

# Addressing barriers to care for people with advanced Parkinson's

Report of the AbbVie/Parkinson's Europe roundtable  
on ***Advanced Parkinson's care pathways held on 18th  
January 2024***

*Disclaimer: This non-promotional meeting was organised and funded by AbbVie, in partnership with Parkinson's Europe, who helped co-host the roundtable under a service agreement for unpaid consultancy to AbbVie. The content of this report is a summary of the group discussions, and it is based on the collective views of the expert attendees. It is intended primarily for healthcare professionals, policy makers and Parkinson's advocates.*

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## Executive Summary

Experts in advanced Parkinson's gathered at a roundtable hosted by AbbVie and Parkinson's Europe on 18 January 2024. These experts – movement disorder specialists, nurses, researchers, people with Parkinson's and representatives of Parkinson's organisations – gave their insights into the barriers in care pathways for people with advanced Parkinson's. They also shared best practices to address these barriers from their respective countries: France, the Netherlands, Spain, Sweden and the UK.

Pre-interviews carried out with the experts and the roundtable discussion highlighted critical gaps in care pathways for people with advanced Parkinson's across Europe, even in the most efficient systems. In many cases, these barriers delay identification, referral and management of individuals whose symptoms are no longer controlled by oral treatments, which in turn impacts their quality of life.

Four common areas of improvement to ensure effective care were identified:

- a lack of systematic **referral** of advanced Parkinson's patients
- **geographic disparities** in advanced Parkinson's management, particularly between urban and rural contexts
- inadequate **funding or resources**, such as specialised workforce
- gaps in **patient home support systems**.

While these barriers looked slightly different in each healthcare system, each of them hindered equitable access to comprehensive care and advanced therapeutic options for patients in need.

The roundtable did, however, identify some promising solutions currently applied in the different settings considered, that helped to enhance the standards of care:

1. The role of **specialised Parkinson's nurses**, whose involvement coordinates the care pathway, strengthens in-home support, facilitates patient communication and accelerates identification of disease progression and referral to specialists to consider advanced treatment options.
2. **Multidisciplinary care teams (MDTs)**, which play a crucial role in addressing patients' multifaceted needs.

3. The **integration of technology**, such as teleconsultations and wearables, which are particularly effective to reach people living in remote areas or to track symptoms progression.
4. Harmonised but tailored **accreditation systems**, that enhance care quality by setting standards and implementing continuous improvement processes.

To ensure advanced Parkinson's patients can access the best care, independently of where they live, two clear areas of work emerged from the roundtable discussion as a call to action:

- Firstly, **accelerating the care pathway** through earlier identification of disease progression and referral, reducing delays in accessing advanced treatments options.
- Secondly, **enhancing the quality of care**, by setting minimum standards and measuring the outcomes.

Achieving these ambitious goals requires a two-phase approach. In the short term, the solutions identified above could be replicated in other countries or regions, adapting them to the local context. In the long term, the impact of these strategies should be measured in order to build a strong evidence base to advocate for structural improvements, such as increased workforce capacity and funding to support optimal care standards and infrastructure. These plans should be collectively supported by Parkinson's advocates and the healthcare community, as well as by policymakers, in order to accelerate identification, referral and enhance care and quality of life of advanced Parkinson's patients everywhere.

## Introduction

This report is based on insights collected during individual interviews with experts followed by a virtual roundtable on Addressing barriers to care for individuals with advanced Parkinson's, co-hosted by AbbVie and Parkinson's Europe on 18th January 2024. This roundtable meeting was fully developed and funded by AbbVie. Parkinson's Europe co-hosted the meeting under contract to AbbVie. The roundtable was an important milestone in the collaboration between AbbVie and Parkinson's Europe, having previously worked together to identify a significant care gap for people with Parkinson's in Europe (see "The current situation" section below).

The roundtable brought together experts to share their insights on advanced Parkinson's care pathways. The experts encompassed the whole spectrum of care: movement disorder specialists, nurses, researchers, industry representatives, people with Parkinson's, care partners and patient organisation representatives. The geographical scope was limited for this roundtable to countries in Europe where best practices had already been identified: France, the Netherlands, Spain, Sweden and the UK. The insights gleaned from the roundtable were therefore largely country-specific, though several experts operate also at a pan-European level and were able to speak from experience about care pathways in other countries. It is important to note that the experts spoke from their own experience of specific cases, and the examples they gave may not be representative of common practice nationwide.

