



# European Inventory

Findings from the secondary research study

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## 1. INTRODUCTION

The European inventory is an initiative of My PD Journey (MPDJ), a multi-stakeholder project for people with Parkinson's in Europe. It aims to identify the gaps in Parkinson's care that currently exist across Europe, and to seek out examples of good practice that are shown to have a measurable and positive impact on improving the quality of life for people with Parkinson's (PwPs).

The recommendations of the European inventory, put forward by the My PD Journey European Strategic Committee and Parkinson's Specialist Panel as a result of their analyses of the findings, 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, and to PwPs, their families and carers.

The researchers recognise that there is a substantial body of past research around the performance and value of various good practices, and many authoritative guidelines that are grounded on more research and sound evidence. In practice, there is no precedence for organisations or healthcare professionals (HCPs) to replicate good practices or to adopt guidelines because there is no edict to review or act upon them. Often, making changes will involve many actors for whom the benefits may not be sufficiently persuasive for them to support.

It is the aim of the MPDJ project to build upon the recommendations of the European inventory report by establishing and developing national coalitions in countries across Europe. The coalitions will hope to demonstrate the value, practicability and transferability of good practices in the clinical, home and work environment in order to provide further evidence of the recommendations to have a substantive, beneficial socio-economical impact upon the entire care pathway. The hope is that these practices will become models of care that can be applied across different healthcare systems with the support of decision makers and payers.

The research leading up to the recommendations is divided into two streams:

- a primary research study with survey and interviews, providing a picture of the current Parkinson's management and care in 11 countries across Europe; and
- a secondary research (presented here) that identifies compelling examples of good practice from existing care pathways, care systems, feedback from multiple stakeholders<sup>1</sup> in Parkinson's disease, data collected during the EPDA's Learning in Partnership workshops (EPDA General Assembly 2014), and a literature review of existing academic and scientific research papers, relevant European and international guidelines as well as unpublished "grey" literature (this being relevant reports, policy documents, information resources, conference abstracts, or research studies conducted by relevant third sector organisations and government departments, relevant newspaper articles, online discussion forums, and blogs).

The findings present a more comprehensive picture of the Parkinson's care and management within Europe than has been possible in previous studies. It provides a strong foundation for learning that will influence future MPDJ discussions and activities.

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<sup>1</sup> Healthcare professionals (HCPs), people with Parkinson's (PwPs), their families and carers, Parkinson's disease organisations across Europe

## 2. METHODS

A rapid review of published and unpublished evidence was carried out to identify evidence from scientific and academic studies, reviews and meta-analyses evaluating multi-disciplinary interventions and the care pathways for patients with Parkinson's across Europe. The rationale behind conducting a rapid review of the secondary data before starting the primary review was to identify the main 'knowledge gaps'<sup>2</sup>. The knowledge gaps were then used to guide the development of the survey questions and qualitative discussion guide (used in the data collection of the primary research).

Rapid searches using electronic bibliographic databases, including CINAHL, EMBASE, MEDLINE, PsycINFO, PsychArticles as well as the COCHRANE database were made to identify relevant articles published in peer-reviewed journals<sup>3</sup>. In addition to this, web-based searches used to identify reports, policy documents, information resources, conference abstracts, or research studies conducted by relevant third sector organisations and government departments in each of the 36 included countries.

Due of the sheer volume of publications, evidence or high level recommendations supported by web-based research have been limited to those of particular note (cited by many other research pieces) or otherwise published within the last 2 years (late 2012 - 2014). Additionally, all searches were carried out specifically with reference to Parkinson's disease.

The lists of guidelines therefore do not represent every guideline that may exist. In some cases, guidelines would reference other previous guidelines and to that extent, we have not tracked back to the previous work since we assumed the later publication would have distilled some or all of the previous guidelines recommendations into their own. We acknowledge that a limitation and inherent weakness of the searches carried out through Internet search engines is they have been limited to English and unless a reference to non-english guidelines or reference material is mentioned or referred to within English texts, or they have been mentioned by healthcare professionals during interviews, a truly thorough search is not possible.

### 2.1. Research limitations

The limitations of the review should be noted. This is by no means a full and comprehensive review of the literature across all of the 36 included countries. Time and budget constraints meant that the search was not as extensive as we would have liked. It does not cover palliative care guidelines for instance or the many treatment options, including certain complementary therapies that have been shown to be effective in the management of Parkinson's. In addition to this, and due to the very limited time the research team had to identify and review data from each of the 36 countries, if evidence and reports were written in English, then they were more likely to be included in the review, as there was limited time and budget for translation work.

However, in regards to the aims of the review - to identify the knowledge gaps and to help inform the research questions asked in the primary study – then the review was a useful and informative process.

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<sup>2</sup> By the term 'knowledge gaps', the research team are referring to identifying where gaps in the current literature/evidence-base remain.

<sup>3</sup> The following MeSH search terms were used (care OR treatment OR pathway OR managed OR diagnosis OR rehabilitation OR intervention) AND (Parkinsons OR Parkinson's disease OR Parkinsonism). The search terms were changed slightly for the databases where MeSH terms are not used, to ensure that the correct terms were being used for all of the databases searched.

### 3. THE PARKINSON'S PATIENT ORGANISATION PERSPECTIVE IN EUROPE

The size and capacity of patient organisations in a particular country varies dramatically between those in northern, western and southern Europe to those in central/eastern Europe. Economics and funding aside, there are often social and cultural barriers that are factors to how well patient organisations are established within the particular country.

During the 2014 Learning in Partnership workshops held at the EPDA General Assembly, EPDA members – Parkinson's patient associations from 36 countries in Europe – held discussion workshops to build a picture of how Parkinson's is currently diagnosed and managed across Europe. The associations were divided into geographical groups or those that had similar health systems<sup>4</sup>:

Central/Eastern Europe	Northern Europe	Southern Europe	Western Europe
• Bosnia	• Denmark	• Cyprus	• Austria
• Bulgaria	• Finland	• Greece	• Belgium
• Croatia	• Iceland	• Israel	• France
• Czech Republic	• Baltic States	• Italy	• Germany
• Georgia	• Sweden	• Malta	• Ireland
• Hungary	• Norway	• Portugal	• Luxemburg
• Poland		• Spain	• Monaco
• Romania		• Turkey	• Netherlands
• Russia			• United Kingdom
• Slovakia			
• Slovenia			

It should be noted that, in relation to the findings detailed below, not all member-countries of the EPDA were represented at the General Assembly. Therefore, the information detailed below is more focused on those countries who were represented.

