

MAPPING PARKINSON'S DISEASE: POLICY BRIEF ON NURSE SPECIALISTS

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1. BACKGROUND

The prevalence of Parkinson's disease (PD) will double between 2015 and 2040. There has not been enough investment in PD healthcare services in Ireland. Under-staffing is a problem across all disciplines in these services (NAI, 2021). The role that is lacking most is the PD nurse specialist. PD nurses improve patient outcomes and save money for the health system, e.g., avoided hospital admissions.

2. METHODS

We have data on PD nurse availability and access, and patient experiences of same through:

1. National Survey of people with PD (N=1504)
2. PD Service Mapping (N=14)
3. Interviews with people with PD (N=25)

3. KEY FINDINGS

Service Mapping:

There are just 14 specialist PD outpatient clinics nationally, for a population of approximately 12,000 people with PD.

There are 480 specialist PD clinic sessions per year in Ireland. For each patient to be seen twice annually at a specialist PD clinic (as per NICE guidance), each clinic would have to see **50** patients per clinic session. Clinics can only see 8-25 (mean=15) patients per session, indicating the vast level of under-provision.

Only half (7/14) of the *specialist* PD services have either a PD nurse specialist or an advanced nurse practitioner attached to them.

Just 21% of people with PD reported having had any access to a PD nurse specialist since diagnosis.

"We have nowhere near enough PD nurses, and considerably less than what they have in other countries".

Nurse specialists, where available, provide hugely valuable services:

- Medication review/adherence
- Care coordination
- Emotional Support/Counselling
- Treating non-motor symptoms
- Domiciliary visits
- Self-management support

4. ACTIONS REQUIRED

Specialist PD services are under-provided.

All patients should have, at a minimum, access to yearly clinic visits.

All specialist clinics should have at least one PD nurse specialist.

All patients should have access to a PD nurse specialist.

A minimum of 30 PD nurses is required, to cater to the current population of people living with PD.

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