The objective of the roundtable was to collectively identify effective solutions to improve advanced Parkinson's care pathways and opportunities for replication across Europe – which are outlined in this report. Given the breadth of the challenge, it was necessary to limit the scope somewhat so as to keep the discussion focused. In addition to the limited geographies, it was agreed that education (of both patients and healthcare professionals) would not be included in the scope, as this topic is already being explored in detail in a parallel workstream coordinated by Parkinson's Europe.

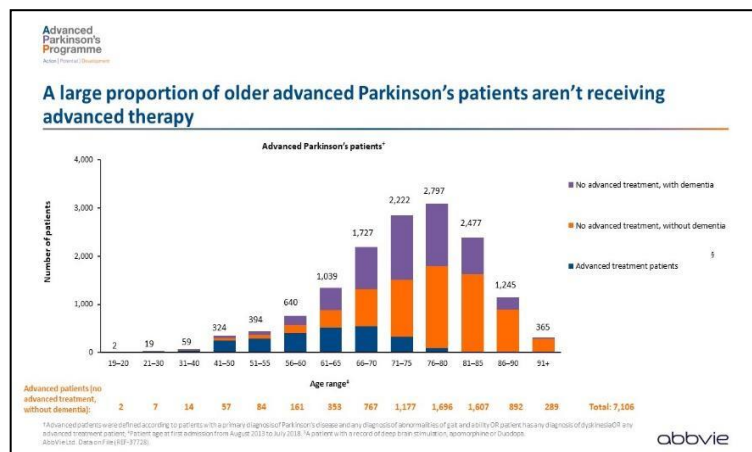
It is important to note that improving care pathways for people with advanced Parkinson's is a complex, multi-faceted challenge which will also vary across countries and communities. There is not one single problem, nor one single solution. Nevertheless, this report puts forward some commonly identified barriers, as well as some approaches – illustrated by case studies – that have been successful to address the care gaps.

The content of this report summarises the discussion which took place in the roundtable on 18th January 2024, along with additional insights from individual exchanges with each of the experts before the event. The experts who took part in the discussion have subsequently reviewed and endorsed this report.

## The current situation

People with advanced Parkinson’s have reached a stage where their symptoms have become more complex and have a greater impact on their daily life. At this point, non-oral therapies are considered as a viable option to manage symptoms.

Evidence points to serious gaps in care for people with advanced Parkinson’s; while non-oral therapies are considered a viable option, a number of patients eligible to advanced treatments are not receiving them in clinical practice<sup>1</sup>. In addition, many patients receiving oral treatments



The above graph also shows advanced Parkinson’s patients in the UK are not receiving advanced therapy options (source: UK HES (Hospital Episode Statistics) data focusing on UK Parkinson’s Disease patients’ access to Parkinson’s centres, referral patterns and locations. AbbVie Ltd. Data on File (REF-37728)).

continue to experience symptoms that suggest inadequate symptom control, yet there may be a lack of communication and therapy escalation discussions with their healthcare providers<sup>2</sup>. It was suggested this is due in part to the limited access to specialist centres and advanced therapies and this shortfall in care can result in a diminished quality of life not only for patients but also for their caregivers and families.

<sup>1</sup> Moes, H.R., Henriksen, T., Sławek, J. et al. “Tools and criteria to select patients with advanced Parkinson’s disease for device-aided therapies: a narrative review”. J Neural Transm 130, 1359–1377. (2023). <https://doi.org/10.1007/s00702-023-02656-z>

<sup>2</sup> Parkinson’s Europe. “Insights, knowledge and experience of treatment for people with advanced Parkinson’s” [https://parkinsonseurope.org//app/uploads/2024/02/advanced-parkinson-s-survey-results-report\\_web.pdf](https://parkinsonseurope.org//app/uploads/2024/02/advanced-parkinson-s-survey-results-report_web.pdf)

Another significant issue is the vast variation in care pathways and available services across Europe, including disparities both across and within individual countries. This leads to a “postcode lottery” for patients with advanced Parkinson’s, impacting referral, support, and access to advanced treatments.

### **What is a “care pathway”?**

When talking about care pathways in the context of Parkinson’s disease, this refers to the clinical or medical care and support that people with Parkinson’s receive from the point of diagnosis to death.