#### 3.1. What professionals do PwP have access to?

Within western and northern Europe there was generally good access to:

- General practitioners (GP)
- Neurologists (not many Parkinson's specialists in Norway or Malta)
- Parkinson's nurses (though only to a limited extent in Norway and Ireland (5)) in Denmark, a trial has been established across three municipalities in which nurse visits are available soon after diagnosis to give advice and counselling to the PwP and their families)

<sup>4</sup> It should be noted that the countries were simply divided into the four groups to manage the group activities run at the EPDA General Assembly, and that the findings from the primary research were not clustered and analysed in relation to the groups.

- Neuropsychologists and neurosurgeons (in Norway and Sweden only and these are within University hospital settings; in the Netherlands, university hospitals also treat PwPs and are becoming more specialised; in Ireland PwPs are referred to UK hospitals for neurosurgery)
- Sex therapists (apart from Norway and Denmark)
- Nutritionists (private only in Denmark)
- Geriatricians (apart from Norway and Denmark)
- Family therapists (although in Denmark, these were not Parkinson's specific)
- Social workers
- Dentists (private only in Denmark)
- Multidisciplinary (MDT) teams (except Finland and Norway). In the Netherlands, depending on the level of insurance, a PwP can make a direct appointment with a physiotherapist and without referral
- Patient organisations (the Danish patient organisation has a rehabilitation project being assessed for possible inclusion in the country's healthcare system)
- Free prescriptions (except in the Netherlands)
- State funding of therapies (although in Norway, Sweden and Denmark, there is less choice than is available for private payers. In Finland, there is a national health service (that also provides impulse disorder advice) but private healthcare is deemed not expensive for PwPs. In Malta, people will seek private support when the waiting times are long – around 15 patients have received deep brain stimulation treatment from a Maltese neurologist practicing in the UK).

In many countries, even though general access to many services was good, crucially, this also depended on the region in which people lived and upon individual awareness of what is available in their region. The waiting times could also vary (further information on these points are presented in the primary research study)<sup>5</sup>.

Within central/eastern Europe, there are very little resources to address or treat non-motor symptoms. In many cases getting to see a good physiotherapist is as expensive as in western Europe: however, the wages in central/eastern Europe are much lower. In relation to other therapists (OT, physiotherapy and speech and language) – in Eastern Europe, there are very few therapists and access is not always state funded. In addition to this, the costs are considered very expensive and comparable to Western Europe despite lower incomes.

### **3.2. What is the referral system for specialist care/neurologists/PD nurse specialists/other?**

Within nearly all of the 36 included countries, evidence was found to show that GPs/family doctors would usually refer PwPs to a neurologist, who would then make the diagnosis. After diagnosis, a neurologist or Parkinson's disease nurse specialists (PDNSs) would make referrals to other services such as physiotherapy. In most countries, GPs could also make referrals, but this was less frequent<sup>6</sup>.

Specifically in the Nordic countries, the GP or neurologist made referrals to the other services. In Finland, the geriatrician also had responsibility to make referrals. In Denmark, Parkinson's specialists often made referrals with the help of PDNSs.

<sup>5</sup> [www.epda.eu.com/european-inventory](http://www.epda.eu.com/european-inventory)

<sup>6</sup> These findings were subsequently validated by the primary research study.

### 3.3. What are the average waiting times to see a specialist or other professionals?

Waiting times varied in the different countries even at a regional level. It is generally the case, once you have a diagnosis and are under the care of a neurologist, PwPs are routinely seen once a year (twice a year maximum), but more often if the PwP are on certain treatments such as pump therapy, or their symptoms are deteriorating. The differential in waiting times between the state-paid and private treatment is striking.

#### **Denmark**

- 1st visit – 2 months
- 2nd visit – 6 months on average

#### **Finland**

- 1st visit – 1 week to 6 months (hospitals are penalised if not seen within 6 months)
- 2nd visit – 12 months
- Continued visits are state paid until titration of medication is stabilised
- 1st visit – 1 week to 2 years
- 2nd visit can then take 1 year or more unless you go private, where the wait is 1 week

#### **Malta**

- 2 months

#### **Sweden**

- 1st visit – 3 months or more (first visit paid by the state)
- 2nd visit can take 1-2 years depending on the hospital
- Follow-up visits might take 2 years

#### **UK and Ireland**

- In the UK and Ireland (who follow the UK NICE guidelines), access was usually in keeping with the 6-week recommendation by NICE. However, healthcare professionals (HCPs) stated that this was not always feasible (although it was their aim).

In many central/eastern European countries, people can wait between 1 and 2 years to see a specialist, and then it may not be a specialist in Parkinson's – rather it is by and large a neurologist who will cover many disease areas. As mentioned previously, this varies both at a regional and country level. Access to a neurologist in more rural areas (or outside of the capital cities) was often very limited. Care provision by nurses is also very "generic" with very few courses dedicated to nursing PwPs.

### 3.4. What treatments are available (both clinical and non-clinical)?

It is reported that overall, at least one advanced clinical treatment is available within the 36 included countries. However, the number of PwPs who had access to the advanced treatments, and waiting times involved varied considerably. For example in Spain, patients eligible for advance treatments such as Duodopa or deep brain stimulation (DBS) have to wait more than a year. In Bulgaria one hospital offers DBS but the hospital only

performed the procedure once in 2011<sup>7</sup> and then again in 2013. Currently, there are around 20 patients waiting for such treatment<sup>8</sup>; This is in contrast to other countries, such as France, where DBS is offered consistently across the country. In a few of the countries, for DBS, PwP were referred to other countries to undergo the procedure (for example, in Ireland PwPs are sent to the UK).

The most frequently offered non-clinical treatments (although not available in every country) were physiotherapy and speech therapy. Within Norway, Sweden, Denmark and Finland, all Parkinson's medication and surgical treatments that are available on the market are accessible. In Norway, this treatment options include rehabilitation programmes and, in Sweden, chiropractors.

