AUDIT OF MOVEMENT DISORDER SERVICES
IN THE REPUBLIC OF IRELAND

APRIL 2024

Parkinson's Ireland

nCPOP
National Clinical Programme
for Older People

NEUROLOGY

UCC
University College Cork, Ireland
Coláiste na hOllscoile Corcaigh

Centre for Gerontology
and Rehabilitation
An tIonad Seaneolaíochta
agus Athshlánaithe

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Foreword

We are delighted to present the results of a national audit of Movement Disorder Services performed in 2022/2023, the first such audit performed in Ireland.

This audit was designed and performed as part of a HRB-funded project endowed by a generous bequest from Patrick Quinn.

The audit aimed to generate data to inform and improve the provision of health and social care services for people living with Parkinson's disease (PD) in Ireland (Mapping Parkinson's: PQA-2019-002).

The lead knowledge user for the project data, including the audit, is the National Clinical Programme for Neurology, and the lead patient and public involvement (PPI) representative is Parkinson's Ireland. The National Clinical Programme for Older People is a collaborator.

The audit items are based on standards of care determined by an extensive literature review, and these naturally overlap significantly with the UK PD audit, but also reflect the Irish context and the priorities of our PPI contributors, namely people living with PD.

There are 14 specialist Movement Disorder Services in Ireland and 11 of these voluntarily took part in this audit.

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Principal Investigator

If citing this report, please reference it as follows:

Abbreviations

6-CIT: Six-Item Cognitive Impairment Test

ANP: Advanced Nurse Practitioner

DBS: Deep Brain Stimulation

GP: General Practitioner

H&Y: Hoehn and Yahr (staging system)

HCRs: Healthcare Records

HSE: Health Service Executive

iPMS: Integrated Patient Management System

MCI: Mild Cognitive Impairment

MDT: Multidisciplinary Team

MMSE: Mini-Mental State Examination

MoCA: Montreal Cognitive Assessment

OT: Occupational Therapist

PD: Parkinson's disease

PDNS: PD Nurse Specialist

PD-RANP: PD Registered Advanced Nurse Practitioner

PPI: Patient and Public Involvement

SLT: Speech and Language Therapy

1. Executive summary

This audit measures the quality of care provided to people living with Parkinson's disease (PD) across Ireland against a range of evidence-based guidance and standards. It involves geriatric-led and neurology-led services that care for people with movement disorders (i.e. specialist PD services). The audit identified both several areas of good practice and shortcomings in services.

Evidence of good practice

- Clear documentation of current PD medications.

- Regular motor symptom and mobility assessments.

Areas for improvement

- Delays between referral and first visit, with less than one-third of patients seen within 6 months of referral.

- Insufficient communication and information sharing, especially at the time of diagnosis.

- PD nurse specialists are quite limited throughout the country and are located mainly in Dublin.

- Multidisciplinary input was poor, especially dietetics and social work input; there was evidence of unmet psychological needs, with psychology input mainly confined to a small number of cases attending neurology-led clinics.

- Significant variability between clinics for many assessments.

- Poor attention to the management of bone health.

- Blood pressure and nutritional status assessments were insufficiently recorded in neurology-led services. Cognition, pain, fatigue, and saliva management were poorly recorded generally, with fatigue insufficiently assessed in geriatric-led clinics especially.

- Insufficient use of appropriate standardised assessments (i.e., cognition, mobility, and activities of daily living).

- Low rate of documented discussion on non-medication management of PD symptoms other than physical activity, with insufficient focus on areas such as self-management, sleep, or mood.

- Lack of documentation on anticipatory and advance care planning.

2.   Introduction

The overall aim of this first national PD audit is to provide timely information to clinicians, commissioners, funders, members of the PD community, and the public on how well Movement Disorder services in Ireland are delivering timely, responsive, and patient-centred multidisciplinary care to patients attending the service. The secondary aim is to identify deficits in services and hence improve the quality of care.

Background

Parkinson's disease (PD) is a progressive, degenerative disorder of the nervous system and the second most common progressive chronic neurodegenerative disease. From 1990 to 2015, the number of people with PD globally doubled to over six million (GBD 2015 Neurological Disorders Collaborator Group, 2017). According to estimates, PD affects 1% of people over 60 and 2% of people over 80 (Pringsheim et al., 2014). In many countries, as the median age rises, so does the prevalence of PD (Dorsey et al., 2018). Driven principally by ageing, the current prevalence is projected to double again to over 12 million by 2040 (Dorsey & Bloem, 2018). Consequently, the increasing incidence of PD will impact demand for clinical expertise to care for this complex disease process.

The diagnosis has profound implications for the individual and their family as well as major cost to health and social care services (Martinez-Martin et al. 2019; Yang et al., 2020). For example, it was estimated that approximately one million people in the US were diagnosed with PD in 2017, with a total economic burden of $51.9 billion (Yang et al., 2020). Management is particularly challenging due to the complex mix of problems relating to speech and swallowing, memory and mood, sleep, pain, and continence, which compound the movement disorder. Different professionals are involved in managing PD, including geriatric-led and neurology-led services, specialist nursing, occupational therapy (OT), physiotherapy, and speech and language therapy (SLT).

Countries including the United Kingdom (UK) have carried out audits of PD care to gain a baseline picture of the diagnosis rates and quality of care provision (Parkinson's UK, 2009; 2010; 2011; 2012; 2015; 2017; 2019; 2022). In Ireland, approximately 12,000 people were estimated to have PD based on the 2016 Census population data (Parkinson's Ireland, 2020). However, no audit of PD care in Ireland had ever taken place, even though some individual services had taken part in a previous round of the UK audit to benchmark their service. Therefore, as part of the HRB-funded Mapping Parkinson's project, a national audit of PD services was planned and took place.

It is important to note that many people with PD in Ireland are not under the care of a specialist Movement Disorder service, but rather attend their General Practitioner (GP) only, or more often attend a consultant neurologist or geriatrician at a generic clinic, or privately, where patients with many different diseases attend in that same service. It is unlikely that PD care in those generic services is better than care in a specialist service (O' Shea et al., 2023).

Aim

To compare the practice of specialist Movement Disorder services with agreed standards of care for PD as a baseline for future quality improvement.

Objectives

1. To pilot the methodology and infrastructure for conducting a national audit of Movement Disorder services.

2. To establish the practice of specialist Movement Disorder services compared with agreed standards of care for PD.

3. To highlight areas of good and poor practice for local discussion and the development and implementation of local action plans to improve the quality of care.

4. To establish baseline audit data to allow future:

   • National mapping of geographical variations in the quality of care.

   • Local and national mapping of progress in service provision and patient care through participation in future audit cycles.

3.   Methodology

Introduction and tool development

There were no national standards in place in Ireland for specialist outpatient PD care at the time of this audit. Thus, the project steering committee developed standards de novo based on a systematic review of the literature for PD care quality indicators and clinical guidelines (e.g. the NICE guideline on PD in adults, 2017), in conjunction with the National Clinical Programme for Neurology, Parkinson's Ireland, and an iterative Patient and Public Involvement (PPI) consultation process with 10 people living with PD across Ireland. The audit tool addressed the standards and was operationalised to capture practice from case notes documentation. The audit tool was piloted in eight case notes across two clinics, with minor revisions made to the wording or order of questions for greater ease of completion. Many of the items in the tool are consistent with items on the PD UK audit tool, which allowed for some direct comparison across care parameters.

Clinic recruitment & participation

The location and governance of specialist "Movement Disorder" or "PD" clinics that see adults with known or suspected PD in the Republic of Ireland was established as part of the larger project, where all neurologists and geriatricians were asked to indicate if they, or their colleagues ran or might run such a clinic. Consultants known by the research team to provide such a clinic, or known PD specialist nurses, were particularly targeted both to confirm their own service and to name others, reasoning that specialist services generally know the location of other specialist services. Some consultants who were known to have expertise in PD clarified that they did not run a specialist clinic but saw people with PD in a generic clinic thus were not included in this audit. Based on this consultation 14 services/clinics were identified and participated in other aspects of the project. All were later invited to participate in the audit and 11 agreed.

Some of these clinics are more correctly called services as they operate a Monday-Friday telephone-based and/or walk-in patient service outside of a single clinic session, but for convenience all are called clinics. The invitation to participate in this audit was sent to the clinic leads, i.e., the consultant neurologist, consultant geriatrician, PD nurse specialist (PDNS), and/or registered advanced nurse practitioner (PD-RANP) who led the clinic.

Data collection

Data collection for this audit was conducted over a 10-month period between April 2022 and February 2023. The originally planned data collection period was six months duration, starting in April 2021. However, there were two significant contextual barriers faced by all clinics during the data collection period for this audit. These were 1) the COVID-19 pandemic, and 2) the May 2021 ransomware cyberattack on the Health Service Executive (HSE) IT systems. This delayed the ability of clinics to pilot the tool, and later to collect the required data. The audit tool was finalised in March 2022 and distributed to services for data collection in April 2022. Some clinics were not able to begin collecting the data until later that year.

A comprehensive audit guidance document was developed and distributed as a guide for auditors, to facilitate consistent and accurate recording of data. Auditors included

doctors, nurses, and other health and social care professionals attached to each clinic. It took approximately 30-45 minutes to complete a review of each patient's healthcare record (HCR) for the purposes of data collection for this audit. The HCRs (i.e., case notes) of 6-30 patients were audited per participating clinic.

The audit collected data on factors relating to referral, diagnosis, assessments conducted, care coordination, and continuity, availability of specialist nursing and other multidisciplinary (MDT) input, pharmacological interventions, device-assisted therapies, and advance care planning. When it was not provided by auditors, to provide context to the data where possible, Hoehn and Yahr (H&Y) stages were retrospectively assigned by a movement disorder specialist based on the recorded information.

At the end of each section of the audit tool, comment boxes were provided to facilitate auditors to provide additional explanatory information to qualify responses to items, where necessary. This was with a view to increasing inter-rater reliability and interpretation of unclear responses. The comment boxes also allowed auditors to provide feedback on the tool itself; this will help us further refine this new tool, to facilitate future rounds of this national audit.

It is important to note that to uphold patient confidentiality, we informed auditors not to record any information about patients in the comment boxes, that might make them directly identifiable.

Sample selection

Eligible HCRs were identified for review by clinic staff through the Integrated Patient Management System (iPMS), by applying the following criteria and procedures:

ICD-10 code: G20

The included HCRs were from patients with a current, formally recorded clinical diagnosis of PD (ICD-10-CM, Code G20). This includes the following:

- Hemiparkinsonism

- Idiopathic Parkinson's disease

- Paralysis agitans

- Parkinsonism or Parkinson's disease "not otherwise specified"

- Primary Parkinsonism or Parkinson's disease

Auditors were explicitly asked to exclude patients who were referred to the clinic for assessment or a second opinion querying PD, but were ultimately not assigned a PD diagnosis.

Case note selection process

Auditors were required to choose a random selection of five clinic sessions that had occurred within the most recent 12-month period. Within each of these clinic sessions, they were asked to identify (where possible) two new and four return cases at random.

New patients

'New' patients were defined as individuals who attended the clinic for the first time during the audit period. Most were newly diagnosed with PD at that clinic or sub- or a subsequent clinic visit; some attended the clinic de novo with known PD. For newly diagnosed PD patients, auditors were asked to focus on all clinic visits to date (approximately 1-3 visits total).

Returning patients

For returning PD patients, who were defined as having more than six visits to the clinic, we asked auditors to focus on their first three clinic visits (relating to diagnosis and early post-diagnostic support), if that took place in the clinic in question, and their three most recent clinic visits (follow-up and ongoing management).

'Complex' PD

Auditors were asked to mark cases of complex PD within the above case finding exercise. Complex PD was operationalised in the audit to apply to patients who were diagnosed 4+ years ago; AND are taking 4+ doses of dopaminergic agents per day; AND present with troublesome 'wearing off', dyskinesia, or other motor fluctuations, or with non-motor fluctuations, despite optimisation of medical therapy.

Care partners/carers

Auditors were requested to report on the interactions with care partners. We use the term care partners/carers to describe anyone who provides unpaid care and support to someone with PD.

Data analysis

Most data were categorical in nature and valid percentages were reported, with the numerator/denominator value also reported whenever the denominator is less than 90% of the total dataset. To compare categorical data between distinct groups, chi-square tests were performed (at a statistical threshold of $p < 0.05$). Median and interquartile ranges were used to describe the distribution of continuous variables, including age and time since PD diagnosis as the data did not have a normal distribution. To compare continuous variables between two distinct groups, when applicable (n>50), a t-test was conducted, otherwise, a non-parametric test (i.e., Wilcoxon test) was conducted (both at a statistical threshold of $p < 0.05$). All analyses were conducted with R, in R studio (R Core Team, 2022).

Caveat

The guidance notes encouraged, but did not mandate, a minimum sample size of 30 case notes for the patient audit which caused variance between samples. There were six case notes in one centre, 15 case notes in another centre, 20 case notes in three centres, and all other centres had 30 case notes. This should be considered when interpreting a centre's performance or comparing it with other centres. Since the clinicians were self-motivated to participate, the results may be biased in favour of more developed services.

Ethics

Clinics in Ireland can perform clinical audits as a part of healthcare delivery without individual patient consent, where the case notes are reviewed by clinical staff or other pre-approved staff authorised to do so. Ethical approval was given by the Clinical Research Ethics Committee (CREC) of the Cork Teaching Hospitals, University College Cork so that, where clinic staff could not perform the audit but wanted to take part, the research team could audit the case notes following explicit patient consent to this external case note review. Each service was assigned a code, kept securely by the audit coordinator (EoS), and individual clinic-level data was only released to each clinic's lead. Similarly, each patient's case notes were assigned a code at the source, stored locally at the site, and no identifying patient details were recorded or shared with the research team. To avoid using date of birth, age was recorded by using the patient's year of birth and a code (1 or 2) for whether the month of birth fell within the first or second half of the year.

