

‘Mapping Parkinson’s disease’

Information for Oireachtas meeting
17.05.2023

Project Information

Principal Investigator

The project was led by principal investigator **Professor Suzanne Timmons**, in the Centre for Gerontology and Rehabilitation, School of Medicine, at University College Cork.

Project Partners

Partners on this project included the **HSE’s National Clinical Programme for Neurology** (Prof Orla Hardiman), the **Parkinson’s Association of Ireland** (PAI, CEO Paula Gilmore), and **Cork Parkinson’s Association** (Chairperson, Tony Wilkinson).

Manager

The project was managed by Dr Emma O Shea, Centre for Gerontology and Rehabilitation, School of Medicine, University College Cork.

Funding

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Key Objective

A key objective of the Mapping Parkinson’s project was to understand the unmet service needs of people living with Parkinson’s disease (PD) in the Republic of Ireland, including levels of access to MDT services for those living in the community.

Methods

To understand patients' experiences of PD care, and any unmet needs they might have, we conducted the following:

A national survey of people living with PD

- A cross-sectional national survey of 1402 people living with PD was conducted with data collection occurring between May 2020-July 2021.

Telephone interviews with people living with PD

- We also conducted 25 in-depth interviews with people living with PD to gain rich data on their experiences of health service access and use.

Findings

Two sets of findings are provided in the sections that follow:

1) Survey and 2) Interview

1. Survey findings detailing rates of access to community-based MDT services.

A note about the survey data detailing access to MDT services

We asked participants 'Have you *seen* any of the following health professionals for issues relating to your Parkinson's disease'.

We know from the open-text responses that some people indicated they had 'seen' a healthcare professional, but not for issues relating to their personal healthcare, i.e., some people meant that they had seen a professional speak at a conference, an outreach event, or a peer support event. Therefore, the data presented below in the graphs is very likely to be an overestimation of the level of access to each of the MDT services.

2. Interview findings detailing direct quotes from people living with PD relating to the experience of trying to gain access to MDT support in the community.

