

European Inventory

Executive summary

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International Parkinson and
Movement Disorder Society

EXECUTIVE SUMMARY

1 INTRODUCTION

My PD Journey is a groundbreaking multi-stakeholder project designed to assist those people living with Parkinson's disease in Europe. The project aims to create a sustainable environment that ensures all healthcare providers coordinate and work with each other to remove the hurdles that currently prevent people with Parkinson's from receiving early and appropriate treatment as well as individualised care.

My PD Journey will address multiple challenges in the healthcare environment. In particular:

- The lack of existing evidence/data
- Late diagnosis and referral throughout the disease progression
- Inefficiencies in healthcare organisation and delivery
- The lack of multidisciplinary and integrated care for people with Parkinson's and their families.

My PD Journey is being implemented by a Parkinson's disease European coalition, which comprises a number of stakeholders involved in Parkinson's care. These include European umbrella healthcare organisations, high-profile European Parkinson's specialists, people with Parkinson's (PwPs), carers, members of the multidisciplinary healthcare team, academia and health economists.

My PD Journey is a European Parkinson's Disease Association (EPDA) project. The EPDA is the only European Parkinson's disease umbrella organisation, and represents national Parkinson's organisations in 36 countries across Europe. It advocates for more than 1.2 million people in Europe who live with the disease. This number is forecast to double by 2030.

The first major My PD Journey activity is the development of a 'European inventory' that aims to identify where gaps in Parkinson's care currently exists, and to seek out national examples of good practices that could be adopted in other regions and countries.

An independent research organisation was commissioned to conduct both primary and secondary research.

2 PRIMARY RESEARCH

The primary research comprised a questionnaire survey (online and print) and in-depth interviews with people with Parkinson's, their carers and healthcare professionals, across 11 European countries. The featured countries were Denmark, France, Germany, Hungary, Ireland, Italy, the Netherlands, Slovenia, Spain, Sweden, and the UK. The findings from these countries are presented in the "Findings from the primary research study report".

The primary research study aimed to provide a 'snapshot' of the therapies, treatments and management that people with PwPs and their carers had access to within the selected countries. In addition, the study sought to gain an in-depth understanding of PwP and carers' experiences of their national healthcare systems, and what treatments and therapies had benefited them the most. By gaining insights into the current situation and by understanding the unmet needs, we believe that effective recommendations can be made that will have socio-economic and cost benefits to the health system, and at the same time enhance the quality of life of all affected by the disease.

2.1 Methods

In order to determine *what* is happening and *when* – as well as *why* this might be the case – a mixed-methods approach was adopted, including both qualitative and quantitative methods. In addition to a questionnaire-based survey, semi-structured in-depth individual and paired interviews were carried out with PwPs, carers and healthcare professionals.

The survey included socio-demographic questions, including age, sex, ethnicity, and a self-rated health analysis. The validated survey tools – EuroQol (EQ-5D) plus *Schwab and England's Daily Living Scale* – were used to determine quality of life. A composite measure of satisfaction in relation to their interaction with healthcare professionals was derived from two items asking PwPs to rate the sensitivity with which they were told they had Parkinson's and how satisfied they were with the treatment and care they received. To enhance the rigour of the qualitative research findings, the principles of grounded theory were used throughout the primary research to guide sampling, data gathering and data analysis. Full details of the methods are presented in Section Two.

2.2 Primary research participants

A total of 1,776 respondents took part in the survey across the 11 European countries. 54% of the respondents were male. The average age at diagnosis was 58 years, with the youngest aged 25 and oldest aged 90 years. Only 19% of those surveyed were currently employed and, when asked to describe the area in which they live, 19% stated rural and 37% said town. The remaining 44% said they lived in cities.

For the qualitative interviews, 194 people took part, including at least five PwPs and three carers from each country. Of the 98 healthcare professionals, there were 23 neurologists specialised in Parkinson's disease, four general neurologists; three general practitioners, 17 Parkinson's disease nurse specialists, four geriatricians, 13 physiotherapists, five general nurses, eight occupational therapists, eight speech and language therapists, three nutritionists/dieticians, one social worker, two art/music therapists, and seven psychologists (including neuropsychologists).