Care pathways look different in different countries, and even within countries there is often not one “standard” care pathway for everyone. However, generally speaking, in most countries represented in this roundtable, an assessment is made by a general neurologist as to whether a patient with Parkinson’s has reached an advanced stage. There are no universally validated criteria to identify advanced Parkinson’s. This is sometimes, but not always, based on scientifically validated criteria, such as “5-2-1”, or “Manage PD”, an AbbVie tool. AbbVie supported and participated in the development of the Delphi consensus that suggested 5-2-1 criteria.

Changes in symptoms and impairments to daily life may be another way to identify disease progression. Based on this assessment, the patient is referred by the general neurologist to a specialist centre and/or a movement disorders specialist or a Parkinson’s nurse, at which stage they will explore options for advanced Parkinson’s treatments. Depending on the local situation, the patient is followed up by either the general neurologist, or by a movement disorder specialist in combination with a specialised nurse, and, in some cases, a multidisciplinary care team (MDT).

## Barriers to advanced Parkinson's care

One of the key objectives of the roundtable was to identify common barriers to people getting proper advanced Parkinson's care, as a first crucial step towards developing effective solutions. Many of the barriers to care identified by the experts came up again and again across different countries and settings (with some notable exceptions which are explored below).

### 1. Gaps and delays in referral of advanced Parkinson's patients

It was also reported that, across Europe, patients with advanced Parkinson's are not always systematically referred, when needed, from general neurologists or geriatricians to movement disorder specialists. Attendees felt that this gap can lead to delays in the management of

*"It is simply unacceptable that a large majority of people with advanced Parkinson's are not referred for advanced treatment."*

**Andrés Álvarez Ruiz**, President of the Spanish Federation of Parkinson's

advanced Parkinson's, preventing patients from accessing appropriate care in a timely manner.

In some cases, the problem starts with difficulties identifying a patient with advanced Parkinson's. The "5-2-1" screening criteria<sup>3</sup> for advanced Parkinson's, despite being utilised in many countries, is

not routinely implemented in clinical care. The same applies for tools such as Manage PD<sup>4</sup> (used in some countries, not in the UK), created by AbbVie to support healthcare providers in the identification of patients with Parkinson's disease uncontrolled on oral medications, or the CDEPA questionnaire, resulting from a Spanish initiative to establish a definition of advanced Parkinson's<sup>5</sup>. The late identification, referral and management of advanced Parkinson's can have

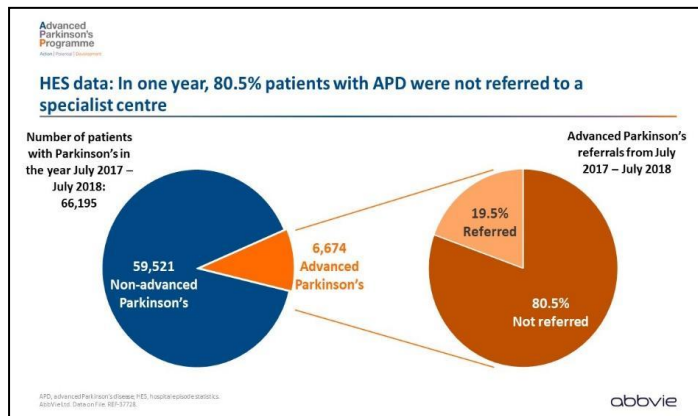
<sup>3</sup> Screening criteria to identify Parkinson's patients uncontrolled on oral treatments: 5 times oral tablets taken daily, 2 hours of "off" time daily, 1 hour of troublesome dyskinesia every day (Moes, H.R., Henriksen, T., Sławek, J. et al. "Tools and criteria to select patients with advanced Parkinson's disease for device-aided therapies: a narrative review". J Neural Transm 130, 1359–1377. (2023). <https://doi.org/10.1007/s00702-023-02656-z>)

<sup>4</sup> Antonini A, Odin P, Schmidt P, Cubillos F, Standaert D.G., Henriksen T, Jimenez-Shahed J, Alobaidi A, Jalundhwala Y.J., Bao Y, Zamudio J, Parra J.C., Kukreja P, Onuk K, Skalicky A.M., Kleinman L, Jones E, Metz S, Fernandez H.H. (2013). "Validation and clinical value of the MANAGE-PD tool: A clinician-reported tool to identify Parkinson's disease patients inadequately controlled on oral medications." <https://pubmed.ncbi.nlm.nih.gov/34695657/>

<sup>5</sup> Moes, H.R., Henriksen, T., Sławek, J. et al. "Tools and criteria to select patients with advanced Parkinson's disease for device-aided therapies: a narrative review". J Neural Transm 130, 1359–1377. (2023). <https://doi.org/10.1007/s00702-023-02656-z>



a considerable impact on quality of life and on people's ability to prepare (along with their caregivers) for changes in lifestyle and the decision to initiate non-oral treatments.