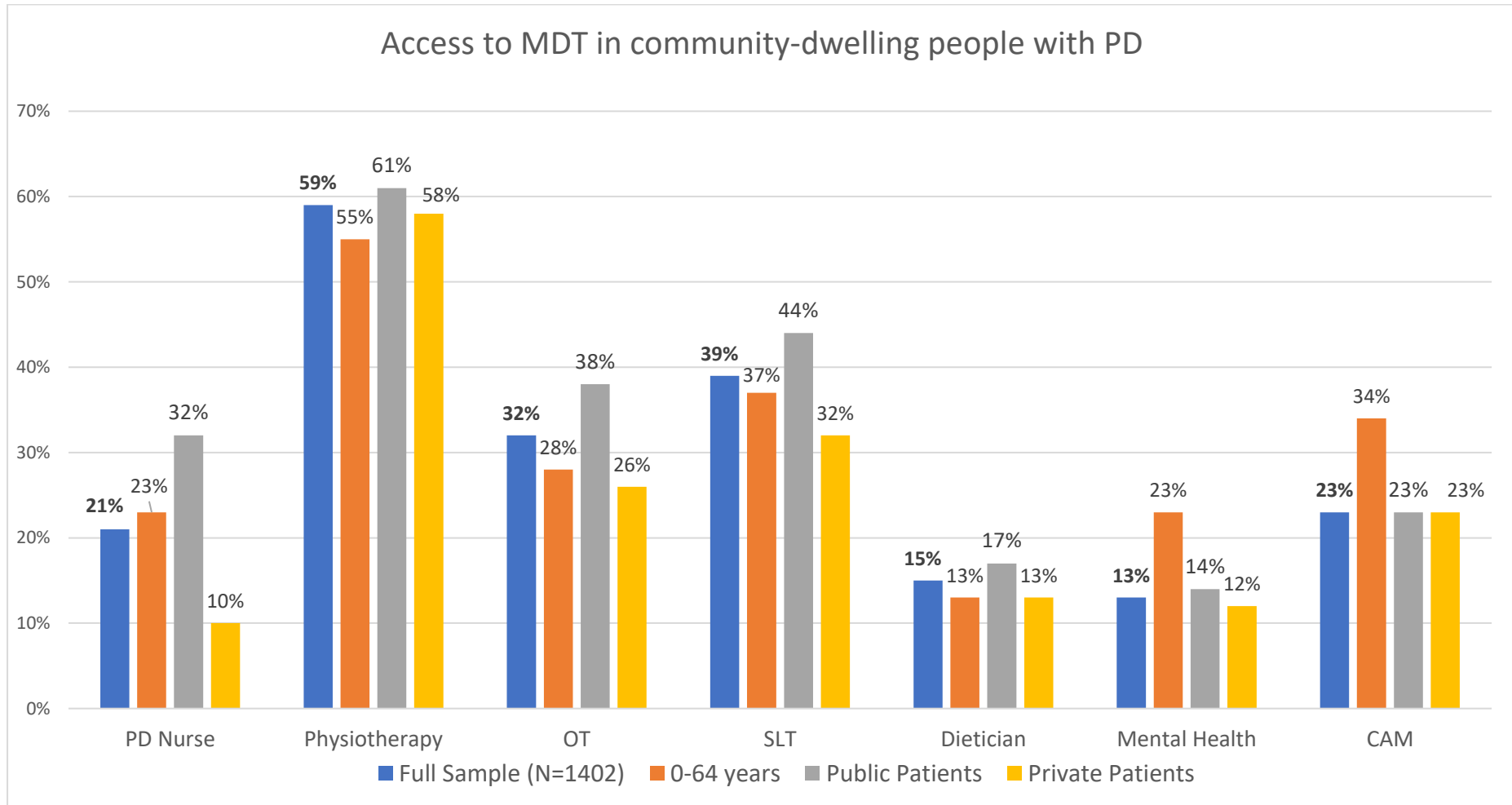
1. Survey Data

A total of **1402** responses were received on the survey. Demographic information about the sample characteristics is included in [Table 1](#) below:

Table 1. Sociodemographic Characteristics of People with PD (N=1402 respondents)

		Valid % (n)
Gender	Male	52.5% (732)
	Female	47.1% (657)
	Non-binary/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)
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)
	Home-maker	5.1% (n=67)
	Unemployed	0.8% (n=10)

The survey data also indicated that access to the range of health and social care professionals, including PD nurse specialists, and community MDT/clinical therapies was universally poor. Further information about access to community MDT services is detailed in the graph below.



2. Interview Data

The data presented here are from a series of in-depth qualitative interviews with 25 people living with PD across the country.

The characteristics of the sample that participated in these interviews, which includes people with PD from across all four provinces in Ireland, are detailed in [Table 2](#) below.

Table 2. Sociodemographic Characteristics of Interviewees

PP	Sex	Age	Years since Diagnosis	Marital Status	Occupation	Urban/Rural	Public/Private Patient
1	Female	63	16	Divorced	Employed	Urban	Public (private@Dx)
2	Female	76	10	Married	Homemaker	Urban	Private
3	Male	62	5	Widowed	Self-employed	Rural	Public
4	Male	47	3	Single	Employed	Urban	Private
5	Female	74	9	Separated	Self-employed	Urban	Public (private@Dx)
6	Female	71	6	Divorced	Retired	Rural	Private
7	Male	74	5	Single	Semi-retired	Rural	Public
8	Female	59	1	Married	Retired	Urban	Public (private@Dx)
9	Female	63	5	Married	Retired	Urban	Public (private@Dx)
10	Male	58	5	Married	Employed	Urban	Public (private@Dx)
11	Female	31	7	Married	Employed	Rural	Public (private@Dx)
12	Female	51	4	Married	Employed	Urban	Public (private@Dx)
13	Female	60	3	Married	Semi-retired	Rural	Public
14	Female	64	4	Partner	Retired	Rural	Public
15	Male	55	11	Married	Retired	Urban	Public
16	Female	72	2	Married	Retired	Rural	Public
17	Male	53	7	Married	Employed	Urban	Public
18	Female	67	2	Divorced	Retired	Rural	Private
19	Female	53	1	Married	Employed	Rural	Private
20	Female	74	N/A	Married	Retired	Rural	Private
21	Male	78	20	Married	Retired	Rural	Private
22	Female	85	N/A	Married	Retired	Rural	Private
23	Male	90	17	Married	Retired	Rural	Private
24	Female	74	20 (M)	Widowed	Retired	Urban	Private
25	Male	71	N/A	Married	Retired	Rural	Public (private@Dx)

Quotes from participants about access to MDT services are provided below, according to the following themes: 'Expertise in PD/Neurology'; 'Cost'; 'Distance'; 'Inequity'; 'Referral & Capacity Issues'; 'Poor Coordination/Continuity'; and 'Comparison to other countries'.