Many of the eastern European countries reported rehabilitation programmes but the availability and costs to gain access to the programmes and the services offered varied greatly. For example, in Bulgaria PwPs are offered a 10-day stay in hospital to receive intensive treatment and rehabilitation once a year. There they can receive treatments such as thermal therapy, physiotherapy, psychotherapy, electrical sleep therapy, music and aromatherapy, and nutritional advice and support. This is contrasted with Finland, where the Finnish Parkinson Association organises 50 rehabilitation courses per year for patients, families and carers. The aims of the courses are to contribute to enabling PwP to lead as normal a life as possible. The rehabilitation team within these courses include: a psychologist, a neurologist, a physiotherapist, an occupational therapist, a speech therapist, a social worker and a nurse.

In Iceland, the Reykjalundur Centre offers a four-week rehabilitation for PwP. They have a specially designed course to help PwP improve their physical, mental and social skills as well as teaching them how to maintain these skills for when they have returned home. The multidisciplinary approach is designed to increase physical strength, stamina and balance of the patient. Instruction is provided on how to combine relaxation and activity, all made in partnership with the individual.

On occasion during the workshop, it was unclear what was actually offered, for example, in Slovakia PwPs had access to rehabilitation "*specialists*" but it is unclear what was meant by the term "*specialists*".

In Italy, the cost for treatments are high and there is a high level of bureaucracy relating to accessing disability benefits and other financial support. General access to services and support also varied widely across the country. While GPs are customarily the main contact point for PwP, their levels of training can vary, and waiting times to see a specialist within the public healthcare system can be very long.

In Malta, there is access to good physical rehabilitation centres with a multidisciplinary team that offer physiotherapy, speech therapy, a falls prevention programme, nutrition and occupational therapy. Complementary medicine such as hydrotherapy, dance classes and a respite service are also available.

### 3.5. What treatments have to be paid for?

Broadly speaking, across western and northern Europe, many of the clinical treatments are paid for or are subsidised by the state. Within Norway, Sweden, Denmark and Finland, all treatments are generally paid for by the state.

The costs for non-clinical treatments varied, with some countries such as Poland and Croatia, charging for the treatments. Where the non-clinical treatments were offered free of charge, this was usually limited. For example, in Spain the Government provides physiotherapy and speech therapy to patients for 20 hours per year. Other than that, Parkinson's patients do not have access to rehabilitation treatment for free, although it can be accessed through Parkinson's Federation (and the patients pay for it), or through private clinics. In Sweden, massage therapy has to be paid for privately.

<sup>7</sup> Offnews.bg (2013, Jul) [online] [www.offnews.bg/news/България\\_1/Безплатни-консултации-за-пациенти-с-Паркинсон-в-болница-Св-Иван-Рилски\\_214624.html](http://www.offnews.bg/news/България_1/Безплатни-консултации-за-пациенти-с-Паркинсон-в-болница-Св-Иван-Рилски_214624.html) (Accessed: September 2014)

<sup>8</sup> Duma.bg (2014) [online] [www.duma.bg/node/76044](http://www.duma.bg/node/76044) (Accessed: September 2014)



In Italy, there are courses and specific training for people to be carers, but on the whole, care is left to the families or private carers. In Malta, grants are provided for special equipment and carers can receive an allowance depending on the stage of the disease.

### **3.6. Are families/carers involved in consultations on treatments?**

On the whole, in the included northern and western European countries, families/carers of PwPs were included in consultations, albeit only at the request of the PwP. However, within Norway, Sweden, Denmark and Finland, it was felt that the families/carers of PwPs were not consulted enough although respite care is available.

In Sweden and Finland, financial assistance is available to carers in the form of a monthly benefit. In Sweden, this allowance stops after the carers reach 66 years of age.

In central/eastern Europe, the feeling was that carers are often ignored or excluded from the decision-making process, and they stress the importance that a “second” person is with the PwP when they are seeing a doctor or any HCP.

### **3.7. What do people think should be done to improve care for PwPs?**

The members were asked what they thought should be done to improve care for PwPs. Across the 36 countries in Europe, the general consensus was:

- Better education and training of healthcare professionals in Parkinson’s disease particularly within general hospitals, especially the importance of taking Parkinson’s medication at the right time. Even a short course for nurses would be very useful
- Greater awareness among the general population of Parkinson’s and for pressure to be put to local government to devote more resources particularly on research. In many parts of Europe, Parkinson’s is still considered to be largely a hidden disease due to social stigma and perceived lack of acceptance
- In central/eastern Europe, the impression is that Parkinson’s is seen to be very low in the order of priorities within government/institutional frameworks that manage the healthcare system – heart disease, cancer and dementia often get the majority of funding and resources – a better balance is therefore urgently needed. Even looking at what would make the lives of PwPs more satisfactory is not on the agenda
- In central/eastern Europe, there is very little public funded research on Parkinson’s; the view is that what research there is in each country, is controlled by the big pharmaceutical companies
- Improved awareness on spotting the early symptoms of Parkinson’s so that diagnosis can be confirmed or ruled out earlier
- Getting PwPs into secondary care as early as possible
- Greater access to multidisciplinary teams, particularly in more rural areas
- HCPs should refer patients to every national patient organisation
- More patient involvement at all levels
- More carer involvement at all levels
- The ability for everyone to be referred for a second opinion
- More investment into healthcare systems, especially for neurology
- More research
- Improved training in care of people dealing with/affected by Parkinson’s

- Greater focus on patient-focused research: research not for the sake of research but rather with a view to improving the care of patients
- Less silo working among researchers and carers
- “One stop shop” approach to care – the Netherland’s ParkNet example was cited
- Develop national guidelines of care and ensure that these are consistently applied
- Increased funding of physiotherapists and speech therapists; plus improve awareness to state that these services are as important as medication or seeing a specialist doctor because it improves Quality of Life (QoL).