As the above graph shows, 80.5% of advanced PD patients were not referred to a specialist center in the UK between July 2017 and 2018 (source: UK HES (Hospital Episode Statistics) data focusing on UK Parkinson's Disease patients' access to PD centers, referral patterns and locations. AbbVie Ltd. Data on File. (REF-37728)).

Where there are guidelines related to identification and treatment of Parkinson's, they often fail to align with reality. In both the UK<sup>6</sup> and France<sup>7</sup>, there are comprehensive and well-evidenced guidelines which recommend, for example, regular consultations with a neurologist and a dedicated specialised nurse – but these recommendations are often

impossible to implement due, in most part, to financial constraints and resource limitations.

There are also issues with the healthcare ecosystem around the patient, for example the availability of general neurologists and movement disorder specialists. There has been an observation that general neurologists can struggle<sup>8</sup> to provide Parkinson's patients with adequate information in the early stages of the disease to prepare them for what to expect as the disease progresses and how to recognise and manage advanced Parkinson's – often due to very real fears around how patients will react<sup>9</sup>. The lack of specialist centres only adds to the burden on general neurologists – and when patients are seen by a specialist they are often reluctant to then return to a general neurologist, adding further complexity to the care pathway.

## 2. Geographical disparities, particularly between urban and rural contexts

<sup>6</sup> National Institute for Health and Care Excellence (NICE). (2017). "Parkinson's disease in adults: diagnosis and management." <https://www.nice.org.uk/guidance/ng71/resources/parkinsons-disease-in-adults-pdf-1837629189061>

<sup>7</sup> Haute Autorité de Santé (HAS). (2016). "Guide du parcours de soins Parkinson." [https://www.has-sante.fr/upload/docs/application/pdf/2012-04/guide\\_parours\\_de\\_soins\\_parkinson.pdf](https://www.has-sante.fr/upload/docs/application/pdf/2012-04/guide_parours_de_soins_parkinson.pdf)

<sup>8</sup> Lökk, J. (2011). "Lack of information and access to advanced treatment for Parkinson's disease patients". <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3256003/>

<sup>9</sup> Auffret, M., Weiss, D., Stocchi, F. et al. "Access to device-aided therapies in advanced Parkinson's disease: navigating clinician biases, patient preference, and prognostic uncertainty". J Neural Transm 130, 1411–1432 (2023). <https://doi.org/10.1007/s00702-023-02668-9>

A common theme across all countries (with perhaps the exception of the Netherlands, the smallest country represented at the roundtable) was the impact of geography on advanced Parkinson's care.

Rural areas often face significant challenges due to fewer available resources, including hospitals, specialist centres, and neurologists. It was reported that while many big cities such as Stockholm are very well equipped to provide advanced Parkinson's care, resource limitations in rural settings can make it considerably more difficult for patients to access advanced therapies. Mobility issues, which are particularly pronounced in later stages of Parkinson's, can also hinder people's ability to travel for medical care. In both the UK and France there exists a "taxi" ambulance service to bring patients to the hospital, but for people in less densely populated areas this can lead to uncomfortably long wait and journey times.

*"It's essentially a postcode lottery."*

**Katherine French**, Head of Service Improvements and Grants, Parkinson's UK

Moreover, the distribution of specialist centres and access to advanced Parkinson's treatments can vary significantly even within urban regions. For example, in countries like Sweden, the popularity and accessibility of different treatments differ from one region to another. This discrepancy in care options further compounds the challenges faced by advanced Parkinson's patients and their families, especially in remote areas.

### **3. Insufficient dedicated funding and resources**

The variability in funding and resources dedicated to Parkinson's plays a significant role in the care of patients with advanced Parkinson's across Europe. A lack of investment underpins the shortage of neurologists referred to above, which was described as particularly evident in countries like Spain and France (less so in the Netherlands), and can lead to delays in diagnosis and ineffective care pathways for patients.