4. Audit sample

Of the 14 Movement Disorder Services across Ireland 11 sites volunteered to participate in the audit and provided data on 261 patients from Ireland, comprising 6-30 patients per participating clinic. Three sites were not able to take part due to insufficient staff capacity for self-audit or the time/resources to facilitate an external audit. All but one clinic was audited entirely by the clinic staff. The distribution of audited case notes across Ireland is shown in Figure 1. Although the majority of the audited case notes are from Dublin (n= 130), the audit also included services from Donegal (n= 30), Cork (n= 45), Limerick (n=30), Waterford (n=20), and Galway (n=6).
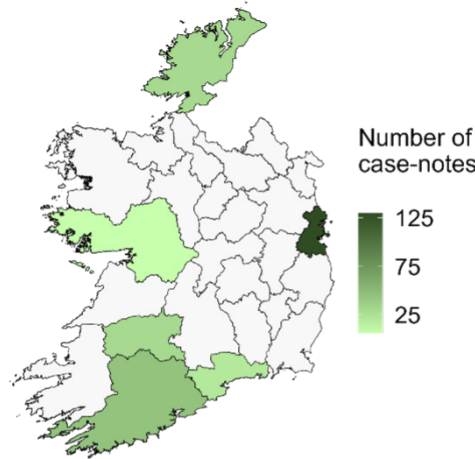

Figure 1: PD case notes audited across Ireland. The darker green shade indicates the higher number of audited case notes.

Demographic information

The sample comprised 65.1% males and 34.5% females (Figure 2B); the median age was 74 years (interquartile range [IQR] 68.5-79 years) and the majority (83.1%) of patients were > 65 years of age while 8% of patients were < 60 years of age (Figure 2A).
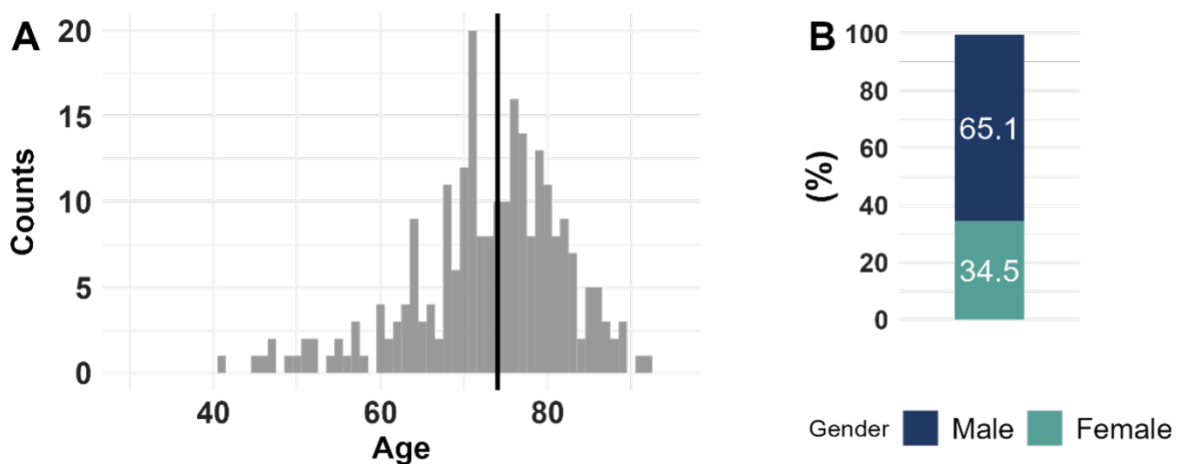

Figure 2: Age (A) and gender (B) of participants. The black line in the age plot is the median of the data with the length of each bar indicating the frequency of ages.

In total, 51.8% (126/243) of people received their diagnosis of PD within the reporting clinic. The median age at the time of diagnosis was 68 years (interquartile range [IQR] 60.25-74 years) (Figure 3A) and the median time since diagnosis was 5 years (interquartile range [IQR] 2-8 years) (Figure 3B).
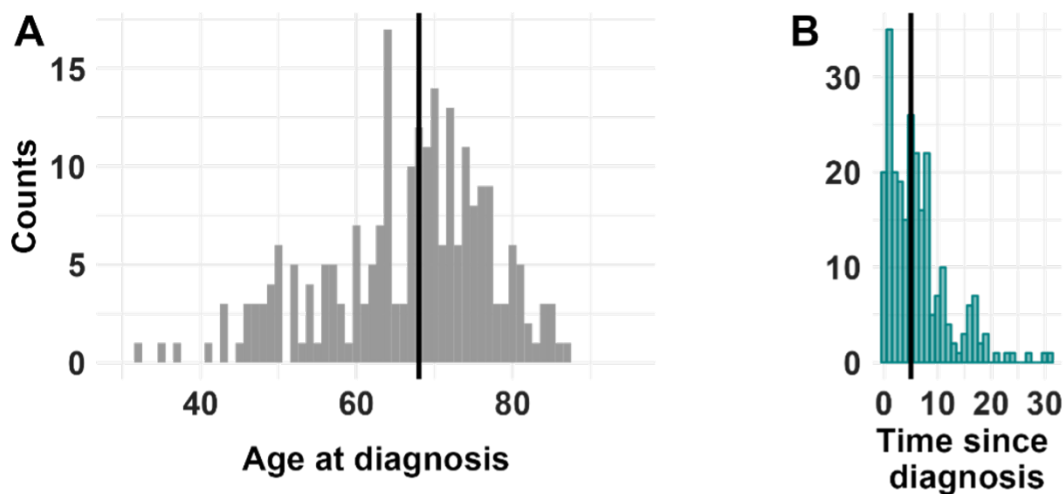

Figure 3: Age at diagnosis (A) and time since diagnosis (B). The black lines are the median of the data with the height of each bar indicating the frequencies.

Regarding their living situation, most PD patients lived with a spouse/partner/family member (82.6%), including almost 67% living with their spouse/partner and 15.6% living with other members of the family. While almost 14% live alone, 2.3% (6/257; all return patients) live in long-term care (Figure 4A). Approximately 57% of patients had carers (Figure 4B).
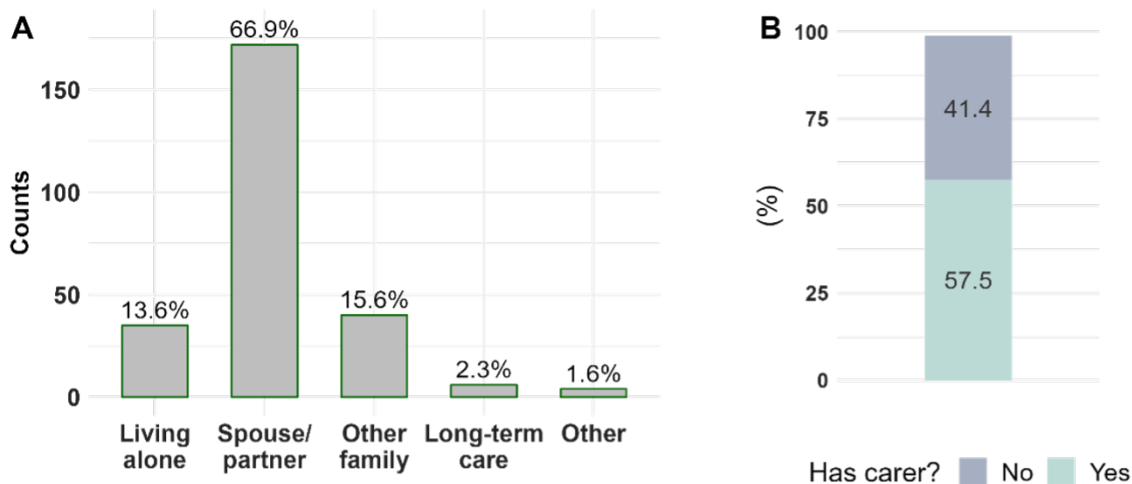

Figure 4: (A) Living situation: most patients live with their families. (B) Percentage of people with a care partner.

When information about ethnicity was available, 93.4% of patients were white Irish (Figure 5).
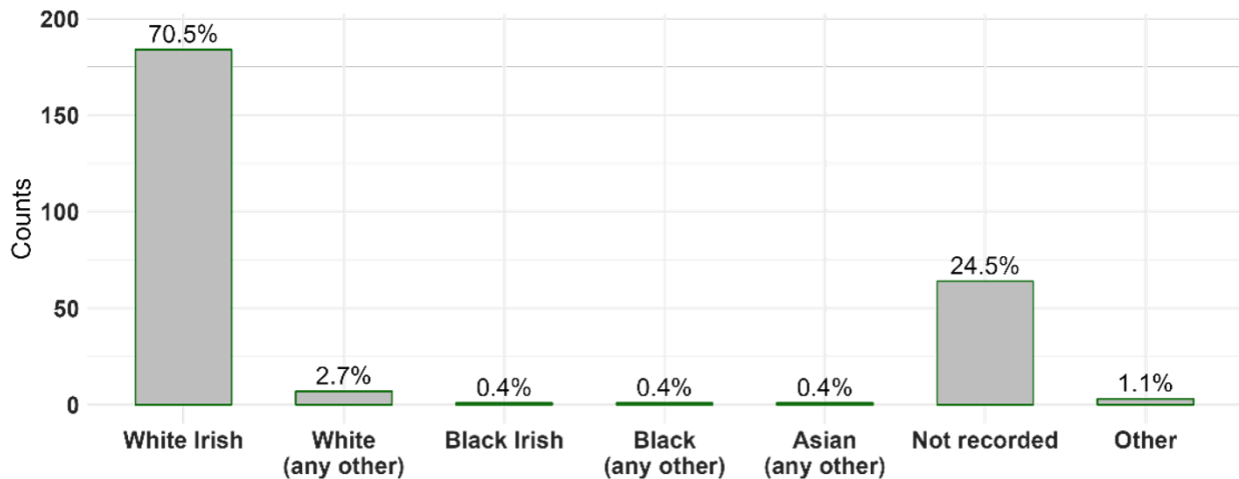

Figure 5: Ethnicity of patients. When information was available, most of the cases were white Irish.

Geriatric-led and neurology-led services

The audit included geriatric-led services (n=5 sites; 115 [44.1% of] case notes) and neurology-led services (n=6 sites; 146 [55.9% of] case notes). Overall, patients audited at neurology-led services (mean age: 70.1, SD 9.28 years) were younger than in geriatric-led services (mean age: 76.5, SD 7.78 years) ($p < 0.001$; Figure 6A). Age data are displayed for individual clinics in Figure 6B, demonstrating that the age profile in a geriatric clinic varies between clinics, with one clinic seeing a proportion of people under 60 years old and three mainly seeing people over 70 (noting the caveat of this being a small sample of overall caseloads).
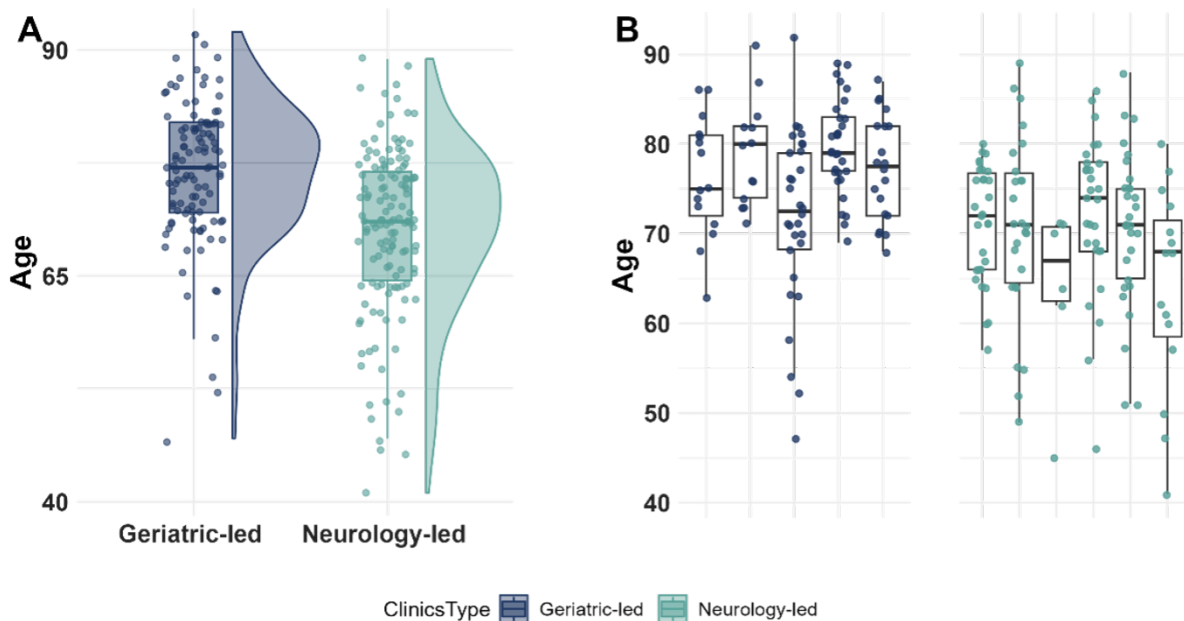

Figure 6: (A) Age of patients admitted to any geriatric-led and any neurology-led services (median and IQR to left (box) and range (line); data spread and frequency to right). (B) Age across individual services (median and IQR to left (box) and range (line).

Disease characteristics

The severity of the PD had been recorded within the last 2 years for 52.1% of patients. The frequency of recording of the stage of PD in patients admitted to neurology-led services was higher than in patients admitted to geriatric-led services (61% vs 40.9%; p<0.001; n=253). To provide context to the audit data, we requested that if the stage had not been recorded then proxy markers could be used to indicate the stage based on evidence in the notes (e.g., unilateral tremor only; or bilateral bradykinesia and falls; or wheelchair-bound; etc.). Assigning a stage to additional patients based on these details (n=130), in 69% of case notes, the H&Y stage of PD was available; with H&Y Stage 2 being the most common (Figure 7).
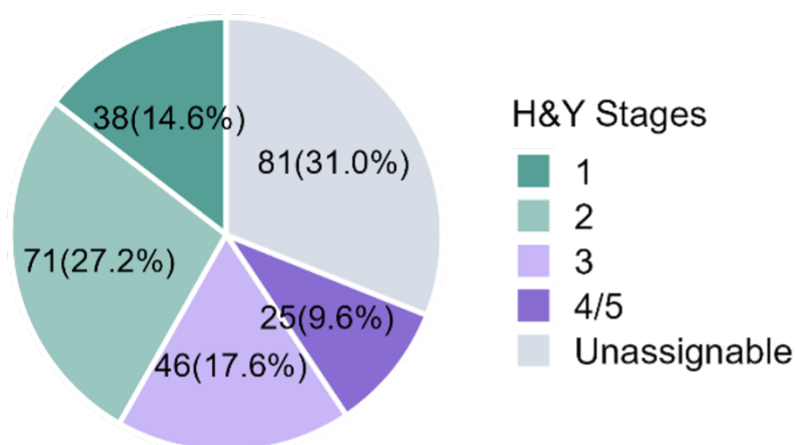

Figure 7: H&Y stages in the audit sample. Stages 1 and 2 are early-stage disease (unilateral or bilateral symptoms but no imbalance); stage 3 represents mid-stage disease (impaired balance and mild-moderate disability). In stage 4, the person is still independent in standing and mobility during good periods but has a severe disability) while in stage 5 the person is bed or chair-bound unless aided.