2.3 Key findings

A number of key insights were identified by this study. These are detailed below and were consistent across the 11 countries.

1. **Informational needs:** Although PwPs and carers wanted to know the basic prognosis (*i.e.* 'Will I die from Parkinson's or will it shorten my life? What will be the probable effect on me physically?' etc) and were eager for possible side effects of their medication to be clearly explained, in-depth information about what could possibly happen in the future was inadequate. When the diagnosis is given, most people reported being in shock, and subsequently could not often remember what information they had been given during their initial appointment. Most would prefer for a follow-up appointment to be arranged (within a week) to discuss all the medication options and possible side effects, in addition to symptom management.
2. **The role of Parkinson's disease nurse specialists:** The highest satisfaction rating was indicated where a Parkinson's disease nurse specialist (PDNS) acted as a disease coordinator. PwPs appreciated the PDNS fulfilling such a role as they often found the nurse easier to talk to, and were more available than neurologists to take calls.
3. **Lack of communication between primary and secondary care:** A frequent cause of complaint was the lack of communication between the multidisciplinary team members, and communication between the primary and secondary care sectors.
4. **Benefits of support groups and learning self-help techniques:** Support groups were seen as a wonderful social outlet for many of the PwPs who attended them; for the carers, the groups were more about gaining information. It is interesting to note that although many of the carers enjoyed attending the groups, they also felt there was no place where they could express their own frustrations and concerns, or

speak freely during the meetings because the specific Parkinson's groups focused predominantly on the PwPs' needs. However, both the carers and PwPs found the advice provided by the support groups very helpful in relation to developing their own self-help techniques.

5. **Lack of knowledge in relation to Parkinson's symptoms:** General practitioners did not always suspect Parkinson's when a patient displayed a tremor or other motor symptom. Additionally, if the person affected was young and/or did not have a tremor, they often delayed asking for help.
6. **Role of general practitioners:** The general practitioners interviewed freely admitted that, due to the limited number of PwPs attending their surgeries, they were not experts in the disease. However, this reinforced the view of other, more specialised, healthcare professionals who did not feel that it would be a good use of resources to train general practitioners in Parkinson's, as they did not see sufficient numbers of PwPs for this training to be productive. It was suggested that more education should be focused at the PwPs and carers themselves so that they become more informed and better able to articulate the symptoms and side effects more effectively.
7. **Support for professionals working in nursing homes and general hospital wards:** Many healthcare professionals highlighted that huge improvements are needed in the way PwPs' medications are administered in both nursing homes and hospital wards. Although training to address this issue was on-going in many of the included countries, more work was reportedly necessary.
8. **Regional variability:** From the qualitative interviews, it was reported that access to care and support outside of the main cities was greatly reduced. Even in countries where healthcare professionals considered Parkinson's facilities to be some of the best in the world, there were still issues with patients accessing specialised healthcare practitioners (including clinical professionals and therapists).
9. **Patient satisfaction and quality of life:** The survey revealed that the more frequently people with Parkinson's had their medication reviewed, the greater their satisfaction became. However, it should be noted that although respondents may report high levels of satisfaction with care, this does not necessarily equate to improved quality of life.
10. **Using new technology to monitor health and support the management of the condition:** The study found that PwPs, when experiencing side effects caused by their medication (which could sometimes result in poor adherence rates), often had to wait more than a month in order to be able to see their consultant and discuss the problems they were experiencing. At the same time, there was concern expressed in relation to the communication and coordination between the different healthcare professionals and with the PwP.

2.4 Research limitations

As with all research studies, there are limitations to the methods used (often as a result of finite resources, as was the case with this study). With regards to the European inventory primary research survey:

1. The sample was self-selecting, potentially resulting in sample-bias.
2. The survey was online (except for one country where internet access was reportedly limited). This would have biased the sample towards the more educated and proactive PwPs, as well as a younger sample.
3. Often the survey questions required respondents to think back over a longer period of time. Therefore, the findings in relation to such questions are not an accurate portrayal of events. This also applies to a number of the questions asked in the qualitative interviews.
4. Finally, the survey did not ask respondents to detail any other conditions, which might have affected their quality-of-life scores – for example, diabetes, hypertension and so on.

