect®)								
	Selegiline (Eldepryl®)								
	Selegiline (Zelapar®)								
	Orphenadrine (Disipal®)								
	Amantadine (Symmetrel®)								

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my PD Journey questionnaire								
14. Your treatment								
					82%			
30. Who pays for the Parkinson's medication you are currently taking? (Please select ALL that apply)  State funded Private (myself / family) Insurance Parkinson's organisation Do not know  31. How satisfied are you with the care you are receiving from: (Please select ONE option in EACH row)								
	Very satisfied	Satisfied	Neutral	Dissatisfied	Very dissatisfied	Does not apply		
General practitioner or family doctor	0	0	0	0	0	0		
Hospital doctor	0	0	0	0	0	0		
General neurologist	0	0	0	0	0	0		
Neurologist who is a specialist in Parkinson's	0	$\circ$	$\circ$	0	$\circ$	0		
Care of the elderly doctor (geriatrician)	0	0	0	0	0	0		
Parkinson's disease nurse specialist	0	$\circ$	$\circ$	0	$\circ$	0		
Physiotherapist	0	0	0	0	0	0		
Occupational therapist	0					$\bigcirc$		
Speech and language	0	0	0	0	0	0		
		Pre	v Next					

My PD Journey que	estionnaire			
15. Your treatment				
			88%	

32. How satisfied are you with the following aspects of your treatment and overall care? (Please select ONE option in EACH row)

,	Very satisfied	Satisfied	Neutral	Dissatisfied	Very dissatisfied	Does not apply
How often your treatment plan is reviewed	0	0	0	0	0	0
The way healthcare professionals communicate with you about your condition and treatment options	0	0	0	0	0	0
The information you have received from healthcare professionals	0	0	0	0	0	0
Your level of involvement in the decisions about your treatment	$\circ$	$\circ$	0	$\circ$	$\circ$	0
Your family's / carer's level of involvement in the decisions about your treatment	0	0	0	0	0	0
The availability and accessibility of suitable treatment options when you need them	0	0	0	0	0	0
The suitability of your treatment for your condition and circumstances	0	0	0	0	0	0
The way the various healthcare professionals work together to deliver your treatment and care	0	0	0	0	0	0
			No4			

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my i b oodiney questionnaire							
16. Your treatment							
					94%		
33. Have you ever be etc.) for your Parkinso			•		ome care / for	mal carers,	
Yes – medication		(, , , , , , , , , , , , , , , , , , ,					
Yes – therapy							
Yes – care							
No							
Do not know							
34. Have you ever be			-			mal carers,	
etc.) for your Parkinso	on's because of	where you live	? (Please sele	ect ALL that app	ıly)		
Yes – medication							
Yes – therapy							
Yes – care							
No No							
Do not know							
35. How often is your	medication revie	ewed and by w	ho? (Please s	select ONF ontic	on in FACH re	ow)	
oo. How onon to your	THOUSE CONTROL	owou and by w	110. (1 10000 0	Once every 2	211 III	,,	
	Every 3 months	Every 6 months	Once a year	years or more	Do not know	Does not apply	
General practitioner or family doctor	0	0	0	0	0	0	
Hospital doctor							
General neurologist	0	0	$\circ$	0	0	0	
Neurologist who is a specialist in Parkinson's	$\bigcirc$	$\circ$	$\circ$	0	$\bigcirc$	0	
Geriatrician	0	0	0	0	0	0	
Parkinson's disease nurse specialist	0	0	$\circ$	$\circ$	0	0	
		Prev	/ Next				

#### 17. Your treatment

				100%
36. Have you had surg	gical treatment(s) for you	ır Parkinson's (e.g.	deep brain stimul	ation, duodopa, etc.)?
O No				
Yes (please specify w	what type of surgical treatment	)		
37. If yes, how soon a	after your diagnosis did y	ou have surgical tr	eatment?	
O Up to 5 years				
6 to 10 years				
11 to 15 years				
More than 15 years				
O Does not apply				
38. If yes, has the sur	gical treatment(s) met yo	our expectations?		
O Yes				
O No				
O Does not apply				
Please explain briefly why t	the surgical treatment has or h	nas not met with your e	xpectations	
		<u> </u>	<u> </u>	
L				
		Prev Done		