Since Parkinson's is a degenerative condition, healthcare resources are often directed towards diseases where there is a higher likelihood of achieving better "results". This seems to be even more challenging in countries where the healthcare coverage is limited to neurologist consultations, meaning that patient organisations have to fill the gaps in providing support networks and non-medical services such as exercise groups.

Even where there is funding, there can be structural issues with the healthcare and reimbursement system. For example, in France, treatments related to chronic diseases (including Parkinson's) are fully covered by healthcare insurance, but this comprehensive coverage can inadvertently hinder the adoption of more integrated care support.

#### **4. Gaps in patient home support systems**

A crucial aspect of the care pathway for patients with advanced Parkinson's is the home support system, including families and caregivers. For people who are isolated or living alone, it can be difficult for healthcare providers to accurately identify advanced symptoms and ensure treatment adherence, particularly if people are reluctant to present to their neurologist.

In some cases, even if well supported in the home setting, people with Parkinson's may not fully share their experiences or flag when symptoms worsen, to prevent burdening their families further – and indeed it is often the caregivers who will notice a change first. This can also come down to education and awareness of people with Parkinson's and their caregivers, especially about the non-motor symptoms of advanced Parkinson's. Insufficient knowledge and awareness can again lead to delays in identification and access to non-oral treatment. In most countries, patient associations and volunteers are filling the knowledge gap, to make sure patients and those supporting them are well prepared for the advanced stages.

## **What works well**

As well as identifying common barriers to advanced Parkinson's care, the objective of the roundtable was to hear from the experts of “best practices” in their experience, and what works well in their country. These are not catch-all solutions, and while many of the barriers identified earlier in this report are prevalent across countries, there are of course specificities in each country and region which necessitate a tailored approach. Nevertheless, the examples below of what works well can be seen as a starting point for replication across Europe, provided that this is done in a way that makes sense for local needs.

## 1. Specialised nurses

The most effective care pathways for people with advanced Parkinson's tend to be linked to where there exists a "care coordinator", coordinating with the patient's neurologist but with oversight of the whole spectrum of their needs, from treatment to support networks. In the Netherlands and Sweden, two countries where advanced Parkinson's care is particularly strong, this role is played by specialised Parkinson's nurses.

The role of specialised Parkinson's nurses is multifaceted, encompassing various responsibilities and addressing specific challenges in patient care. In countries where they exist, specialised nurses are instrumental in reducing waiting times between neurologist appointments and serve as a crucial link between hospital-based care and in-home assistance. They are

*"There must be a coordinator for care right from the very beginning to help with healthcare pathways and disease progression - we can't wait until it becomes a global reality."*

- **Marie Fuzzati**, Scientific Director, France Parkinson's

critical in identifying disease progression, but also for recommending treatment escalation, especially in alignment with MDTs (see below). The fact that in many cases the nurses go into patients' homes also has the advantage of fostering a sense of comfort and trust (this is particularly important for people living alone or in isolated areas), leading to more open and honest communication about their symptoms and living circumstances.

In the Netherlands, and more recently in a pilot project in France<sup>10</sup>, part of the nurses' role is to support patients in living with advanced treatments. They not only manage the technical and pharmacological aspects but also give people confidence to continue living their life with the system. In Sweden and in some circumstances in the UK, specialised nurses are able to adjust dosages, and in the Netherlands nurse and neurologist work in close collaboration.

Funding, education and remuneration of specialised nurses vary according to the national setting. In the Netherlands and Sweden, specialised nurses, especially those with a Master's degree, seem to receive a level of remuneration reflecting their advanced training and skills. In France, where a pilot project for nurses specialised in neurological diseases is currently

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<sup>10</sup> Neuro-Bretagne. "Les IRENE (Infirmières Référentes en Neurologie)." <https://www.neuro-bretagne.com/les-irene.php>

underway, there is a push for increased salary recognition to reflect their expertise while ensuring the nurses' primary focus remains on patients with neurological conditions.

## 2. Multidisciplinary teams and integrated care

A complex disease like Parkinson's requires multidimensional care. An approach that provides this kind of care makes use of multidisciplinary care teams (MDTs). These teams are made up of specially-trained professionals, working together to support the patient's needs; this can include physiotherapists, speech and language therapists, dieticians, pharmacists, and occupational therapists.