Although there were some missing data, it seems that there was a variation in the PD stages between the services (Figure 8).
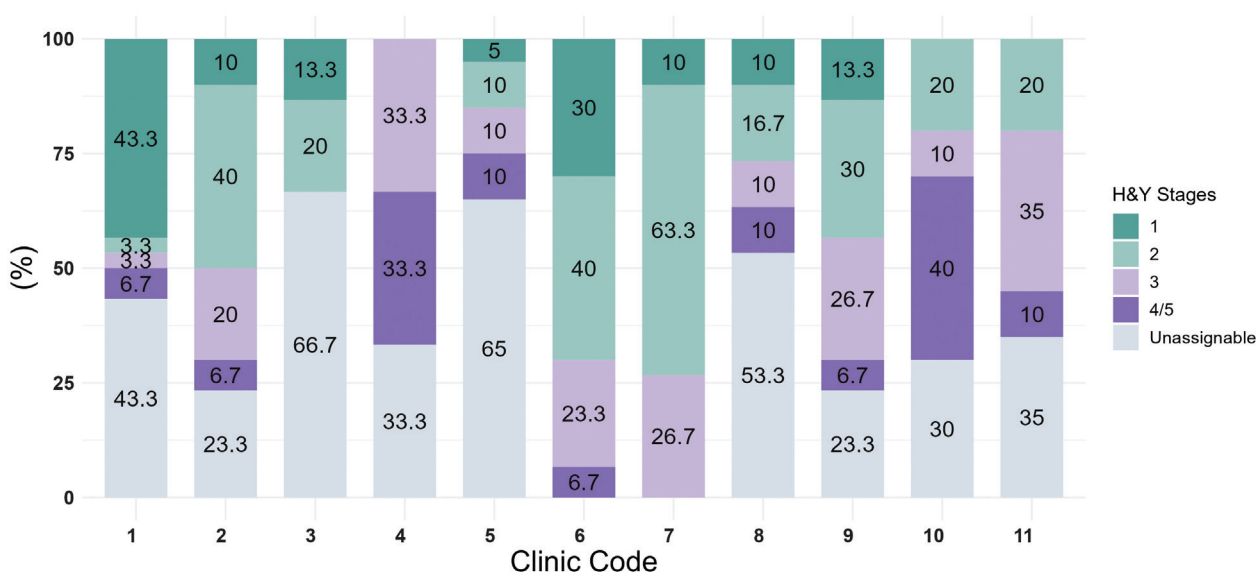

Figure 8: H&Y stages of PD in each centre (n = 261). While there is missing data in some of the services, there is variation in the severity of PD between services.

There was evidence of a significant difference in PD stages between neurology-led and geriatric-led services (Figure 9; p < 0.001).
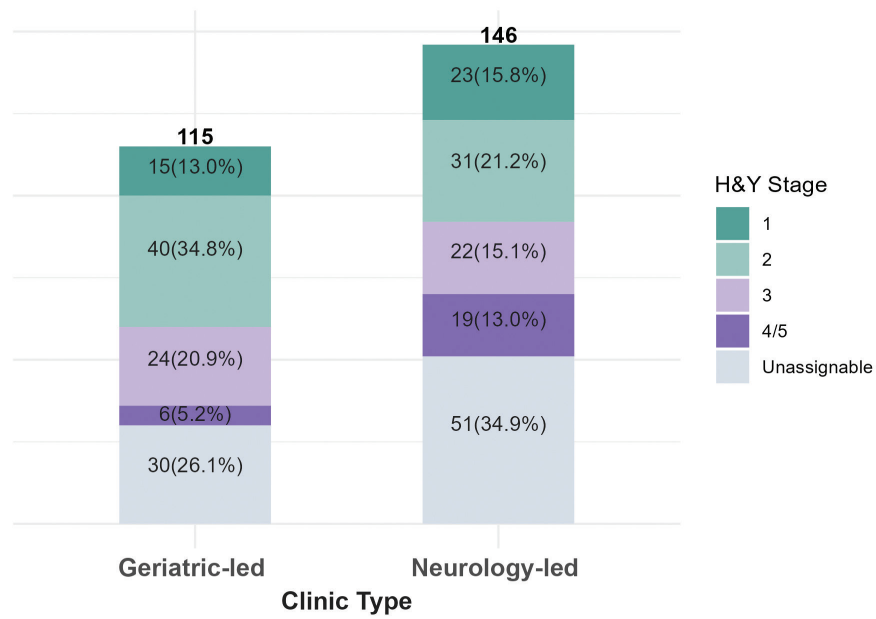

Figure 9: H&Y stages of PD grouped by clinic types (n = 261).

5.   PDNS and multidisciplinary input

Evidence of input from PDNS

Overall, 64.7% (158/244) of patients were from services with access to a PDNS or a PD-RANP (Figure 10A). A slightly lower proportion of the sample 56.5% (147/259) had documentation of being seen by a PDNS (Figure 10B).
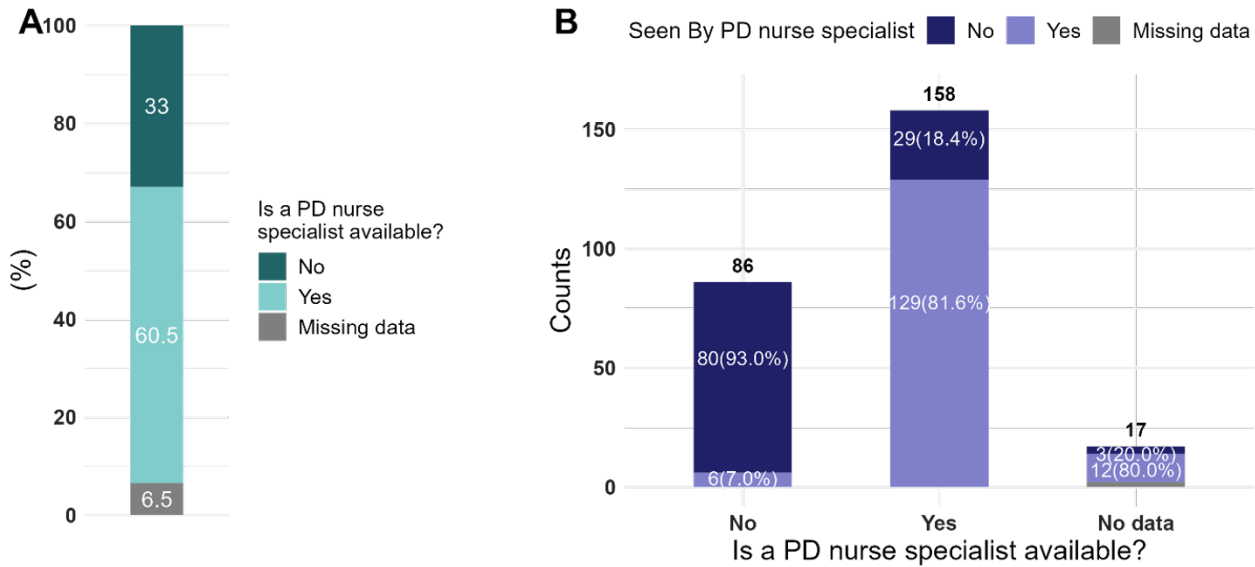

Figure 10: PD nurse specialist input. (A) The percentage of patients which were in a service with access to a PDNS. (B) The percentage of patients were seen by a PDNS or not grouped by access to a PDNS.

Three clinics (of 11) had no access to a PDNS at all; another clinic reported that although they had access in the past, they no longer did. There was a variation in case notes seen by a PDNS across each clinic as well (Figure 11).
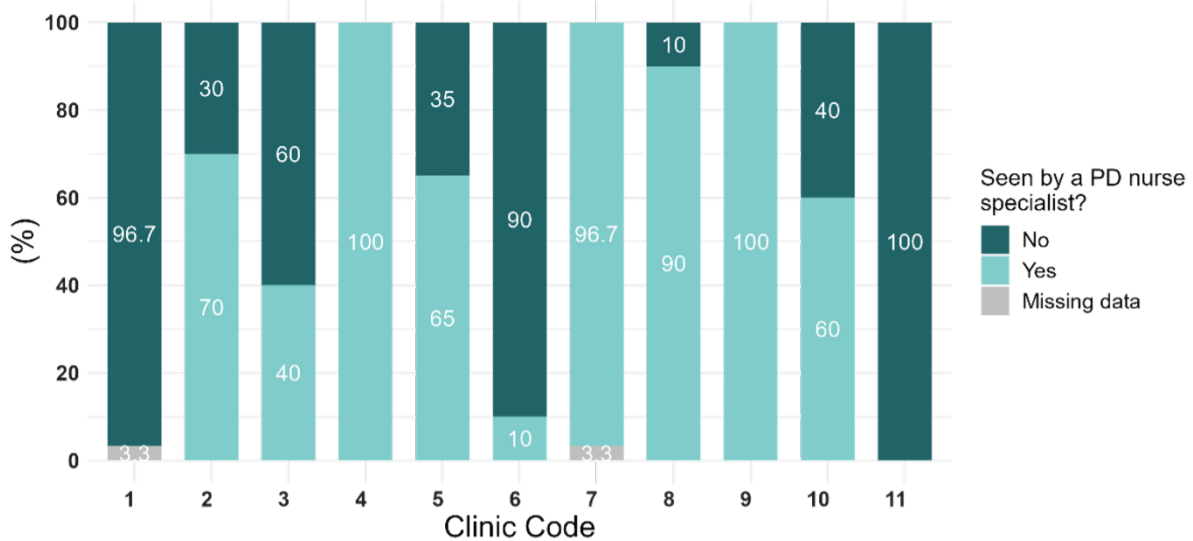

Figure 11: The proportion of cases seen by a PDNS in each clinic (n = 259). Though some of the patients in some services had access to PDNS, they were not seen by a PDNS.

The availability of PDNS across the country was inconsistent. While all patients have access to a PDNS in Dublin city (124/124), 29% (28/95) of the patients from Munster province and 17% (6/36) of patients from Ulster/Connacht provinces have access to a PDNS (Figure 12).
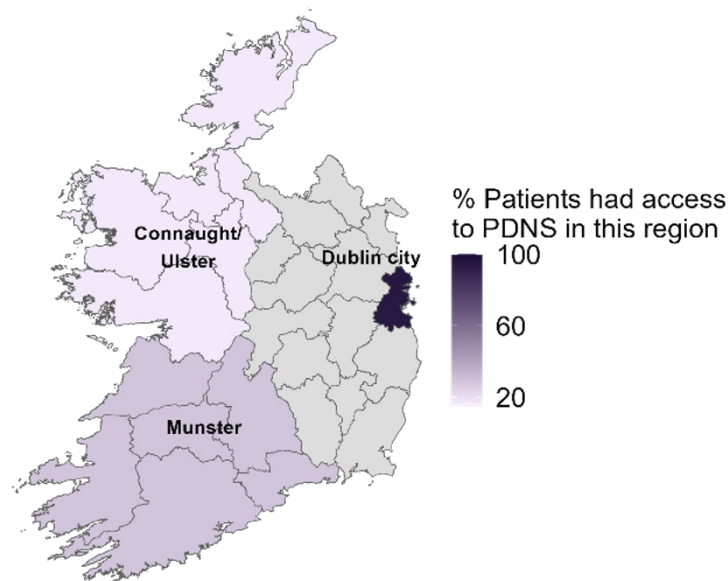

Figure 12: PDNS availability across Ireland. The darker purple shade indicates the higher number of PDNS available in the area for case notes. No information is available from the rest of Leinster other than Dublin.

The access to a PDNS was higher in neurology-led services (77.9%) than in geriatric-led services (49.6%) ($\chi2 = 20.07$, $p < 0.001$; n=244). Also, there was a significant difference between cases actually seen by a PDNS in neurology-led and geriatric-led services (66.2% versus 44.7%; $\chi2 = 11.13$, $p < 0.001$; n=259).

Evidence of multidisciplinary involvement

Whilst 68.6% of patients received physiotherapy involvement (or it was documented that no involvement was needed), this figure was lower for OT (50.2%) and SLT (52.9%). This figure was lower again for dietician or social work involvement, with documentation of involvement or no need for involvement in under 31% of patients. In fact, only nearly 8% of cases had seen either of these disciplines. While almost 36.8% of cases had documented problems with mood/anxiety, 73.2% of cases did not receive neuro/clinical psychology involvement (Figure 13). Thus, in 60% (57/95) of cases with recorded mood/anxiety issues, there was no involvement from psychology services.
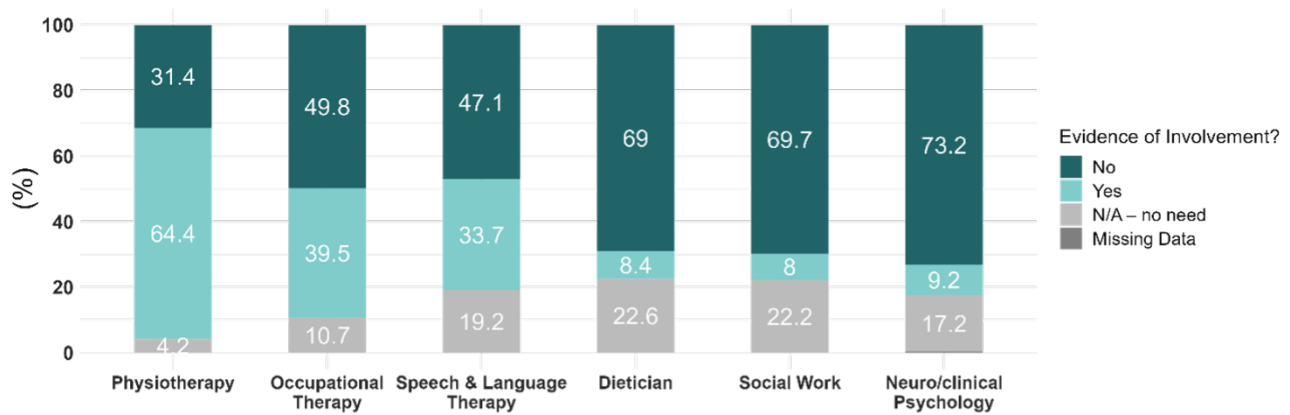
Figure 13: Evidence of multidisciplinary involvement.