### **3.8. How can good practice be transferred across Europe? How can we share good practice between countries?**

While the members realised that the transfer of good practices can be difficult due to different health system structures, there were common themes in how they felt good practice transfer can be achieved or effectuated:

- To collect all research and publish and disseminate across Europe, particularly via the EPDA’s MPDJ website
- Getting together to encourage the sharing of experiences – for example, EPDA meetings, World Parkinson Congress and Nordic meetings
- Setting up a buddying system between countries and monitoring
- Effective training with HCPs on how to deal with PwPs care more effectively – especially non-motor symptoms
- More research at European Union level – why must all research be undertaken by private sector?
- A European clinical framework needs to be developed by the European Commission with similar functions to the UK’s NICE. This framework should stipulate the ideal care that someone with Parkinson’s should get, set minimum standards of care should be received – such as drugs, number of visits to see a specialist.
- Better communication between patient organisations through networking and exchanging visits to share good practices. Use public/private partnerships to facilitate exchanges
- Better awareness of good practices that exist
- For research and patient databases – introduce Open Source concept to all pan-European access; for example, Spain has developed a patient information database and would like to share it.

The Nordic countries have a very well established practice of sharing information across the countries in the region. This practice could be a model for other regions within Europe, particularly where language and commonalities in the healthcare system existed.

For members within central/eastern Europe, the members felt that good practice can be improved through greater access to HCPs, in particular to neurologists who specialise in Parkinson, and for the health systems to devote more resources to Parkinson’s, such as to address non-motor symptoms care.

Recognition by the EU and state through national or EU funding would also make it possible for patient organisations to produce more information to educate and promote awareness. Funding would also enable them to provide training to health advisers or “advocates” so that PwPs can be better informed about treatment options and state entitlements.

The reaction of the MPDJ programme was generally very positive. The members felt that “action clearly needs to take place at the European level” and the EPDA is a vital organisation to achieve this. Their thoughts in relation to what the MPDJ programme could do include:

- Building a network at a European level to enable national coalitions to share and transfer knowledge and best practices – “there needs to be large-scale funding for this, which cannot just come from pharmaceutical companies but also from national and European institutions”.
- More awareness-building projects to educate but also garner public support – “more walks and events”.
- To establish a minimum level of care that PwPs receive across Europe and for this to become statutory. MPDJ needs to devote some of its resources building a strong relationship with the EU and work towards influencing EU strategy and adoption that incorporates the MPDJ findings
- Establishing a fund to ensure central/eastern Europe gets its share of funding for research in partnership with universities/medical schools – “current funding is insufficient for any meaningful research”.
- Building strong relationships with other European HCP organisations such as European nurses/physiotherapists/occupational therapists, so that it can develop joint projects – “it is only by joining up with these organisations that we will be able to build effective coalitions”.

## 4. EXISTING GUIDELINES AND PROTOCOLS

Numerous guidelines and protocols exist, the result of much detailed and extensive research, investigations and analyses examining almost every facet of Parkinson's treatment, management and care provision. As a part of the secondary research, a review of published studies, guidance documents, adapted guidelines, multidisciplinary peer-reviewed journals has been carried out.

This section provides further details on a number of the national guidelines. As mentioned in the limitations (detailed in Section Two), it is not a comprehensive list due to finite time and financial resources. Therefore it is recognised that not all the national guidelines are included in this section.

Over the past decade, a number of countries have also developed their own guidelines. Two examples of this include Romania and Russia. The Romanian Society for Neurology first published guidelines '*Guide in Diagnosis and Treatment Parkinson's Disease*' in 2006. The guidelines were updated in 2009<sup>9</sup>. There is also a '*Protocol for Parkinson's Disease Treatment*', published in 2008<sup>10</sup>. In 2005, the Health Ministry of the Russian Federation guidelines approved the "*Protocol of patients with Parkinson's Disease*"<sup>11</sup> guidelines developed by a team of experts, including leading experts in Parkinson's. In some cases, where countries do not have their own guidelines, they often adopt from another country, for example, physiotherapists in Denmark use the guidelines from the Netherlands, and Irish healthcare professionals refer to the UK NICE guidelines.

Although these guidelines are often focused predominantly on clinical treatments, they have reportedly been helpful in improving HCPs' awareness of Parkinson's disease.

In an external review<sup>12</sup> of literature to identify practice gaps in the management of the hospitalised Parkinson's disease patient, it was concluded that educational programmes, recommendations and guidelines are needed to better train interdisciplinary teams in the management of the Parkinson's patient. These initiatives have the potential for both cost savings and improved outcomes from a preventative and a hospital management standpoint.

Good practices should not be limited to practices aimed solely at optimising medication or treatment of symptoms alone. Research suggests<sup>13</sup> that while there is a lack of knowledge of factors that influence health-related quality of life (QoL), factors other than disease severity and medication such as depression, satisfaction with the explanation of the condition at diagnosis, and current feelings of optimism, have a statistically significant impact on QoL.

The results of a single-centre prospective feasibility study<sup>14</sup>, which explored the effect of a specialised in-patient Parkinson's unit on medication management, length of stay and patient experience, found patients who received Parkinson's unit care had shorter length of stay, better experience of care and better adherence to medication.

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<sup>9</sup> MS.ro (2009) [online] [www.ms.ro/documente/1223 Anexa 9\\_8729\\_6649.doc](http://www.ms.ro/documente/1223_Anexa_9_8729_6649.doc) (Accessed: August 2014)

<sup>10</sup> Neurology.ro (2008) [online] [www.neurology.ro/media/protocoale/protocol-bparkinson.pdf](http://www.neurology.ro/media/protocoale/protocol-bparkinson.pdf) (Accessed: August 2014)

<sup>11</sup> Rspor.ru [online] [www.rspor.ru/db\\_standarts/PVB\\_parkinsonism.doc](http://www.rspor.ru/db_standarts/PVB_parkinsonism.doc) (Accessed: 2014, Sept)

<sup>12</sup> Aminoff, Michael J. et al. "Management of the hospitalized patient with Parkinson's disease: Current state of the field and need for guidelines." *Parkinsonism & Related Disorders*, Volume 17, Issue 3, 139 - 145

<sup>13</sup> "Factors impacting on quality of life in Parkinson's disease: Results from an international survey." *Mov. Disord.*, 17: 60–67. doi: 10.1002/mds.10010

<sup>14</sup> Skelly, Rob et al. "Does a specialist unit improve outcomes for hospitalized patients with Parkinson's disease?" *Parkinsonism & Related Disorders* (<http://dx.doi.org/10.1016/j.parkreldis.2014.09.015>)

#### 4.1. Canada: Canadian guidelines on Parkinson's disease<sup>15</sup>

Although outside of the 36 included European countries, the Canadian guidelines are included in this review as they draw on a number of European guidelines in their development. The Canadian guidelines, published in 2012 with a planned review in 2014, was established with a goal not to create new recommendations, but to select from currently published, high-quality guidelines whose recommendations were most clinically relevant for healthcare in Canada. Based upon strict criteria, the guidelines sought recommendations off the American Academy of Neurology (AAN), the European Federation of Neurological Societies (EFNS), the Movement Disorder Society–European Section (MDS-ES) and the National Institute for Health and Clinical Excellence from the United Kingdom (NICE).