With regards to the sampling for the in-depth qualitative interviews, as with the survey, the participants were self-selecting and often actively involved in their national Parkinson's organisation. This, again, potentially results in a biased sample.

Finally, with grounded theory, the number of in-depth interviews to be conducted should not be pre-determined, while recruitment should continue until *data saturation* is reached (the point at which no new themes are identified and the emergent theory appears complete). However, for this study due to the number of countries included in the project, coupled with time constraints, the number of research participants to be interviewed was agreed before the study commenced. A full list and description of the limitations is provided in Section Seven.

3 SECONDARY RESEARCH

The secondary research identified compelling examples of good practice from existing care pathways, care systems, a literature review of unpublished 'grey' literature, and feedback from multiple Parkinson's stakeholders. The secondary research also examined evidence-based recommendations from existing academic and scientific research papers, and relevant European and international guidelines. These findings present a more comprehensive picture of the Parkinson's care and management within Europe compared with previous studies and provides a strong foundation that will influence future My PD Journey discussions and activities.

4 TRANSFER OF GOOD PRACTICES

All through the discussions and research, it has been acknowledged that the transfer of good practices can be difficult to achieve if only because there will be differences that exist between health systems and availability of care/treatment provision at a country and regional level. However, this did not mean that it was considered to be an unachievable goal, and the discussions around what can be done to facilitate transfer of good practices recurred around common themes:

- A common (web) repository where research information and data can be easily accessed
- Getting together to encourage the sharing of experiences – for example, EPDA meetings, Parkinson's congresses and regional meetings
- Setting up a buddying system between countries and monitoring
- Healthcare systems to devote more resources to Parkinson's such as effective training with HCPs on how to deal with PwPs care more effectively – especially non-motor symptoms
- Improving access to HCPs with a specialty in Parkinson's
- More research at European Union level
- A European clinical framework needs to be developed by the European Commission with similar functions to the UK's NICE. This framework should define establish a minimum level of care that PwPs should receive across Europe as well as setting minimum standards of care
- Better communication between patient organisations through networking and exchanging visits to share good practices. Use public/private partnerships to facilitate exchanges
- Carry out activities that create better awareness of good practices that exist
- Establish national research and patient databases

It was also suggested that recognition by the EU and state of the role of patient organisations as an important provider in the care pathway, through national or EU funding, to make it possible for patient organisations to provide information and resources, help educate and support, and promote awareness of Parkinson's.

5 RECOMMENDATIONS

The recommendations below follow analysis of the European inventory findings as carried out by the My PD Journey multi-stakeholder coalition. The recommendations can be applied within a national or regional setting to effect improvements in the management of Parkinson's and, at the same time, offer potential socio-and health economic benefits to healthcare systems, Parkinson's care pathways, people with Parkinson's, their families and carers.

1. People with Parkinson's should receive a **personalised approach to treatment and care** – one that is tailored to individual needs and preferences.
2. **People with Parkinson's should have access to – and be referred within six months to – appropriate healthcare professionals with a specialty in Parkinson's.** This should apply both to the diagnosis (by a neurologist or doctor with a special interest in Parkinson's) as well as the continued management and review of the disease (by a multidisciplinary team of experts).
3. **People with Parkinson's and their carers should have access to a Parkinson's disease healthcare professional who is trained to monitor and manage the disease progression,** be a continuing point of contact for support (including home visits) when appropriate, and provide a reliable source of information about clinical and social issues.
4. It is essential that **coordination and communication between primary and secondary healthcare professionals is significantly improved and monitoring methods be developed.** This will ensure people with Parkinson's care plans remain consistent, regular and cohesive, resulting in their individual needs and preferences being met;
5. **Improved training about Parkinson's for professionals** working in nursing homes and general hospital wards is essential.
6. People with Parkinson's and their carers should have the **opportunity to ask for – and receive – all relevant information concerning the management and treatment of their disease,** enabling them to make informed decisions. In particular, patients should be able to request:
 - an appointment with a healthcare professional within two week of their initial diagnosis (if possible)
 - information on relevant support organisations and services.