Access to an MDT can allow for people with advanced Parkinson's to receive care that can improve their quality of life (compared to stand-alone care from a general neurologist)<sup>11</sup>, encompassing not only the physical symptoms but also the psychological and emotional well-being of patients and their caregivers. MDTs seem to work best when there is a clear connection and line of communication between specialist centres and general hospitals.

Despite MDTs being an important part of the care pathway for people with Parkinson's, they are not accessible everywhere – and, as outlined above, barriers arise for patients living in less densely populated areas. In the UK, despite national guidelines underlining the need for patients' access to an MDT, it was reported that only 17% of patients with advanced Parkinson's can actually access them<sup>12</sup>.

What is missing is a clear definition of the minimum requirements for an advanced Parkinson's MDT, both in terms of numbers and specialities (which will likely vary to some extent across countries). Despite some existing guidelines, it may not always be feasible to assemble a large number of MDT members. A more feasible approach would focus on the care that is absolutely essential for patients with (advanced) Parkinson's – but this must be based on evidence and must integrate patient input.

Unique to the Netherlands is ParkinsonNet<sup>13</sup>, a network of trained allied healthcare professionals which, among other things, allows nurses and other HCPs to exchange best practices and enhance patient care. While it is an important collaboration network which has

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<sup>11</sup> van der Marck MA, Bloem BR, Borm GF, Overeem S, Munneke M, Guttman M. (2013) "Effectiveness of multidisciplinary care for Parkinson's disease: a randomized, controlled trial":

<https://movementdisorders.onlinelibrary.wiley.com/doi/10.1002/mds.25194>

<sup>12</sup> Parkinson's Excellence Network, 2022 UK Parkinson's Audit – Summary report:

<https://www.parkinsons.org.uk/sites/default/files/2023-06/2022%20Summary%20Report%20-%20FINAL.pdf>

<sup>13</sup> ParkinsonNet: <https://www.parkinsonnet.nl/>

already been replicated in some countries (Luxembourg and Norway) and could be further replicated elsewhere, it requires the right level of resources, funding, skills and specialised workforce.

### 3. Technology

The integration of technology into different stages of the care pathway for people with advanced Parkinson's can effectively overcome some of the barriers outlined earlier in this report.

A silver lining of the COVID-19 pandemic was a rise in the use of telemedicine, enabling patients to access healthcare services remotely. Remote consultations can be particularly useful for people in rural areas, to save on the time and resources required to travel. They can also reduce the waiting time for patients in between in-person consultations with general or specialist neurologists. While teleconsultations should not totally replace in-person consultations (which are crucial for an in-depth understanding of the patients' needs, and to establish a connection between patient and neurologist), they are an important tool to ensure continued care and follow-up.

Such consultations are not limited to the patient-doctor relationship. In Sweden, regular virtual consultations<sup>14</sup> between healthcare specialists (general neurologists, specialised nurses, and movement disorder specialists) allow them to discuss patient cases, exchange experiences and ultimately refer patients for advanced treatment more quickly and effectively.

*"Since the pandemic we have increased our use of video calls with patients. This has proved to be very time effective to screen patients who need to be visited or directed to the right care."*

- Pia Rousu, Registered Nurse, Academic Specialist Centre of Neurology, Sweden

Beyond virtual consultations, wearables, such as smartwatches and sensors, serve as valuable tools for monitoring Parkinson's symptoms. They can identify issues that patients might not report themselves, such as early morning off periods or nighttime symptoms. Wearables provide a broader view of people's symptoms and offer

essential data for discussions during medical appointments, which can be particularly useful in identifying disease progression.

<sup>14</sup> Parkinson's Life. (2015). "Telemedicine: How Sweden is reducing waiting times for Parkinson's treatment." <https://parkinsonseurope.org/2015/12/08/telemedicine-how-sweden-is-reducing-waiting-times-for-parkinsons-treatment>

However, it's important to consider the digital skills of patients, especially among older generations. While some studies<sup>15</sup> show high adherence to wearables (including among older people), many people might be hesitant to even admit they are uncomfortable with it, or might not have the capacity to improve their skills even if they want to. Therefore, technological solutions must take into account the digital literacy gap – which exists even in the more ‘literate’ European countries – and should help, not hinder, the patient experience.