Patients who were seen by a PDNS compared to those not seen by a PDNS were more likely to receive physiotherapy (or no involvement was needed; 74% vs 60.7%; $\chi2$ = 4.70, p=0.03; n=259). Patients attending a gerontology-led service had a higher frequency of dietician involvement (or it was documented that no involvement was needed) (40%) than those attending neurology-led services (24.1%) ($\chi2$ = 6.99, p=0.008; n=261), and also more social work involvement (41.1%) compared to neurology-led services (21.2%) ($\chi2$ = 11.86, p<0.001; n=261). However, there were no significant differences between the other disciplines in these two groups.

6.   Care received: assessment and non-pharmacological management

The time between referral and first visit

When available (n = 108), the median time between the date on the filed referral letter, and the date the patient was first seen at that specific clinic/service was 2.25 months but with a significant range (IQR 1.5- 5 months, range 0.25–20 months). This time was less than six months in 29.6% (32/108) of cases.

Frequency of visits

The majority of the audited cases were returning patients (79.5% [202/254]). Where data were available (n = 202), the median time between the patient's last visit and their second-to-last visit at that clinic/service was six months (IQR 4- 9 months, range 0-44). This time was less than six months for under 38.6% (78/202) of cases (Figure 14A). For 83.2% (168/202) of cases, the time between their last visit and second last visit was less than a year.
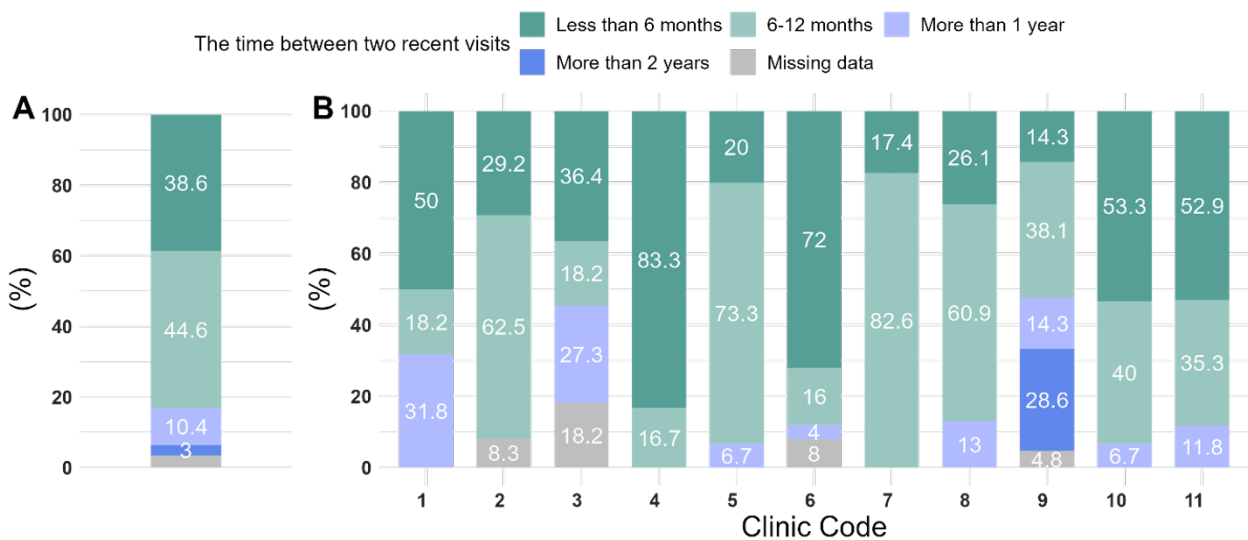

Figure 14: The time between two recent visits for returning patients (n=202). (A) The data from all the case notes. (B) The time between two recent visits across services. In the majority of cases, the time between two recent visits was less than a year.

The interval between the two most recent visits varied between services (Figure 14B). This was longer in neurology-led (median 6 months [IQR = 4-11 months]) than geriatric-led (median: six months [IQR = 3.25-6.75 months]) clinics (p =0.007). It must be noted that inter-visit intervals may relate to patient needs as well as to service capacity.

Adoption of remote consultations

During the COVID-19 pandemic, due to the mandated restrictions, outpatient services supporting people with PD had to cease or be delivered remotely. Remote consultations have both advantages and challenges for this population. These results show that of returning patients, 23.8% (48/202) had a remote visit during three recent visits, with this becoming less common over time as restrictions eased (Figure 15).
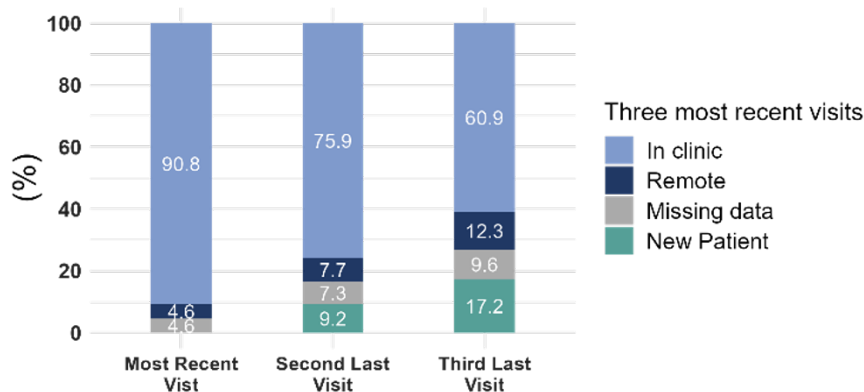

Figure 15: Adoption of remote consultations in three most recent visits.

Overall, 6% (17/303) of visits in geriatric-led services and 13.2% (47/355) of visits in neurology-led services were remote across all 658 documented visits, i.e., the three most recent for each patient ($\chi 2$ = 9.98, p=0.002; n=658). Clinics that had access to PD-RANP/PDNS had a greater number of remote consultations than clinics that did not (13.4% [54/402] vs. 3.5% [8/229]; $\chi 2$ = 15.2, p<0.001; n=631).

Received written information about PD

According to the case-note documentation, almost 23.8% of patients were given written information about PD upon diagnosis (Figure 16A). Overall, 51.9% (126/243) of patients had been diagnosed within the clinic services; with none of the patients of one of the clinics having been diagnosed there (code 9). For these 126 cases, receiving written information about PD upon diagnosis was inadequate (23.8%; 30/126) and varied between services. One service had documentation of providing written information for all cases on diagnosis, while two clinics had provided written information to none, and four others provided written information to less than 15% (Figure 16B). Where there was PDNS/RANP availability, services provided written information about PD upon diagnosis more frequently (35.7% [25/70] vs 8.5% [4 /47]; $\chi 2$ = 6.24, p=0.01; n=260).
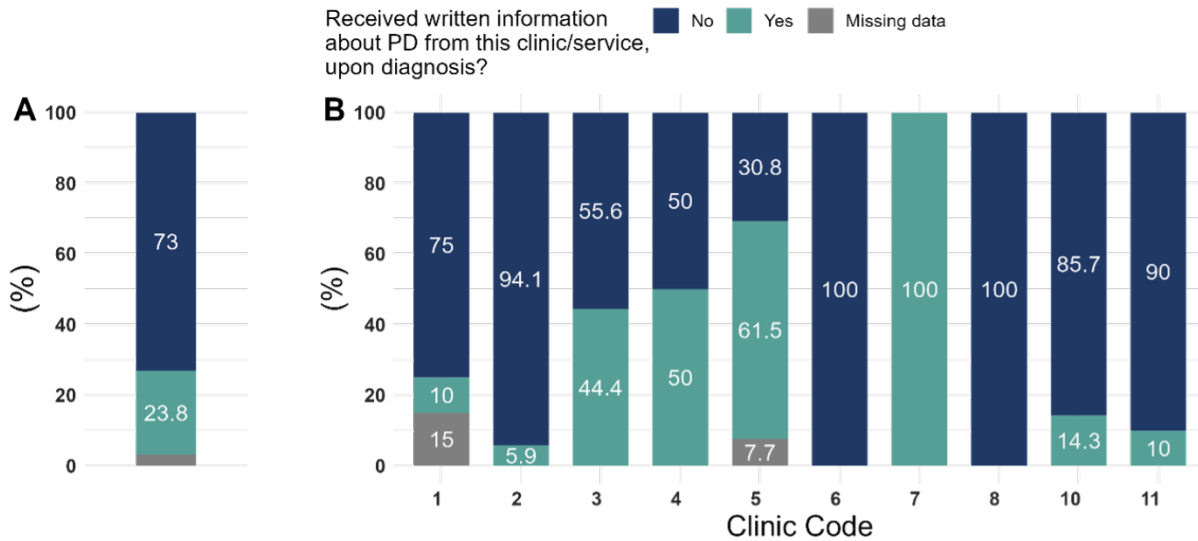
Figure 16: Received written information about PD from this clinic/service, upon diagnosis (n = 126). (A) The data from all the case notes. (B) The data across services. Clinic 9 is omitted as no relevant data.

Primary contact details and information on peer support

There was documentation in over two-thirds of case notes (70.5%; Figure 17A) that the patient was offered details of a primary point of contact linked to the clinic/service. From the available data, the contact's role was a PDNS in 36.2% (68/188) of cases, an advanced nurse practitioner (ANP) in 21.3% (40/188) of cases, a PD-ANP in 13.3% (25/188) of cases, a clinic nurse in 7.6% (14/184) of cases, and the remaining were mostly the clinic phone number. While three services had this documentation for all patients, one service did not appear to provide a contact number for 29/30 patients (Figure 17B). Overall, 34.5% of patients received information on available peer support, again varying between services.
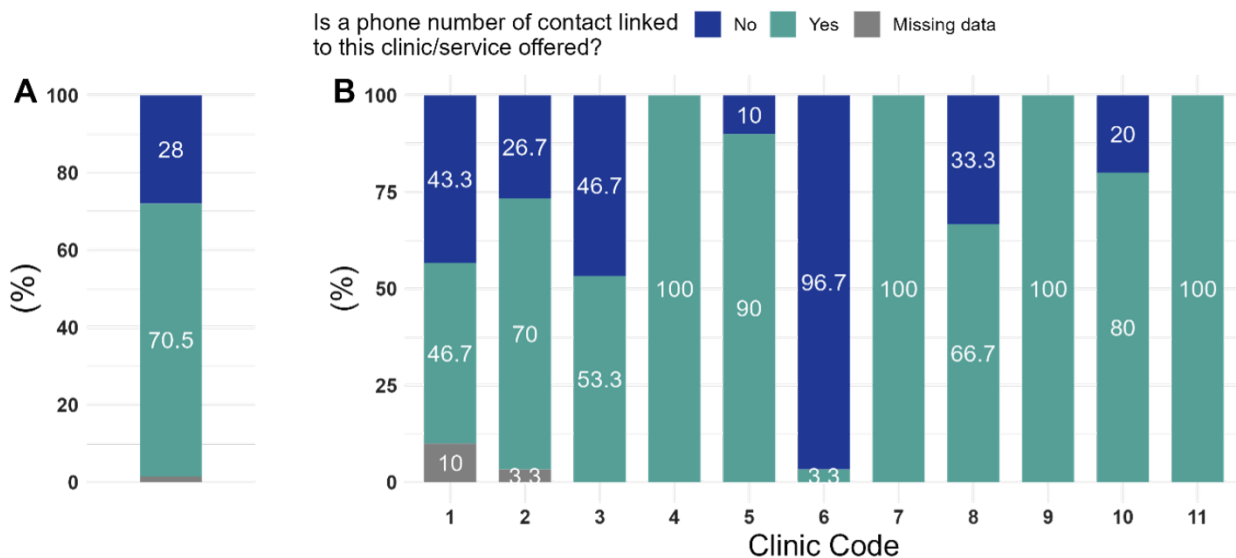

Figure 17: Contact details are offered between clinics (n = 257). (A) The data from all the case notes. (B) The data across services.

Advice and information on driving, employment, financial support

Based on documentation for the first three visits, the frequency of advice and/or direction in relation to driving, and information on employment, financial supports and entitlements, was audited. In total, almost 28.7% of patients received driving advice, while advice on employment was documented in 12.6% (Figure 18A). Overall, from 191 who were driving, 18.8% (36/191) of cases had documentation that they had no issues. Of the remainder, only 48.4% (75/155) had a documented discussion about driving (i.e., if any issues).

In total, 137 people were retired. Within the people still employed, there was documentation of a discussion on their employment (i.e., any issues) in 38.4% (33/86). Overall, 11.1% of cases received financial advice (Figure 18B).
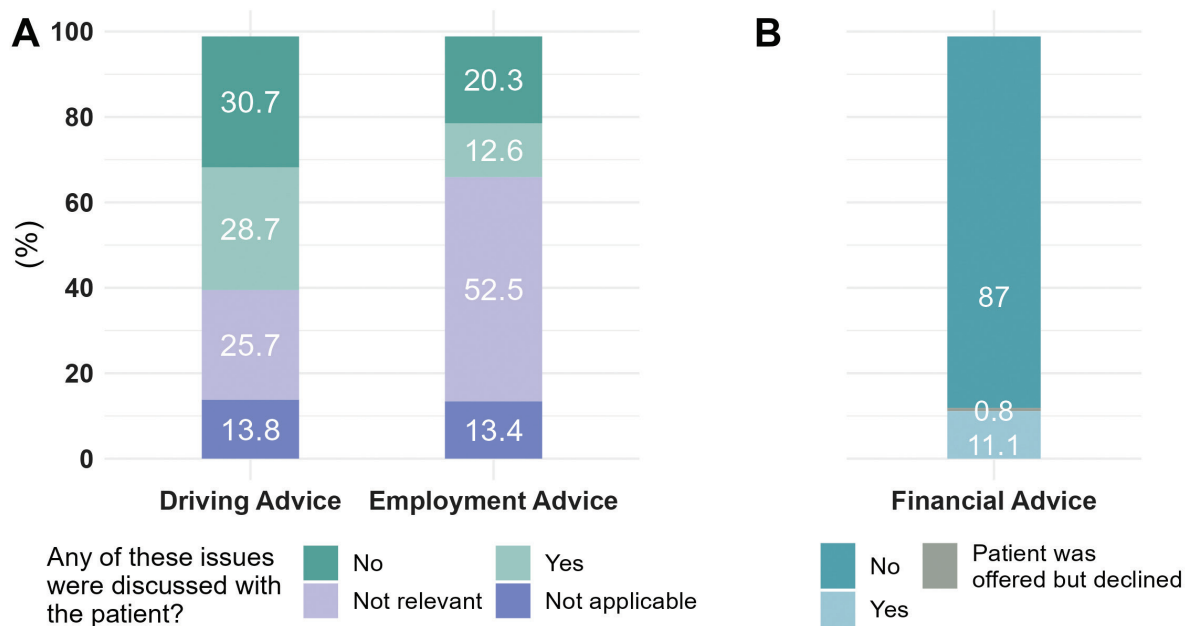

Figure 18: Received advice/direction/information. (A) Documentation of case notes receiving driving and employment advice (N/A means not applicable, either because the issue is not relevant (i.e., not driving or not employed) or because there are no issues) (B) Documentation of case notes receiving financial advice.