Expertise in PD/Neurological conditions

- "I was seen by a basic grade physio who didn't have any experience in Parkinson's."
- "Part of the problem is that many of these therapists are not trained in Parkinson's or neurological conditions."

- “We are not being referred, but there's also the fact that even if you get referred, the actual therapists aren't usually trained, and don't understand our specific problems.”
- “They (MDT) need to be properly trained in neurology and we need to invest in this way more than we're doing at the moment. When I talk about awareness, I'm not just talking about awareness with the general public. I'm talking about awareness with health professionals as well.”

Cost

- “So the OT was great. But I pay for that. I pay basically 100 quid a month to see her, which is a lot of money to me.”
- “I'm paying for those services myself like they're not just provided to you, I'd have no physio or OT if I couldn't pay for it.”

Distance

- “I did see a physio once for pain and stiffness and other problems. I got referred, but it was kind of disappointing because we live two hours away from where I got the referral... We don't mind coming to the city for doctors' appointments but it really didn't work going to a physio that far away... It's a shame really because I haven't found anything like that very close to home.”

Inequity

- “MDT care is a no-brainer. You can get it for diabetes, you can get it for cancer, why the hell aren't they doing for us?”
- “We are a bit disadvantaged where we live. We country people don't get as many services as those who live in cities. From what I can see, there isn't an effort to cater to us.”
- “I really hope that they don't forget about us on the outskirts though... It would be a great thing in my opinion if we could stay connected more to these healthcare professionals using technology, especially since I'm two hours from the city.... it's not a blanket solution, but I think this would save time and money all round.”

Referral & Capacity Issues

- “No, they [*consultants*] are not referring to therapists, even when people should be referred, because they know people will only be seen when they get very bad. The clinical therapists all play a huge role, especially when it comes to neurological conditions.”

- “There was a specialist nurse I spoke with once. She was excellent, but it's very limited service and at the time when I tried to ring her, it was probably five to seven days later before she was able to call me back. And the way I was at the time physically and mentally, I was truly contemplating *[suicide]*.”
- “I rang after 3 months of waiting and they said, ‘Oh, we've referred it out to community speech and language therapy’ and then months later, nothing was happening so I rang again, and they said to me, ‘can you please write a letter of complaint’, because apparently that’s the only way they could get me up the list.”
- “There are many sitting at home, waiting to be seen for therapies, and they are just deteriorating. And deteriorating way faster than they ought to be”.
- “There’s a bit of a chasm, you know? Don't get me wrong, the people delivering the care, they are so overworked and overstressed. But many of them are brilliant and they really do care. There just isn't enough of them.”

Poor care coordination/ continuity of care

- “I saw the OT at the Health Centre once and she said she would get back to me for an assessment. That was about three years ago now, I still haven't heard from her.”

Comparisons to other countries

- “I went to a place in Italy because again, I couldn't find any true multidisciplinary care in Ireland. I went over there for a week, and I basically had intensive physiotherapy from a neuro-physiotherapist. This was completely different than ordinary physio in Ireland because they understand what they are trying to do. I saw a dietician, a speech therapist, a psychologist. It was absolutely fantastic. It made a real difference in my life. I knew then what it was that I needed to look for, but there are no services like that in Ireland.”
- “From my own research, I think we are way behind other countries. Other countries like Italy, the UK and the US – they all have Centres of Excellence.”
- “Parkinson's is one of the fastest growing neurological conditions that we have because of population ageing. And the way we're treating it at the moment, it's just a recipe for disaster. It's side-lined. It is pushed aside every time. Every now and then, somebody famous who is diagnosed with it, comes out and goes public, and it's huge news with them, but then it just fades away. And, you know, we're not doing much in Ireland for people with Parkinson's.