#### **4. Accreditation systems to raise the quality of care**

While the creation of pan-European harmonised protocols for advanced Parkinson’s care would be both unrealistic and ineffective, the development of protocols at a local level has been shown to improve patient outcomes.

A strong example comes from Spain, where the establishment of an accreditation system<sup>16</sup> for hospitals driving excellence in Parkinson’s care provides a structured foundation for setting standards. The accreditation system is based on a set of minimum requirements in terms of healthcare professionals’ skills and knowledge, services provided, as well as a set of protocols for standardising disease management. This allows for patient variability and to focus on impairments to the patient’s life rather than just on their symptoms, identifying and responding to complications, and developing contingency plans.

The strength of this accreditation system also lies in its continuous monitoring and evaluation, integrating KPIs and feedback from both patients and HCPs. This iterative approach ensures that the protocols remain effective and up-to-date in meeting the evolving needs of advanced Parkinson's patients in the hospital.

While the Spanish accreditation system remains one of the more developed in Europe, other countries also make use of protocols in some form. For example, in Stockholm, monthly meetings with patient groups provide insights and feedback which again strengthen the existing guidelines and protocols to ensure they are tailored to patients’ needs.

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<sup>15</sup> Bloem, Bas. “Parkinson Op Maat-onderzoek.” [https://www.radboudumc.nl/expertisecentra/parkinson-en-bewegingsstoornissen/onderzoek-en-innovatie/research-support/basis/onderzoeken/onderzoeken-geen-deelnemers-\(meer\)-nodig/parkinson-op-maat-studie](https://www.radboudumc.nl/expertisecentra/parkinson-en-bewegingsstoornissen/onderzoek-en-innovatie/research-support/basis/onderzoeken/onderzoeken-geen-deelnemers-(meer)-nodig/parkinson-op-maat-studie)

<sup>16</sup> Sociedad Española de Neurología. (2020). “El Manual de Acreditación de la Sociedad Española de Neurología para Consulta Monográfica de Trastornos del Movimiento (CM), Unidad de Trastornos del Movimiento (UTM) y Unidad de Trastornos del Movimiento Médico-Quirúrgica (UTM-MQ)” <https://getmcert.sen.es/images/doc/manual-acreditacion-sen.pdf>

## Conclusions & call to action

The roundtable discussion was a crucial step towards enhancing care pathways for people with advanced Parkinson's in Europe. While there are good examples of efficient care systems across countries, critical gaps need to be addressed to improve standards in advanced Parkinson's management everywhere. To address these challenges effectively, there are two clear avenues for improvement.

- 1) First, there is a **need to accelerate care by streamlining and speeding up the identification of disease progression and referral process**, reducing delays in patients accessing advanced treatments and essential multidisciplinary care, wherever they live and whatever their home set-up.
- 2) Second, the **quality of care must be enhanced**, setting up high but realistic standards, including protocols for continuous improvement, and encompassing the whole patient experience and quality of life, from long before the condition reaches the advanced stages.

As far as possible, care should be equalised across regions and countries, mitigating disparities in accessibility of expert centres, standards for management of advanced Parkinson's, specialised workforce capacity (such as nurses and neurologists) and infrastructure. These goals are ambitious, and indeed they must be if the current care for people with advanced Parkinson's is to be enhanced. Therefore, they necessitate a two-phase approach, thinking both short and long term.

In the short term, the solutions identified by the experts in this report can be leveraged at a local (hospital) or regional level, or via pilot projects, with adaptations tailored to the local environment. Examples include:

- **Better use of available technology:** as the Swedish Consultative Neurology example shows, virtual calls between movement disorder specialists and general neurologists to discuss patients' cases can accelerate the referral and treatment escalation, when needed, and overcome accessibility barriers due to lack of specialised centres or long waiting times. Furthermore, the use of wearables can support symptoms' monitoring and data generation, even at night, which in turn supports evidence-based decision making. As the digital infrastructure and literacy can vary across the territory and the individuals, it is important to maintain a hybrid and flexible ecosystem.