The resulting Canadian guidelines provide HCPs with practical, clinical advice for the diagnosis and treatment of Parkinson's, based on the best-published evidence and on expert consensus. The 84 recommendations are designed primarily for family physicians, neurologists, and other HCPs, relevant to the Canadian healthcare system, but which have many common themes with European guidelines.

The recommendations that are included within the Canadian guidelines are evidenced graded and of those that are graded as being of expert opinion and/or formal consensus, some of which resonate with the findings of the European inventory research:

##### Communication

- A person-centred approach to care and treatment should be cultivated for PwP.
- PwP with Parkinson's should have the opportunity to make informed decisions based on full disclosure of all relevant information.
- Communication with PwP should be aimed towards empowering them to participate in the judgments and choices about their own care.
- Families and caregivers should be given information about the condition, their entitlements to care assessment and the support services available.

##### Diagnosis and progression

- Parkinson's should be suspected in people presenting with tremor, stiffness, slowness, balance problems and/or gait disorders.

##### Treatment considerations

- Occupational therapy and speech and language therapy should be available for people with PD.

The guidelines recognise that a clear limitation regarding the implementation of the guidelines is due to a lack of adequate access to healthcare providers with expertise in dealing with individuals with Parkinson's. This includes not only specialty physicians but also nurses, speech, occupational and physical therapists with adequate training to deal with these very complex patients as well as access to palliative care treatment. The cost of approved therapies, and decisions about the limitations of their publicly funded healthcare system, are also recognised barriers but considered outside the scope of the guidelines.

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<sup>15</sup> Canadian Guidelines on Parkinson's Disease ([www.parkinsonclinicalguidelines.ca](http://www.parkinsonclinicalguidelines.ca)) - A Peer-reviewed supplement to The Canadian Journal of Neurological Sciences

#### **4.2. Europe: The European Parkinson's disease standards of care consensus statement<sup>16</sup>**

The European Parkinson's Disease Standards of Care Consensus Statement was developed by the EPDA and endorsed by European Parkinson's specialists, PwPs, carers and European Parkinson's organisations to define in plain language what the optimal management of Parkinson's should be.

The Consensus Statement presented eight key areas that called upon European policymakers to:

- Support initiatives that ensure people with Parkinson's receive equal access to good-quality, specialised care across Europe
- Reduce inequalities in the treatment and management of Parkinson's
- Improve funding for Parkinson's research and define research priorities
- Invest in optimum treatment and maintenance strategies
- Increase public and professional awareness of Parkinson's
- Minimise stigma and discrimination
- Strengthen the level of neurological care within European healthcare systems
- Provide adequate funding that supports the continued work of national Parkinson's organisations.

Since its launch in the European Parliament in November 2011 (it was updated in December 2012), the Consensus Statement has been translated into a number of European languages and has been read, supported and endorsed by a number of European policymakers.

#### **4.3. Europe: Guidance for the preparation of neurological management guidelines by EFNS scientific task forces – revised recommendations 2012<sup>17</sup>**

This paper provides guidance to anyone wishing to write a neurological guideline for diagnosis or treatment, and is directed at the scientist panels and task forces of the European Federation of Neurological Societies (EFNS). The aim of an EFNS neurological management guideline is to provide guidance for clinical neurologists, other health care professionals and health care providers about important aspects of management of neurological disease. Representing the views of an expert task force, it presents a peer-reviewed statement of minimum desirable standards for the guidance of practice based on the best available evidence.

#### **4.4. France: National Plan for Neurodegenerative Diseases 2014-2019**

On 11 April (World Parkinson's Day) 2012, Nora Berra, Secretary of State for Health for the French government, announced the launch of a Parkinson Plan 2011-2014, based on an Alzheimer's model.

This was followed in November 2014 with the National Plan for Neurodegenerative Diseases 2014-2019<sup>18</sup>, and confirms the French Government's commitment for research, quality of care and support for patients and their relatives. Announced by the President of the Republic, the latter plan is the result of an extensive consultation with

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<sup>16</sup> The European Parkinson's Disease Standards of Care Consensus Statement (updated December 2012) ([www.epda.eu.com/parkinsons-consensus-statement](http://www.epda.eu.com/parkinsons-consensus-statement))

<sup>17</sup> Leone, M. A., Brainin, M., Boon, P., Pugliatti, M., Keindl, M. and Bassetti, C. L. (2013), "Guidance for the preparation of neurological management guidelines by EFNS scientific task forces – revised recommendations 2012." *European Journal of Neurology*, 20: 410–419. doi: 10.1111/ene.12043

<sup>18</sup> [www.social-sante.gouv.fr/actualite-presse,42/communiqués,2322/une-nouvelle-dynamique-engagee-en,17511.html](http://www.social-sante.gouv.fr/actualite-presse,42/communiqués,2322/une-nouvelle-dynamique-engagee-en,17511.html)

stakeholders, including industry players, and takes into account the specificities of each disease to provide practical needs of patients and their carers.

The plan has three priorities:

- 1 Improving the diagnosis and management of patients. This includes:
  - enhanced coordination between the attending physician and neurologist
  - better access to expertise with the creation of expert centres dedicated to Parkinson's
  - new devices in improving the health the service the elderly
  - the development of therapeutic education for patients and their caregivers.
- 2 Ensuring the quality of life of patients and their caregivers. This includes:
  - increased support at home with new teams to adapt the specialized Alzheimer's approach to Parkinson's
  - strengthening support to caregivers with new support and respite platforms
  - support programmes for patients and their caregivers as provided in the draft Health Act<sup>19</sup>
  - the priority of maintaining employment or vocational rehabilitation for young patients
  - digital solutions such as SMS alerts and applications for smartphones or tablets, to improve patient autonomy.
- 3 Develop and coordinate research. This includes:
  - the recognition of centres of excellence in teaching and research to affirm France's position within European and international projects
  - developing knowledge building tools (cohorts in national databases) to act more effectively on neurodegenerative diseases.