Care plan

Less than half of the patients (46.7%) had documentation that they had received a care plan (Figure 19A). Where this had occurred, in most cases (85.5% [100/117]), the plan was agreed upon with the patient/carer (Figure 19B).
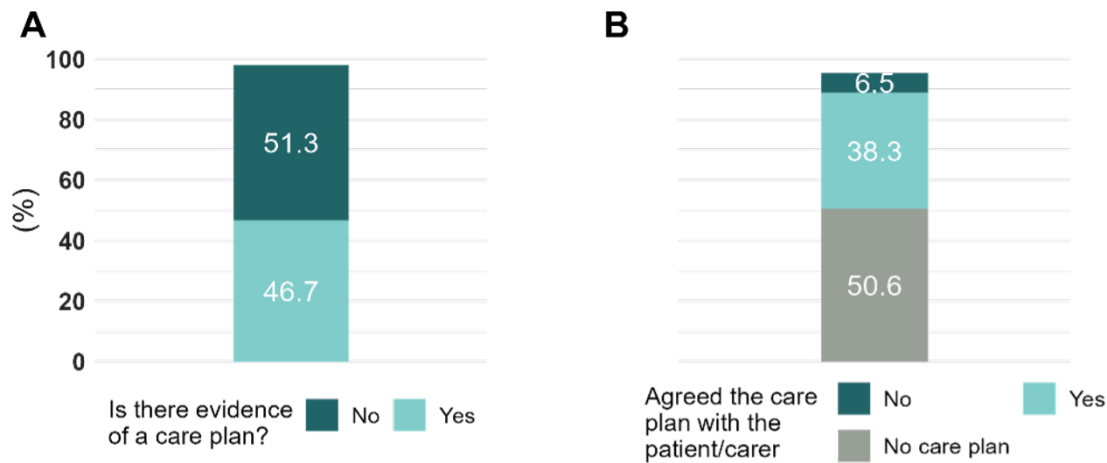
Figure 19: Care plan. (A) The percentage of cases that received a care plan. (B) The percentage of cases in which a care plan was agreed upon with the patient.

Discussions on non-pharmacological management of PD

The audit tool prompted the auditor to indicate whether discussions on non-pharmacological management had occurred, with options including goal setting, self-monitoring of symptoms, managing mood, physical activity, optimising sleep, and possible referral to an educational programme, as well as an option to add other discussions of relevance. Based on documentation for the first three visits, a discussion regarding non-pharmacological management occurred in 88.1% of case notes. Discussion about physical activity was the most frequent (81.2%), followed by self-monitoring of symptoms (62.8%), while the rate of discussion on other subjects was low (Figure 20). Other topics documented in the case notes (n=25) included advice about managing constipation (6/25), advice to specifically walk more, falls prevention, and discussions on referral to physiotherapy, OT, or SLT. There was significant missing data for many items (Figure 20), which likely means there was not a discussion.

Of note, while almost half of the patients (49.4%) had documentation of sleep problems, only 41% of case notes had documentation of a discussion on ways to optimise sleep. In total, only 58% (58/100) of case notes where the patient had a sleep problem had documentation of discussion on ways to optimise sleep.
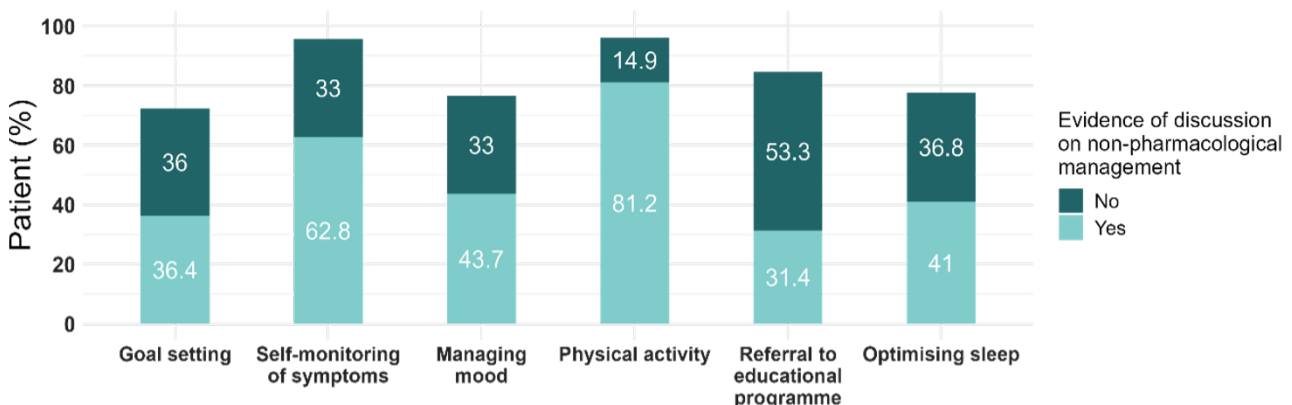

Figure 20: Documentation of discussions on the non-pharmacological management of PD. This included goal setting, self-monitoring of symptoms, managing mood, and physical activity, referral to an educational programme, and optimising sleep (missing data accounts for bar height differences).

Communication with the care partner

Communication with the care partners was infrequently documented, with 25.9% (38/147) of case notes where the patient had a care partner having documentation of the availability of support locally for them, and 12.4% (17/137) documenting a discussion about financial support and/or entitlements (Figure 21).
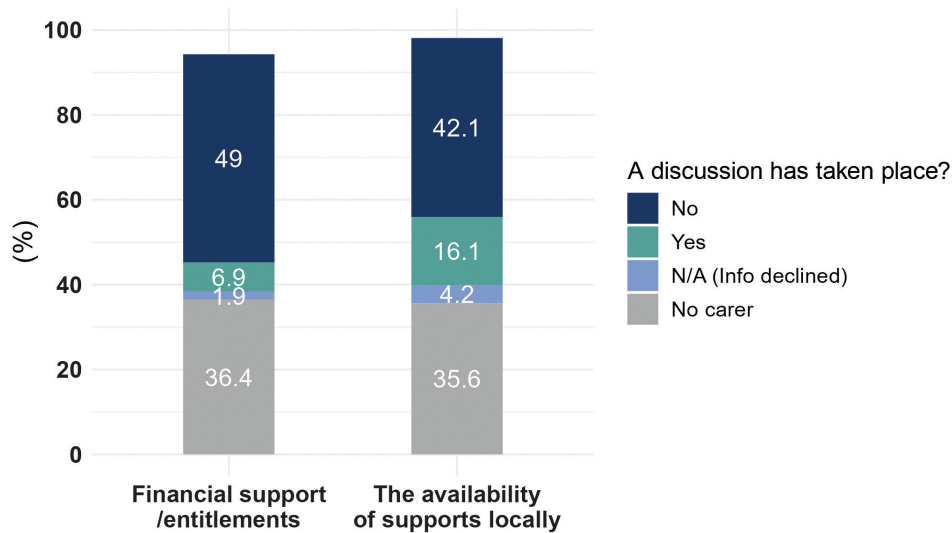

Figure 21: Communication with a care partner (missing data accounts for bar height differences).

Motor symptom and mobility assessment

In terms of motor symptom assessment, this audit investigated the documentation of the presence/absence of symptoms relating to freezing, dyskinesia, wearing off, bradykinesia, tremor, rigidity, and dystonia.

Figure 22A illustrates the rate of documentation of assessment of motor symptoms. The rate was highest for the three-core motor symptoms (bradykinesia, tremor, and rigidity; 91.2-94.2%) compared to less frequently occurring symptoms such as dystonia (59% assessed). Mobility symptoms such as mobility issues, gait issues, and falls were assessed regularly, with 89.7-96.6% of patients receiving these assessments (Figure 22B).
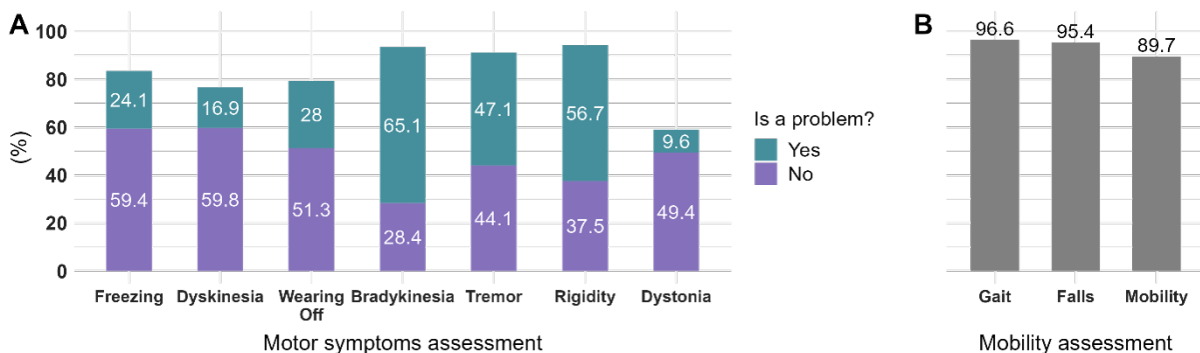

Figure 22: Motor symptom and mobility assessments received by patients during admission (n = 261). Bar height differences reflect this symptom not being assessed, or missing data.

Of note, at least one motor symptom was a problem in 90% of patients. In terms of falls, 32% of cases had documentation of one or more falls. No patient was documented to be assessed for fall risk factors, while 39.8% of cases with documented falls received a standardised assessment of mobility.

In general, there was little difference between practice in neurology-led and geriatric-led services in the assessment of motor symptoms and mobility. However, while geriatric-led services completed a mobility assessment more often than neurology-led services (95.7% vs 84.9%; $\chi 2 = 6.24$, p=0.01; n=260), there was also significant difference in mobility assessment using a standardised assessment between geriatric-led and neurology-led services (51.1% vs 36.6%; $\chi 2 = 5.1$, p=0.02; n=260).

Non-motor symptom assessment

The audit examined assessment for non-motor symptoms associated with daily living such as bladder function, constipation, communication difficulties, swallowing, drooling, sexual dysfunction, functional ability (Activities of Daily Living [ADL]; and instrumental ADLs [iADL]), and pain.

Here, constipation was almost universally assessed (96.6%), followed by assessment of bladder, swallowing function, and functional ability (88.1%, 87.4%, and 83.9% respectively; Figure 23), and then communication difficulties (76.2%). Where communication difficulties were present, 78.8 % (41/52) of cases were referred to a SLT, while when difficulty with swallowing was present, 77.8% (42/54) of cases were referred to a SLT.

There was documentation of the patient being asked about pain in 63.6% of case notes. In cases asked about the presence of pain, 44% (73/166) reported pain. One case had the pain severity assessed using a formal tool (1/73).

Meanwhile, 29.5% of patients were asked about sexual dysfunction where this was potentially relevant (i.e., excluding patients who were single or part of a religious order). Less than 50% of all cases were questioned about drooling.
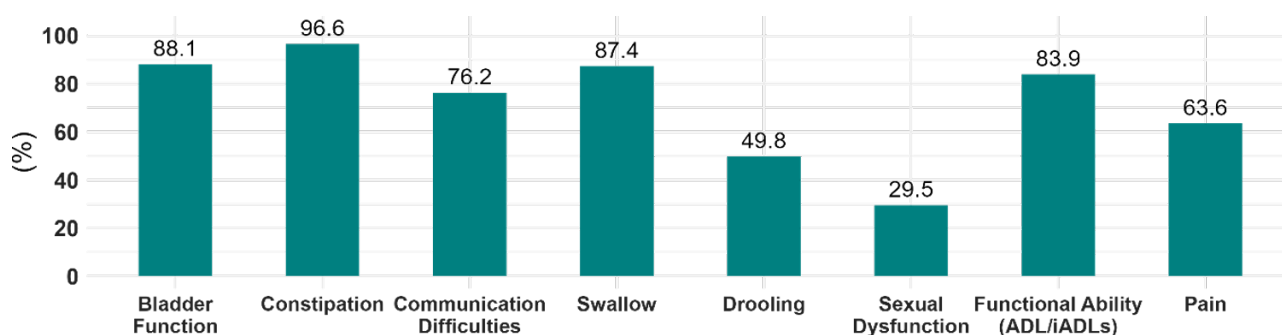

Figure 23: Daily Living symptoms assessments received by patients during admission (n = 261). While some of the assessment was conducted regularly, the assessment of pain, drooling, communication difficulties, and sexual function was conducted less often.