- **Establishing realistic standards for advanced Parkinson's patients' management**, to set a baseline to meet patient needs, including, for example, minimum requirements in relation to MDTs, involving the patients' perspective and including KPIs to measure impact and drive continuous improvement. As an additional step to take, the Spanish accreditation system demonstrates the value of recognising excellence in Parkinson's care and continuously improving services at the hospital level;
- **Enhancing, whenever possible, the role of nurses, as a critical coordinator of care**, close to patients and able to identify early disease progression and referral by connecting the patient with the surrounding care ecosystem. Even countries that do not have established Parkinson's nurses, like France, have demonstrated that it is possible to test (through regional pilots) the value of having trained nurses who support people with Parkinson's in their home setting.

Looking ahead, in the longer term, the impact of these strategies and pilots must be measured, in order to generate and consolidate data that showcases the benefit of care excellence, not only for individuals but for society as a whole. It has been proven that Parkinson's disease progression increases the economic burden on patients and their caregivers, but also on the healthcare systems<sup>17</sup>. Timely management of advanced Parkinson's could reduce the burden on patients and their families, whilst also alleviating the societal cost.

This evidence should form the basis of advocacy for more structural, enduring advances. This would ideally include unlocking investments to increase the number of specialised neurologists and nurses, and ensuring that the standard requirements to deliver Parkinson's care excellence are supported by adequate infrastructure and resources.

In essence, this roundtable discussion has set a course toward a more efficient, equitable, and patient-centred care pathway for people with advanced Parkinson's. Looking ahead, there are both short term and long-term strategies which must be collectively supported by Parkinson's advocates and the healthcare community, in order to accelerate identification, referral and enhance care and quality of life of advanced Parkinson's everywhere.

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<sup>17</sup> Chaudhuri, K.R., Azulay, J.P., Odin, P. et al. (2024). "Economic Burden of Parkinson's Disease: A Multinational, Real-World, Cost-of-Illness Study". <https://link.springer.com/article/10.1007/s40801-023-00410-1>

## Appendix: detailed case studies

### Neurology at home

#### France

Neurology Department of the Saint-Brieuc Hospital, Brittany  
 Association Neuro-Bretagne  
 Regional Health Agency (ARS)



#### Problem

Good quality care for patients with advanced Parkinson's in the hospital, but a lack of support and information beyond neurologist consultations.

#### Solution

A pilot project in which specialised nurses go into patients' homes to provide holistic care and support patient autonomy.

#### Outcome

The pilot project is just coming to an end and so the results have yet to be evaluated.

#### Key Success Factors/Learnings

The importance of a "coordinator" who can look comprehensively at the patients' needs and be the link between hospital, patient and additional services.

**Link to article and flyer (French):**

[Flyer IRENE](#)

[SANTÉ. Parkinson, sclérose en plaques... IRENE, le premier service de neurologie à domicile est expérimenté en Bretagne](#)

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## Consultative neurology

### Sweden

*Project launched by the Neurology Clinic and Innovation Centre at Karolinska University Hospital. AbbVie Sweden funded the Innovation Centre and provided the technology equipment.*



#### **Problem**

Excessive waiting times for the assessment of advanced Parkinson's in Sweden.

#### **Solution**

An innovative system based on video calls between general neurologists from all over the country and Parkinson's specialists from expert centers.

#### **Outcome**

Time to assessment was shortened to 1 week (vs 6 weeks). 4 patients instead of 1 could be assessed during the meeting time. 90 % unnecessary referrals were avoided.

#### **Key Success Factors/Learnings**

Improved referral and accelerated process and increased patients' confidence in treatment decision. However not all general neurologist are aware of this option.

***Link to article and video (English):***

[Telemedicine: how Sweden is reducing waiting times for Parkinson's treatment](#)

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## Quality accreditation for optimal Parkinson's care

### Spain

*Spanish Neurology Society Movement Disorders group study*



#### **Problem**

Absence of standardised healthcare accreditation impacts service quality and user experience and journey in Spain.



#### **Solution**

Recognise those clinical units that treat patients with Parkinson's disease and ensure the best care provision to be achieved through standardised protocols.



#### **Outcome**

Safety, quality, training and other key components of Spain's treatment system were optimised.



#### **Key Success Factors/Learnings**

It was important to implement a solution to monitor and continuously improve the system, adjusting where necessary.

**Link to article (Spanish):**

[El Hospital de Pontevedra acreditado a nivel nacional \(consalud.es\)](https://www.consalud.es/el-hospital-de-pontevedra-acreditado-a-nivel-nacional)

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