#### 4.5. Italy: Diagnosis and treatment of Parkinson's disease<sup>20</sup>

The Italian guideline<sup>21</sup>, reviewed in August 2013, is based on the Scottish National Guidelines and is oriented towards current clinical practice and public health, unlike the documents drawn up by the European Federation of Neurological Societies (EFNS), the Movement Disorder Society (MDS) and the American Academy of Neurology (AAN), which focused more on individual diagnostic tools and treatments.

The recommendations is intended to define the different contribution(s) that individual professionals can provide at the different stages of the disease, and outlines for the first time in Italy a possible diagnostic path of patient care with suspected parkinsonian syndrome.

The guidelines recommend that:

- **Neurologists should be aware of the lack of specificity of the clinical diagnosis of Parkinson's** in the early stages of the disease and to take into account this uncertainty in informing and planning the management of the patient;
- **Patients should be offered regular follow-up appointments** to improve the management of Parkinson's;

<sup>19</sup> [www.assemblee-nationale.fr/14/propositions/pion0752.asp](http://www.assemblee-nationale.fr/14/propositions/pion0752.asp)

<sup>20</sup> [www.snlg-iss.it/Ign\\_Parkinson](http://www.snlg-iss.it/Ign_Parkinson)

<sup>21</sup> [www.snlg-iss.it/cms/files/LGParkinson-web-agosto2013\\_0.pdf](http://www.snlg-iss.it/cms/files/LGParkinson-web-agosto2013_0.pdf)

- The most effective therapy for treatment of symptoms is L-Dopa although prolonged use of L-Dopa can result in various complications such as dyskinesia,
- Therefore for Parkinson's patients with an early onset, consideration should be given to treating with dopamine-based drugs such as pramipexole, ropinirole and rotigotine;
- The benefits of deep brain stimulation are recognised for patients with advanced Parkinson's disease;
- Exercise is recommended to improve physical performance and quality of life; in particular the guidelines recognise the benefits of Tai Chi and dance;
- Speech and language therapy may assist in treatment of patients' communication disorders and problems with swallowing;
- Occupational therapy can help patients overcome problems with daily living and improve quality of life.

#### 4.6. Germany: Diagnosis and therapy in Neurology<sup>22</sup>

In Germany, the Guidelines for Diagnosis and Therapy in Neurology were published in 2012. Many of the recommendations are in common with the guidelines already mentioned particularly in relation to the use of specific medication and treatment regime. It further recommends that:

- **Pharmaceutical treatment must be initiated immediately after diagnosis** as it positively influences the course of the disease.
- Deep brain stimulation is used in patients with advanced Parkinson with dopa-sensitive fluctuations and has proven more effective in improving quality of life, symptoms and daily activity, than oral medical treatment. There is not sufficient data currently in existence about the use of deep brain stimulation in early or mid-term phases of Parkinson.
- There is no indication for the use of COMT-blockers with L-Dopa first time users or with patients with a stable L-Dopa response.
- Patients who receive medical treatment for fluctuations, benefit from deep brain stimulation, positively affecting movement and quality of life.

#### 4.7. The Netherlands: Multidisciplinary guideline for Parkinson's disease (2010)<sup>23 24</sup>

This Dutch guideline covers the multidisciplinary management of Parkinson's disease including the diagnostic process, treatment and organisation of care. A timely and accurate diagnosis, an individualised treatment, an optimally organized care network and a central role for the patient are guiding principles in the guideline. Organizations of 21 disciplines and patients were involved in the developing the guideline.

An appendix specifically focused on the management of Parkinson patients in nursing homes and residential care was added in 2011.

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<sup>22</sup> Leitlinie für Diagnostik und Therapie in der Neurologie. Stuttgart, Germany: Thieme; 2003. Klinische "Leitlinien" der deutschen Gesellschaft für Neurologie.

<sup>23</sup> [www.parkinsonnet.info/guidelines](http://www.parkinsonnet.info/guidelines)

<sup>24</sup> [http://parkinsonnet.info/media/2733747/7994\\_multidisciplin\\_rl\\_parkinson\\_c\\_-\\_2011.pdf](http://parkinsonnet.info/media/2733747/7994_multidisciplin_rl_parkinson_c_-_2011.pdf)



#### 4.8. The Netherlands: Guideline for physical therapy in Parkinson's disease<sup>25</sup>

The original guideline developed in 2004 has been revised in collaboration with other European physical therapy association as the European Guideline for Physical Therapy in Parkinson's disease (2014).

This is an evidence-based clinical practice guidelines developed by the Royal Dutch Society for Physical Therapy (KNGF) and ParkinsonNet, involving professional physiotherapy associations from 19 European countries together with PwPs.

The guideline includes information for people with Parkinson's: self-management support and how to get the best out of physiotherapy care as well as information for clinicians: when to refer to physiotherapy and what to expect.

International accessibility of clinical practice guidelines in physical therapy makes it possible for physical therapists to use guidelines as a reference for treating their patients. At a national level, countries could endorse and apply the Guideline recommendations, adjusting this to their local situation if necessary. The guidelines, developed with 20 European Associations, detail a number of measurement tools that can be used to assess: physical capacity (for example, the 6 minute walk test); reduce risk of falls (falls diary); balance (e.g. Berg Balance Scale); and gait (e.g. Modified Parkinson Activity Scale). The guidelines also made recommendations around the types of exercises that can benefit PwPs (dance, tai chi, etc.), movement strategy training and general treatment considerations (for example, the use of ehealth).

#### 4.9. The Netherlands: Guideline for occupational therapy in Parkinson's disease rehabilitation<sup>23</sup>

Published in Dutch in 2008 (translated in English in 2011), this guideline provides recommendations for referral of a PwP to occupational therapy (OT), OT assessment tools and OT intervention strategies. The role of the OT in identifying and addressing possible needs of the caregiver of the PwP is highlighted. The 31 recommendations are based on relevant international evidence (also from related fields) and considerations from experts in the field.

Key principles for the OT process in the guideline are the patient-centred approach in assessment and treatment planning, and the focus on participation and activity. The great influence of the living- and social context on performance in daily activities for PwP is considered in the recommendations in location of OT assessment and treatment (preferably in the performance context).