There were significant differences in the assessment of ADL between clinics, with two clinics assessing 30% of cases or less, and four clinics assessing all patients (Figure 24B). In terms of the method of ADL assessment, in 35.2% (77/219) of cases with this assessed, this was documented to be via a formal tool. More than half of the participating clinics (7/11)

were using an ADL assessment proforma for some of their cases (Figure 24B), There was no significant difference in the rate of using an ADL assessment proforma between neurology-led services (40.3%) compared to geriatric-led services (29%) ($\chi 2$ = 2.59, p=0.11; n=219).
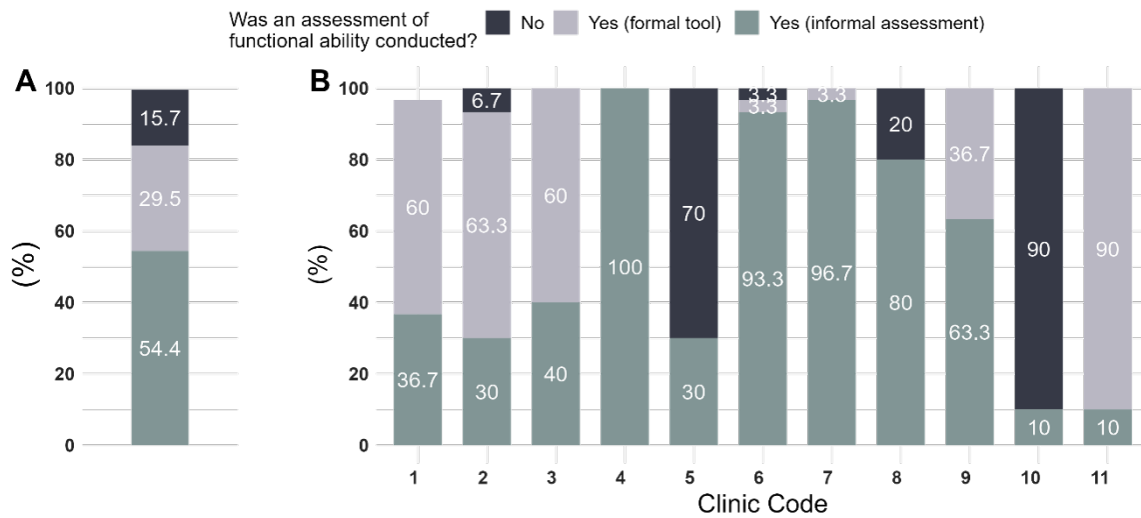

Figure 24: ADL assessment received by patients. (A) The data from all the case notes. (B) ADL assessment received by patients across services. Assessment varied across services, with where assessed, most of the services used informal assessment to record the assessment of activities of daily living (missing data accounts for bar height differences).

Advance care planning

A discussion was documented between the clinician, the patient, and their family/care partner (where applicable), regarding advance care planning in 9.2% of cases. Where it occurred, this was mainly related to creating an enduring power of attorney (83.3% [20/24]; Figure 25). Discussions on advanced PD care needs, resuscitation decisions, and preferred place of death occurred rarely (Figure 25). Of note, in recent years the importance of earlier conversations about the future and particularly future decision-making is emphasised, as people with advanced PD may have significant cognitive impairment and may no longer be able to take part in such discussions or direct their own care. This audit showed that overall, 7.8% of cases were documented to have taken part in a discussion about future decision-making.
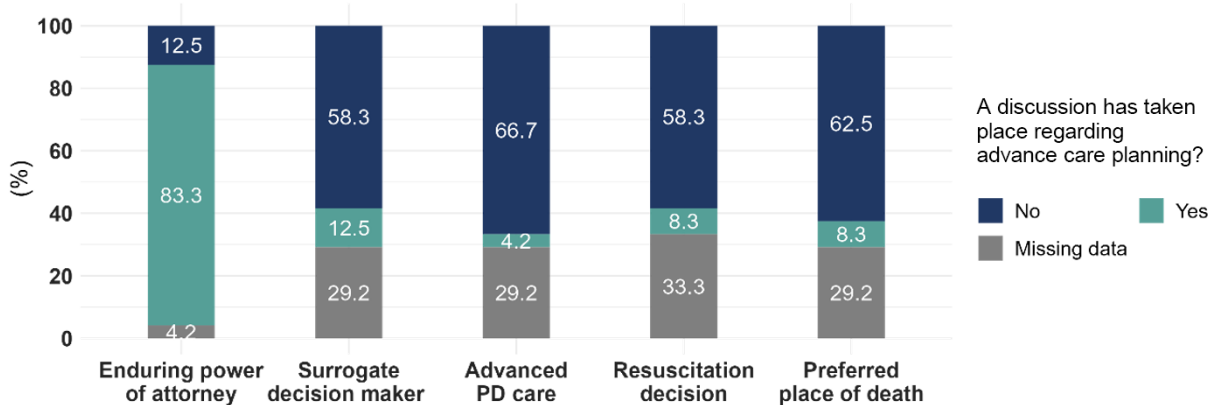

Figure 25: Advance care planning practice, showing the focus on creating an enduring power of attorney.

Where applicable (i.e. the patient had PD Stage 4/5 and also had a family carer), there was a separate discussion with family/carers regarding their palliative support needs in only 5.9% (1/17) of cases, resulting in 94.1% (16/17) of cases with no separate discussion with family/carers.

Mental status assessments

The audit investigated whether assessments for possible cognitive issues, fatigue, sleep problems, and mood/anxiety were carried out. As seen in Figure 26, although assessment of mood/anxiety (92.3%) and sleep problems (96.2%) were commonly performed, the level of assessments of cognition and fatigue were poor.
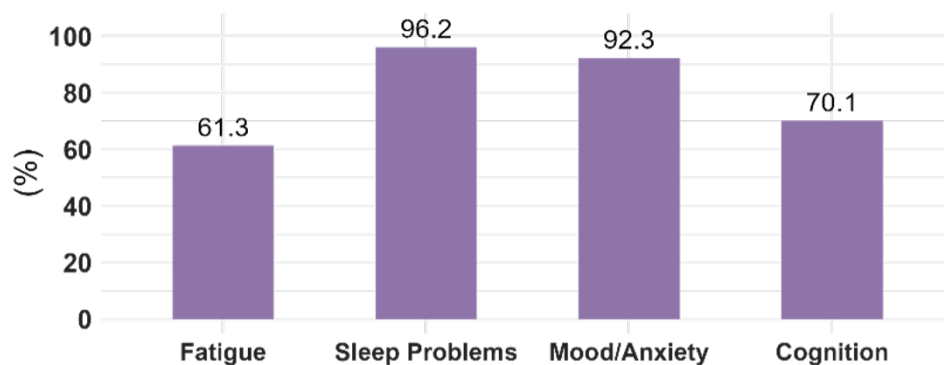

Figure 26: Frequency of mental status assessments (n = 261)

Within the cases assessed for sleep problems, 51.4% (129/251) reported that they had sleep problems. Within these, 74.4% (96/129) were specifically asked about Rapid Eye Movement (REM) sleep behaviour disorder, while 63.6% [82/129]) had documented clarification of sleep latency issues versus problems staying asleep, and 40.3% [52/129] had documentation about the presence or absence of daytime sleepiness (Figure 27).
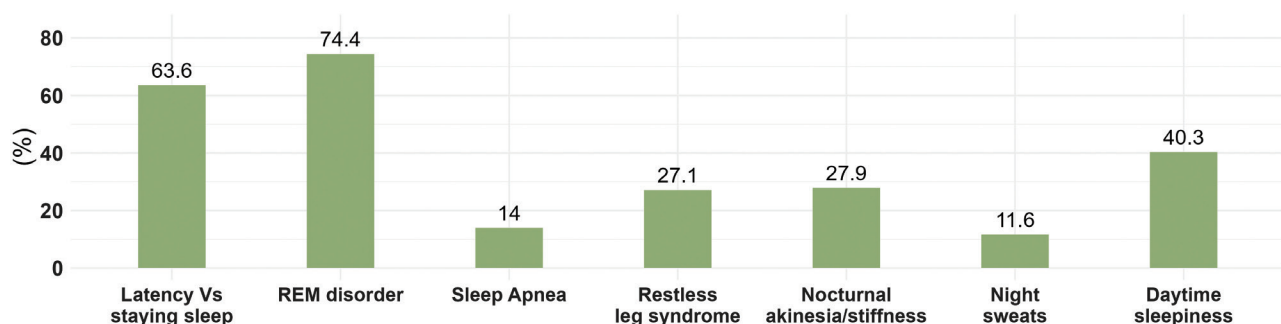
Figure 27: Frequency of documented enquiry to determine possible aetiology of poor sleep, in patients with reported sleep problems (n=129).

Of the cases asked about problems with mood/anxiety, 40% (96/240) reported that they had mood/anxiety issues. Within these, 61.5% (59/96) had documentation about severity/persistence, while 10.4% (10/96) were asked about possible suicidal ideation, or suicidal intent (9.38% [9/96]). In 27 (of the 96 cases), antidepressant medication was commenced, and eight cases were referred for specialist mental health input. The need to probe about possible suicidal ideation or intent and the appropriateness of treatment decisions can't

be judged in an audit, but it is reasonable to think that everybody with reported mood and/or anxiety issues should be asked about severity/persistence as part of the assessment.

As per Figure 26 (earlier), only 70.1% of cases had documentation of an assessment of cognition. A further 5.7% had no assessment within the clinic, but cognitive impairment was documented in the clinic letter. In the cases where an assessment was conducted, in 53.6% (90/168) a formal tool was conducted. Where performed, this was mostly using the Montreal Cognitive Assessment (MoCA) (92.2%; 83/90), with occasional use of the Mini-Mental Status Exam (MMSE), Six-Item Cognitive Impairment Test (6-CIT), and Addenbrooke's Cognitive Examination (ACE-R). The median MoCA score was 22 (IQR 7.5, range 8–29). As predicted, there was a negative correlation between this score and both age (Figure 28A) and the PD stage (Figure 28B). Of note here, the number of available MoCA scores for cases in Stages 4/5 was very low (n=3).
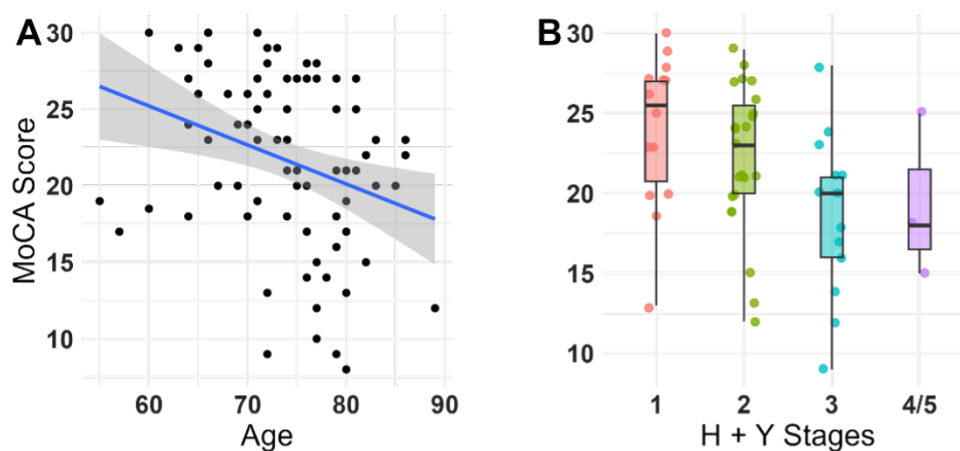

Figure 28: Results of formal cognition testing using the MoCA formal tool (n=90), show the negative correlation between this score and i) age (A; scatter plot with trend line) and ii) the PD stage (B; showing median and IQR [box] and range [line]).

More than half of the patients in the two clinics lacked any documentation of a cognitive assessment. In contrast, some services had recorded formal assessments for cognition for all or almost all attending patients (Figure 29B). There was evidence in 15.1% (13/86) of cases that a cholinesterase inhibitor was considered after a cognitive test, noting that the appropriateness of considering such treatment can't be judged in an audit, where only a cognitive test result is available, but not the functional ability, course of cognitive decline, presumed baseline cognition, other comorbidities, etc.
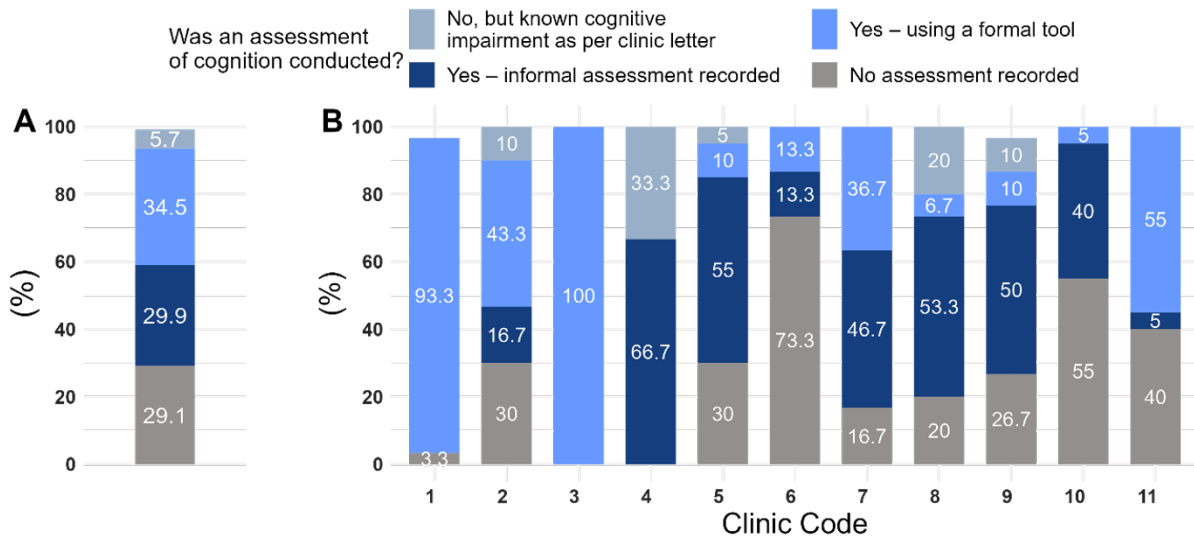
Figure 29: Cognitive assessments (n = 259). (A) The data from all the case notes. (B) The data across services (missing data accounts for bar height differences).

Fatigue, sleep problems, mood/anxiety, and cognition assessments were conducted at a similar rate in neurology-led services and geriatric-led services.