The guideline forms the basis of the training of occupational therapists in ParkinsonNet in The Netherlands. Effectiveness of a 10 week home based intervention following this guideline has recently been established in a large scale randomized controlled trial<sup>26</sup>.

The carers' involvement is also included in the guidelines. They recommend that to identify the carers occupational issues, the Canadian Occupational Performance Measure (COPM) should be administered and a caregiver burden interview to gain further insights.

To clarify the context of problems related to specific activities in which the PwP and the carer experience problems, the recommendations state that the therapist should evaluate the following:

- meaning of the activity
- habits/routines

<sup>25</sup> <http://parkinsonnet.info/guidelines/european-guidelines>

<sup>26</sup> Sturkenboom, Ingrid HWM, Maud JL Graff, Jan CM Hendriks, Yvonne Veenhuizen, Marten Munneke, Bastiaan R. Bloem, Maria W. Nijhuis-van der Sanden, and OTiP study group. "Efficacy of occupational therapy for patients with Parkinson's disease: a randomised controlled trial." *The Lancet Neurology*13, no. 6 (2014): 557-566.

- social aspects
- space and objects
- complexity of activity
- coping strategies

This can be done through observation and/or interviews. Further recommendations are also given in relation to dealing with those suffering from fatigue or fluctuating performance (through keeping an activity log for three days); the observation of skills and activities; assessment of impairment in body function and structures; environment; and supervising the general learning process.

#### **4.10. The Netherlands: Guideline for speech and language therapy in Parkinson's disease<sup>23</sup>**

Published in Dutch in 2008 (translated in English in 2011), this evidence-based guideline provides recommendations for referral of a PwP to speech and language therapy (SLT), SLT assessment tools and SLT intervention strategies.

The guideline covers the three SLT domains: speech, swallowing and drooling, discussed in separate chapters. In each domain best practice is recommended for assessment and treatment, including the role of caregivers; in total 60 recommendations. Validated questionnaires and other relevant materials are included in the appendices.

The guideline forms the basis of the training of speech and language therapists in ParkinsonNet in The Netherlands.

#### **4.11. The Netherlands: Guidelines for nutrition and dieticians<sup>23</sup>**

A mono-disciplinary Dutch guideline for dieticians working with Parkinson's disease was developed in 2012, as well as a multidisciplinary guide for nutritional issues in Parkinson's disease and a patient guide on nutrition in Parkinson's disease.

The guidelines form the basis of the training of dieticians in ParkinsonNet in The Netherlands and for multidisciplinary training on nutrition.

#### **4.12. Scottish National Guidelines<sup>27</sup>**

Developed by the Scottish Intercollegiate Guidelines Network (SIGN), these 2010 guidelines were produced in consultation with multidisciplinary groups of practising clinicians using a standard methodology based on a systematic review of the evidence.

The guideline provides recommendations based on the then current evidence for best practice in the diagnosis and pharmacological management of Parkinson's, including comparisons of the accuracy of diagnoses carried out by different HCPs, the value of different diagnostic tests for differentiating Parkinson's from other associated conditions, and a comprehensive assessment of pharmacological management of motor and non-motor symptoms associated with the disease. It also includes a narrative review of qualitative evidence describing the attitudes, beliefs and opinions of patients with Parkinson's across six themes. The role of the allied health professionals and the benefits of neurosurgical management of Parkinson's disease, such as deep brain stimulation, are not covered. The management of some non-motor symptoms is also not included in this guideline as, in many cases, their management is not significantly different from that in PwP.

Three key clinical recommendations include:

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<sup>27</sup> [www.sign.ac.uk/pdf/sign113.pdf](http://www.sign.ac.uk/pdf/sign113.pdf)

- **Clinicians should be aware of the poor specificity of a clinical diagnosis of Parkinson's** in the early stages of the disease, and should consider this uncertainty when giving information to the patient and planning management
- **Patients with suspected Parkinson's should be referred** untreated to a hospital clinician with sufficient expertise in movement disorders to make the diagnosis
- Patients should be warned about the potential for dopamine agonists to cause impulse control disorders and excessive daytime somnolence, and be informed of the implications for driving/operating machinery

#### 4.13. Slovenia: Slovenian Clinical Route<sup>28</sup>

In summary the Slovenian Clinical Route for patients with Parkinson's disease state that:

- If Parkinson's disease is suspected, GP's should refer the patient to a neurological clinic where a neurologist assesses whether the patient has the disease. In the case of patients less than 40 years, of age, or if they are currently employed but unable to perform their duties, they are referred for review in 4 weeks. Otherwise, a second review with the neurological clinic occurs within six months.
- During the appointment, the patient's medical history should be examined, symptoms observed and a physical examination performed.
- If additional clinical information is required, further tests should be carried out (e.g. MRI, SPECT-DAT, CT);
- If treatment is considered, the first follow up appointment is in three months to check the effectiveness of the treatment and any side effects. In cases where the patient's treatment is non-responsive, patients should undergo daily medication tests in hospital (levodopa test, apomorphine, and additional imaging diagnostics);
- Patients are referred for further follow up appointments every six to nine months.
- Non-medical measures are recommended in the form of talks with patients and their relatives about the disease, directing them to nurses, providing information on treatment options and introducing the Parkinson's organisation *Trepetlika*.

#### 4.14. Spain: Official guide for clinical practice in Parkinson's disease

In Spain, there are various protocols/guidelines as regions often have their own, for example the *Protocol management and referral of patients with Parkinson's disease*<sup>29</sup> (prepared from Directorate General Patient Care in Madrid). Although they differ slightly, they are all based on the national *Official guide clinical practice in Parkinson's disease* (2009)<sup>30</sup>.

The guidelines state:

- If Parkinson's disease is suspected, **a patient should be referred to a neurologist in less than eight weeks**. This should be done before any drug treatment is started. During the initial consultation, if deemed necessary, patients should be sent for further tests including CT, EEG, MRI, SPECT scans.