Orthostatic hypotension, nutrition, and bone density

In terms of common complications of PD, the audit investigated whether patients received assessments for orthostatic hypotension, nutrition status, and bone density (Figure 30). Considering orthostatic hypotension first, only 21.8% of case notes had documentation of lying and standing blood pressure readings (i.e., an 'active stand'), while 39.1% had sitting-to-standing readings, and 11.4% of case notes had documentation of sitting-only blood pressure readings (Figure 31A). The H&Y stage of participants indicates that many more patients could have had lying-standing blood pressure readings. There was no documentation of any blood pressure reading in one-third of cases.
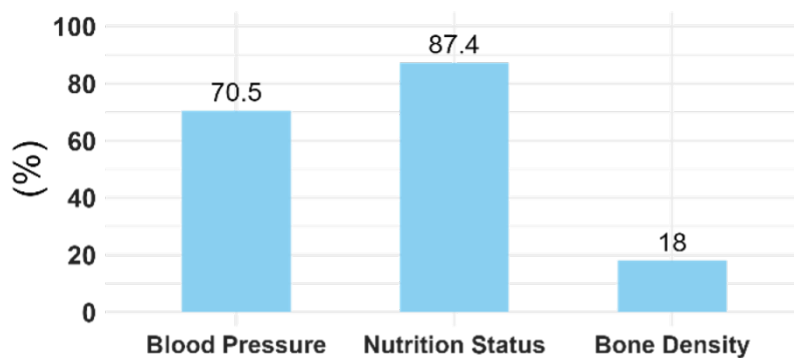
Figure 30: Frequency of assessment for selected common (non-motor) PD complications (n = 261)

There was a variation in blood pressure assessment methods between services; while two clinics did not record any blood pressure at all, and another had blood pressure documentation in only one-fifth of cases, six services recorded blood pressure across two positions for almost all of their cases (Figure 31B). Geriatric-led services conducted a blood pressure reading in most cases (93.9%), but neurology-led services conducted this

assessment significantly less often (52.1% of case notes) ($\chi 2 = 67.47$, p<0.001; n=252). When blood pressure was recorded, the rate of active stand testing was higher in neurology-led services compared to geriatric-led services (65.3% [49/75] versus 7.4% [8/108]; $\chi 2 = 66.58$, p<0.001; n=184), also, neurology-led services had significantly higher rate of recording blood pressure in two readings (i.e. active stand and sit-stand) compared to geriatric-led services (97.3%[73/75] versus 79.6% [86/108]; $\chi 2 = 10.7$, p=0.001; n=184). This might relate to greater immobility in attending patients at geriatric-led clinics or differences in emphasis on the need for this.
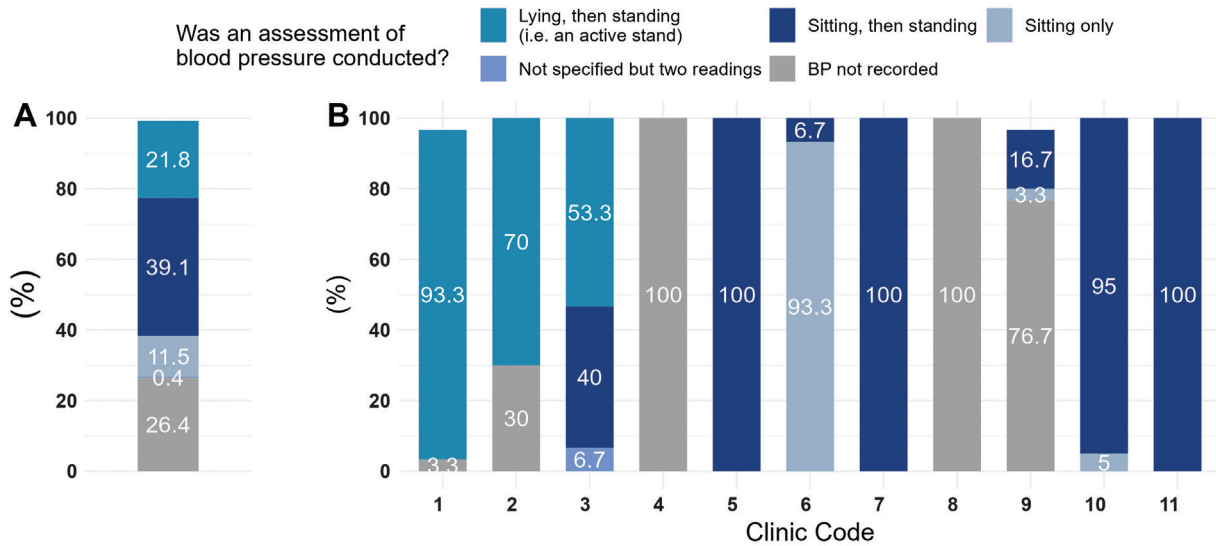

Figure 31: Blood pressure measurement practice. (A) The data from all the case notes. (B) The data across services (missing data accounts for bar height differences).

The nutritional status assessment could include any of the following: a formal nutrition screen, including Mini Nutritional Assessment (MNA); Malnutrition Universal Screening Tool (MUST); body mass index (BMI- i.e., height and weight ratio); weight only; or informal assessment (report of loose clothes/weight loss or documentation that the patient looked underweight or sarcopenic). Overall, 87.4% of cases had some recording of nutritional status, wherein 46.7% of cases had weight recorded, 1.1% had recorded BMI, 8% had a recorded formal nutrition screening tool (MUST/MNA), and 31.4% had documentation of informal assessment (Figure 32A). The methods used and performance in various centres varied greatly: one clinic had a recorded formal nutrition screening tool for all of its cases; five clinics had documentation of weight or BMI for almost all of their cases; one clinic had no recording at all of the nutritional status for 83.3% of cases; three clinics recorded informal assessment for the majority of their cases and another one varied in this percentage (Figure 32B).
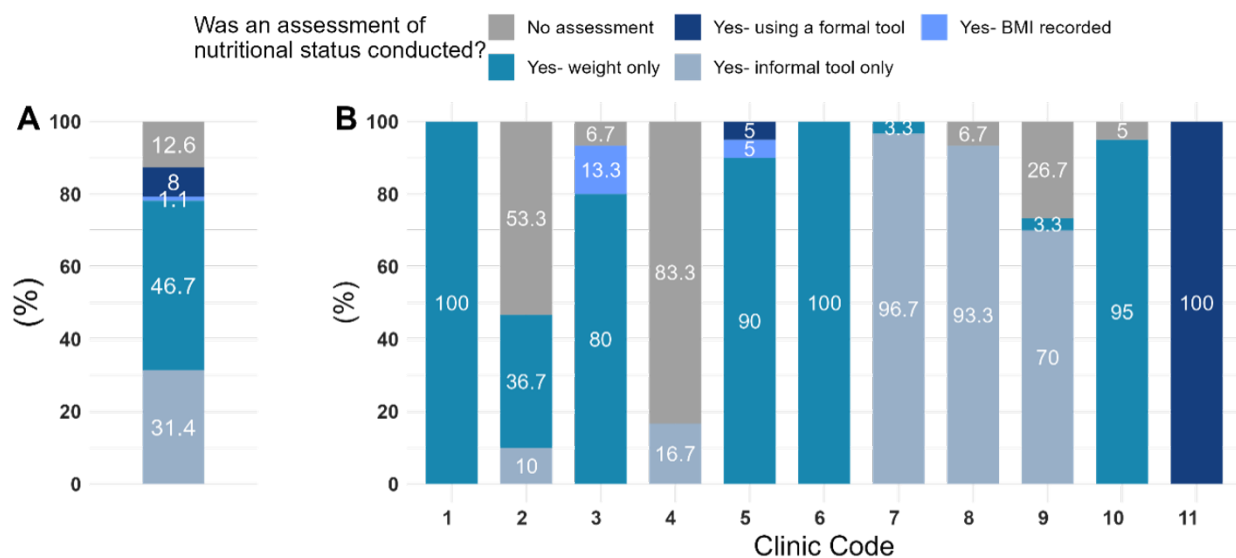
Figure 32: Details of nutritional status assessment in each clinic. (A) The data from all the case notes. (B) The data across services.

While nutritional status was universally assessed by geriatric-led services (99.1%), almost one in four cases were not assessed in neurology-led services (21.9%) ($\chi 2 = 26.2$, p<0.001; n=261). Similarly, geriatric-led services more often documented using formal tools with 70% (70/100) recording one of MUST/BMI/weight, compared to neurology-led services, where 36.1% (43/119) of case notes had documentation based on formal tools ($\chi 2 = 23.93$, p<0.001, n=219). It must be noted that some of this variation in practice likely relates to the difference in patient cohorts, with somewhat frailer, older people attending geriatric-led services, where nutrition issues are more expected. However, four clinics never or almost never weighed a patient; thus, future quantification of weight loss would not be possible in these services, which is a concern.

In total, 9.5% (23/243) of case notes reported being at risk for or currently malnourished or having low BMI or evidence of weight loss. In case of risk for or currently malnourished, 82.4% (28/34) of cases were asked about anorexia/appetite, 48.1% (13/27) of cases were asked about nausea/vomiting, and 84.4% (27/32) of cases were asked about swallowing difficulties. In total, ten cases were documented to be referred to a dietician.

As can be seen in Figure 30, the assessment of bone mineral density (BMD) was quite poor, with only 18% of case notes containing documentation of this assessment. The International Society for Clinical Densitometry recommends BMD testing in all women 65 years and older and all men 70 years and older (The International Society for Clinical Densitometry, 2019). In total, only 19.1% (35/183) of patients in these age/sex groups had documentation of bone density, which was higher in females aged over 65 (31.9% [23/72]) than in males aged over 70 (10.8% [12/111]) ($\chi 2 = 11.3$, p<0.001, n = 183). In cases where a history of falls was recorded, only 8.4% (5/59) had bone density recorded, while an additional 10.1% (6/59) were already known to have osteopenia/osteoporosis. Thus, 81.3% (48/59) of patients with a history of falls, in an age group vulnerable to osteoporosis did not have BMD documented. Similarly, limiting the analysis to the case notes of people with documented malnutrition (n=23), only six had bone density assessment recorded and two others were known to have osteopenia/osteoporosis, i.e., 15/23 very vulnerable patients did not have any bone density assessment. There was no significant difference in BMD testing between neurology-led services (17.1%) and geriatric-led services (19.1%) ($\chi 2= 0.07$, p=0.80, n = 261).

7.   Pharmacological and Device-Assisted management of PD

PD medications

Overall, 97.7% of patients were receiving at least one 'PD medication', which in this context included any dopaminergic medication; COMT inhibitor; MAO-B Inhibitor; amantadine (Symmetrel); anticholinergic; or antipsychotic.

In total, almost 96.1% (244/254) of cases were receiving dopaminergic medication, i.e., one or more of levodopa (with benserazide [co-beneldopa; Madopar] or carbidopa [co-careldopa; Sinemet]), or a levodopa/catechol-O-methyltransferase (COMT) combination agent, or a dopamine agonist. About 48.0% (121/252) of patients were receiving dopaminergic medication alone.

Overall, 37.9% of cases were receiving MAO-B Inhibitors, typically in combination with dopaminergic medications; in 1.2% (3/252) of overall cases, an MAO-B inhibitor was prescribed alone. Very few people received anticholinergics, antipsychotics, or amantadine (Figure 33), all of which were used as adjuncts to dopaminergic medication.

There were no significant differences between dopaminergic medication, MAO-B inhibitor, amantadine or antipsychotic medication prescription between geriatric-led and neurology-led services; anticholinergic medication was prescribed by neurology-led services more commonly (9.6% vs 1.7%; $\chi 2$ = 5.0, p=0.03, n = 261), likely reflecting patient age/cognitive status.

A current list of the patient's PD medications was documented in 97.7% of cases (i.e., list was updated in the most recent clinic visit).
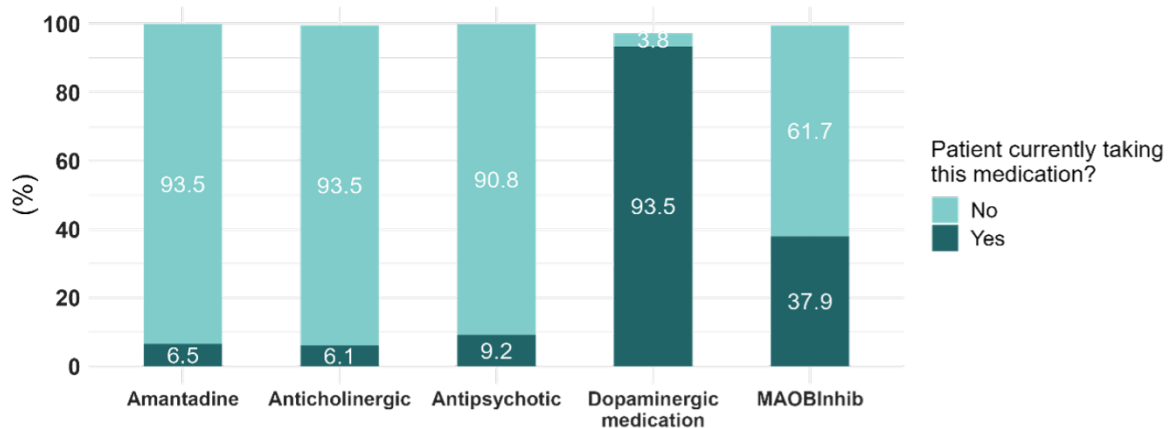

Figure 33: 'PD medications' grouped into dopaminergic medication (i.e., levodopa preparations, or a levodopa/COMT combination agent, or a dopamine agonist, given by any route); MAO-B Inhibitors; Amantadine (Symmetrel); Anticholinergics; Antipsychotics (missing data accounts for bar height differences).

Number of medication classes

The number of different types of PD medications varied between patients. More than half of cases received one or fewer class of medication (Figure 34A), while 0.8% received four different classes of PD medications. There was a slight variation across clinics in the number of medication classes (Figure 34B). While in three clinics (code 3, code 5, and code

11), most of the cases received one or less class of medication, in three clinics, the majority of cases received two or more classes of medication (code 2, code 4, and code 8).
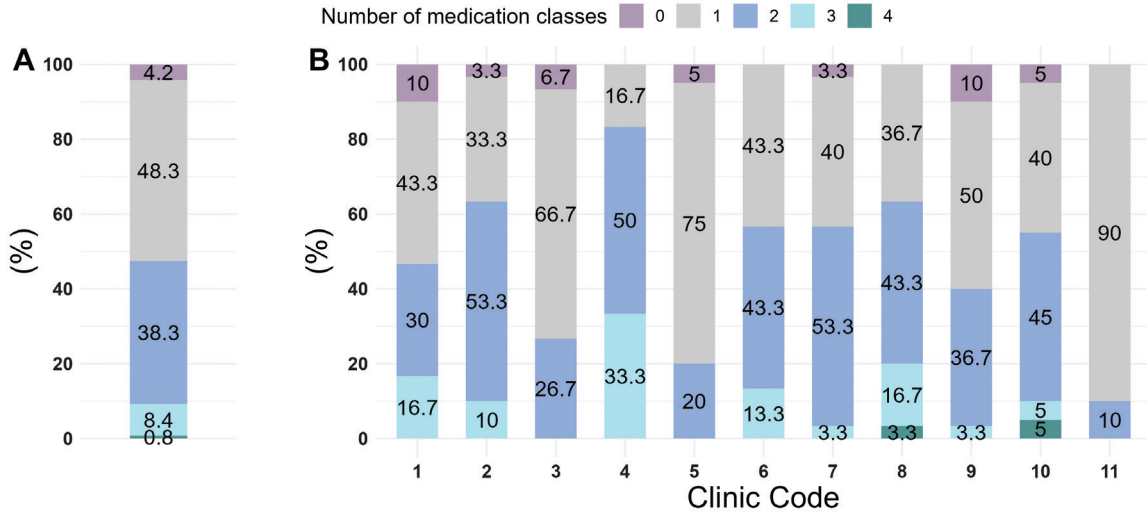

Figure 34: The number of classes of PD medications received by patients. (A) The data from all the case notes. (B) The data across services. While more than half of the patients received no or one class of medication, the number of medication classes varied across services.

Documentation of new medications

Within those taking dopaminergic medication, the medication commenced most recently included Sinemet in 60.1% (143/238) of the cases, followed by Stalaevo (11.7% [28/238]), an unspecified levodopa formulation (8.8 % [21/238]), Madopar (6.3% [15/238]), and other dopamine agonist medication in 14.3% (34/238). There was no documented indication for a new prescription in 33.7% of case notes (Figure 35A). This documentation varied across clinics, with an indication documented in almost all case notes in four clinics, while in two clinics, the indication was not recorded in more than 80% of cases (Figure 35B).
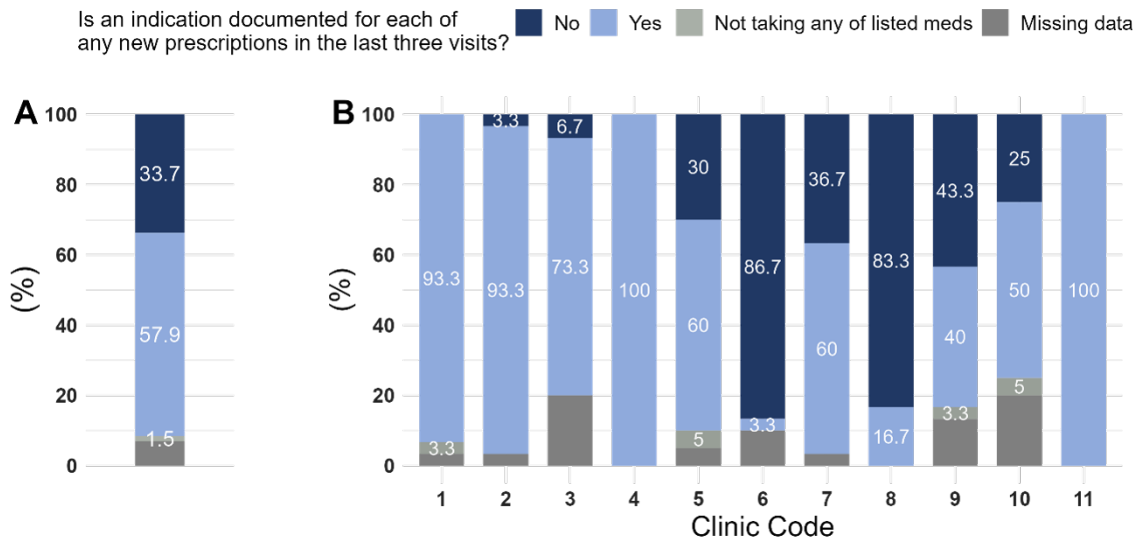

Figure 35: Frequency of documentation of the indication for each new prescription in the last three visits. (A) The data from all the case notes. (B) The data across services.

When a medication was first prescribed (n=278 occurrences), discussion of potential risks/side effects was documented to have happened in 77% (214/278) of cases. This occurred most commonly for dopaminergic medication, but was surprisingly lower for anticholinergic or antipsychotic medication, given their significant potential for side effects (Figure 36). Documentation of a discussion around risks/side effects was more common in geriatric-led services (94.7%) than neurology-led services (64.6%) ($\chi2$ = 32.7, p<0.001, n = 278).
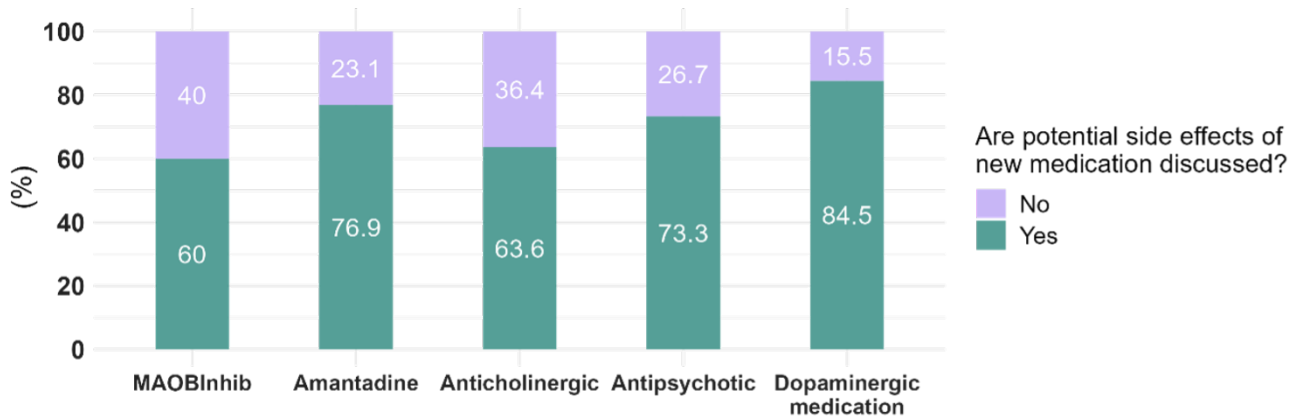

Figure 36: Documentation of discussion around potential risks/side effects for each of the medication classes, when first prescribed.

When this data was available, at the return visit after commencing new medication (n=309 occurrences), enquiry for any possible side effects happened in 89.6% (277/309) of cases (Figure 37). This was more common in geriatric-led services (97.3%) than in neurology-led services (85%) ($\chi2$ = 9.90, p= 0.002, n = 309), but overall, this was documented more often than a discussion on risks/side effects prior to commencement.
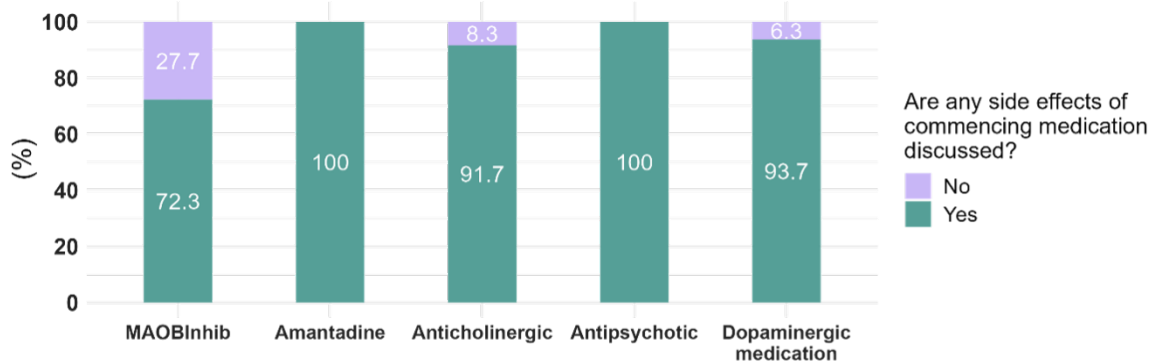
Figure 37: Documentation of discussion of potential side effects for each of the medication classes at the return visit after the medication was first prescribed.

Apart from new prescriptions, it is expected that all patients are asked about medication issues during their visits. In the last three visits, 74.8% (169/226) of medication-taking, returning patients were asked about medication adherence, and 30.2% (64/212) were asked about the need for medication-taking support (Figure 38).

Figure 38: Discussion about medication issues (missing data accounts for bar height differences).

Device-Assisted Therapies

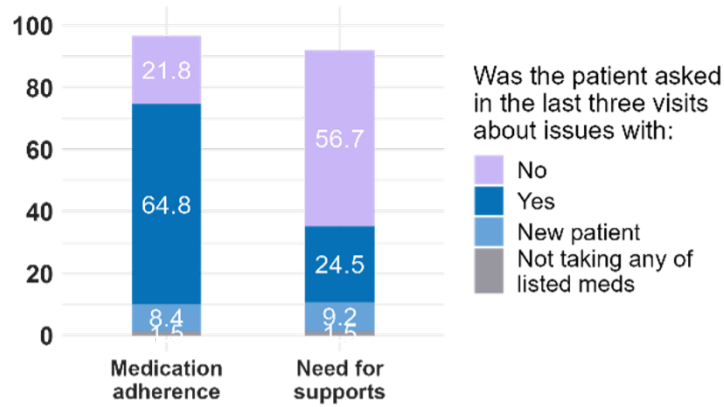'Complex' PD was operationalised in the audit by the project steering group to apply to patients who were diagnosed 4+ years ago; AND taking 4+ doses of dopaminergic agents per day; AND presenting with troublesome 'wearing off', dyskinesia, or other motor fluctuations, or with non-motor fluctuations, despite optimisation of medical therapy. In total, 20.7% of patients (52/251) had complex PD as defined above (Figure 39A). Of these, 49 had the audit item on Deep Brain Stimulation (DBS) completed by an auditor. Within these 49 cases, two had documentation of not being suitable for DBS while 19 had evidence of a discussion on DBS; thus 57% had no documentation of consideration for DBS despite being potentially indicated (Figure 39B). Of the 52 patients with complex PD, 13 (25%) were receiving continuous subcutaneous apomorphine infusion and 15 (28.8%) Duodopa intestinal gel.
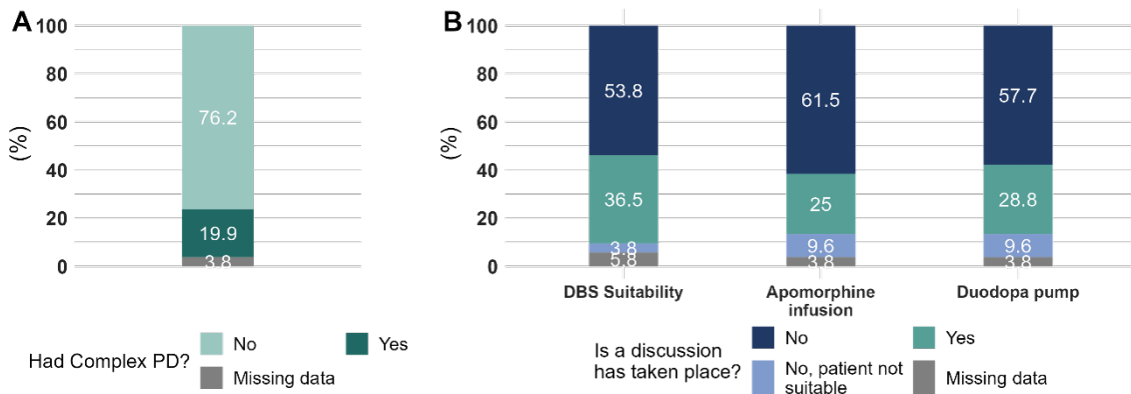

Figure 39: Complex PD. (A) The percentage of cases who had complex PD (B) Documentation of potential DBS assessment, and use of Device-Assisted Therapies.

8. Actions indicated by the audit findings

Good practice was evident in areas like clear documentation of current PD medications and documentation of regular motor symptom and mobility assessments. Based on the evidence presented in the case notes, with the caveat that documentation may under-represent actual practice, there is work to be done in the following areas:

PDNS access and having a primary contact's details

According to Statement 1 of the NICE PD Quality Standard (NICE 2018), people with PD should have regular access to a PDNS as a point of contact with specialist services. The audit showed that 30% of patients were not offered details of a primary point of contact linked to the clinic/service. Also, more than a third of the cases who were seen in clinics that did not have access to a PDNS.

Communication and information sharing

Information regarding diagnosis and new medication should be available to people with PD. In addition, information regarding PD support services should also be available, as should information regarding 'lasting' (Enduring) Power of Attorney (UK PD audit, 2022). The audit highlights that many patients did not receive written information about PD when they were diagnosed. Also, very few were documented to have taken part in discussions about enduring power of attorney. Anticipatory care planning in the wider sense should also be considered and documented. Communication with family members and carers about their own current needs should also be considered.

Specialised multidisciplinary working team

Statement 3 of the NICE PD Quality Standard states that adults with PD are referred to physiotherapy, occupational therapy, or speech and language therapy if they have problems with balance, motor function, ADLs, communication, swallowing, or saliva (NICE 2018). The audit highlights that patients in Ireland are not consistently being referred to these services, even when issues are documented that indicate referral.

Standardised practices

The recording of some non-motor symptoms was poor. This could be improved using formal standardised tools and questionnaires to assess cognition and ADLs.

Bone health

Bone health assessment is suboptimal in many clinics. Falls/fractures have a significant impact on people with PD, thus services must explore how bone health may be appropriately investigated.

Common complications of PD

Screening for orthostatic hypotension and malnutrition is particularly lacking in neurology-led services. This could be improved by using a system to check postural blood pressure and weight for every patient on arrival by a clinic nurse. In general, the rate of active stand testing for orthostatic hypotension was low.

9.   Conclusions

Although motor and mobility assessments were performed on a regular basis, some non-motor assessments including pain, fatigue, saliva management, and cognition assessment all require improvement. In terms of bone density, the prevalence of falling and osteoporosis necessitates improvement. The examination of blood pressure, as well as nutritional status assessment, in some of the clinics requires significant improvement. Standardised tools are required for several assessments, such as cognition and ADLs.

The audit's findings show that non-pharmacological care needs to be improved throughout Ireland; access to PDNS was quite limited throughout the country. This mirrors the findings of a previous national survey of people living with PD and linked qualitative evidence, as part of the overall Mapping PD project. There is little documentation of the information provided to patients at the point of diagnosis, again reflecting the patient's lived experience. Furthermore, communication with family members and carers was poor, even though many patients in Ireland live with their family. Although non-medication management of PD symptoms was discussed in a limited way (such as physical activity), there was little evidence of activities to empower patients to self-manage their disease.

Finally, the very low rate of patients attending from long-term care (6/261) indicates a possible lack of access to Movement Disorder Services, given that nearly 25% of people with PD are estimated to reside in long-term care facilities (Safarpour et al., 2015). It is possible that telephone support or physical outreach to long-term care facilities was not captured within the audit, as the audit relied on scheduled clinic appointments, and so some virtual or outreach work may not have been included. Future studies should explore the degree to which long-term care residents with PD have unmet needs which could be improved by access to a specialist PD service.

10.   References

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