<sup>28</sup> Accessed 27th January 2015: [http://www.kobz.si/si/Klinicne\\_poti/klinicna\\_pot\\_PB.pdf](http://www.kobz.si/si/Klinicne_poti/klinicna_pot_PB.pdf)

<sup>29</sup> [www.madrid.org](http://www.madrid.org) \*the protocol is aimed at professionals in the Madrid Health Service

<sup>30</sup> Protocol is based on the Official guide clinical practice in Parkinson's disease, (Guía oficial de práctica clínica en la enfermedad de Parkinson ) Spanish society of neurology (2009) [http://getm.sen.es/wp-content/uploads/2012/02/GUIA\\_SEN\\_Parkinson.pdf](http://getm.sen.es/wp-content/uploads/2012/02/GUIA_SEN_Parkinson.pdf)

- Once diagnosis has been made, **the patient should be monitored every 3 to 6 months**, depending on the case. Advice and information should also be provided for patient and carers by appointment, telephone, or via email.
- If no drug treatment is regarded as necessary, **the patient should be given information, and the details of available support groups**. A health care professional should highlight to the patients the existence of the non-profit Parkinson's organisations for informative purpose, training, maintaining the disease, physiotherapy, and psychotherapeutic support.

#### 4.15. Swedish Movement Disorder Society: Guidelines on diagnosis in treatment of Parkinson's disease

The Swedish Movement Disorder Society, SWEMODIS<sup>31</sup>, is a society for professionals working with Parkinson's and movement disorders in Sweden who have developed guidelines. The guidelines, updated once yearly, are adapted by the Swedish Medical Products Agency. The guidelines are extremely detailed and are designed to facilitate the handling of the investigation, referral, treatment and follow-up of individuals with Parkinson's disease; therefore the research team extracted the data that is most relevant to the survey data collected for this study:

- There is no medical evidence basis for delaying treatment even early in the disease and **early treatment is recommended**.
- **Reassessment of the diagnosis should be done regularly** and the diagnosis may need to be revised.
- Patients should be examined repeatedly, both in terms of progression if not obvious from history, and after treatment trials, with follow-up effects.
- A patient's symptoms should be **assessed by a neurologist experienced in Parkinson's disease**.
- No individual or laboratory tests can identify clearly Parkinson's disease.
- Diagnosis and therapy for very young patients with suspected Parkinson's disease should be made by physicians who have experience with this group of patients, primarily by neurologists with special interest in movement disorders.
- Generally, the neurosurgical treatment of Parkinson's disease should only be used when medical treatment is no longer effective. To be considered for surgical treatment, the patient should be referred to the multi-disciplinary Parkinson's team, who are at university hospitals with a careful neurological diagnostic evaluation therefore requires preoperative neuroimaging investigation with CT / MRI. After considering a patient for intraduodenal levodopa treatment, the patient and also the spouse must be adequately informed about the treatment and the expected results of treatment. The patient must also be given information about the surgical procedures. Information about long-term experiences with Duodopa and the circumstance of living with a pump and the complications must be shared.

In 2014, as part of its overall commitment to the care of people with chronic diseases, the Swedish government decided to develop national guidelines for treating multiple sclerosis (MS) in Sweden<sup>32</sup> to support those who make decisions about how resources should be allocated within the health service.

Working in association with Neuroförbundet, which represents people living with neurological diseases such as MS, Parkinson's disease, stroke or ALS in Sweden, SWEMODIS is developing the 2016 guidelines.

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<sup>31</sup> MDS: About the Swedish Movement Disorder Society - <http://bit.ly/1CPDr1D>

<sup>32</sup> [www.msif.org/news/2014/09/19/swedish-government-to-develop-national-guidelines](http://www.msif.org/news/2014/09/19/swedish-government-to-develop-national-guidelines)

#### 4.16. UK: The NICE clinical guideline: Parkinson's disease – diagnosis and management in primary and secondary care<sup>33</sup>

The NICE clinical guideline on Parkinson's covers:

- The diagnosis of Parkinson's and the checking of the diagnosis regularly
- The way PwPs should receive information
- The medicines that can be used
- Other ways of helping with symptoms
- How to care for people whose mental health is affected
- The care PwPs should receive at the end of their life

Specifically with regards to patient-centred care, the guidelines recommend:

- **Treatment and care should take into account patients' individual needs and preferences.** PwPs should have the opportunity to make informed decisions about their care and treatment
- **Good communication between healthcare professionals and patients is essential.** It should be supported by the provision of evidence-based information offered in a form that is tailored to the needs of the individual patient. The treatment, care and information provided should be culturally appropriate and in a form that is accessible to people who have additional needs, such as people with physical, cognitive or sensory disabilities, and people who do not speak or read English
- Unless specifically excluded by the patient, **carers and relatives should have the opportunity to be involved in decisions** about the person's care and treatment
- Carers and relatives should also be provided with the information and support they need.

Key priorities for implementation include:

- **Quick referral to a specialist with expertise** in the differential diagnosis of Parkinson's for accurate diagnosis before any treatment
- The diagnosis of Parkinson's should be **reviewed regularly** and reconsidered if atypical clinical features develop
- **Regular access to specialist nursing care** that provides clinical monitoring and medication adjustment, a continuing point of contact for support (including home visits) when appropriate, and a reliable source of information about clinical and social matters of concern to PwPs and their carers
- Access to physiotherapy
- Access to occupational therapy
- Access to speech and language therapy
- Palliative care requirements of PwPs should be considered throughout all phases of the disease, and PwPs and their carers should be given the opportunity to discuss end-of-life issues with appropriate healthcare professionals.

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<sup>33</sup> National Institute for Health and Care Excellence - [www.nice.org.uk/guidance/cg035](http://www.nice.org.uk/guidance/cg035)

Following a recent review recommendation (2014), an update of this guideline is currently in the process of being scheduled into NICE's work programme with an anticipated publication date of October 2016.

#### 4.17. UK: Occupational therapy for people with Parkinson's disease, UK<sup>34</sup>

First published in 2010 with a review date in 2015, these guidelines have been written by expert occupational therapists from the Specialist Section – Neurological Practice of the British Association and College of Occupational Therapists. The guidelines were produced in partnership with Parkinson's UK.

The guidelines draw upon relevant knowledge and evidence to describe and inform best practice occupational therapy for people with Parkinson's. They include practical examples of interventions to enable occupational therapists from a diverse variety of health and social care settings to apply new and existing treatments in their day-to-day practice, as well as being of interest to other health professionals, commissioners, service users and carers.

Key recommendations of the report are to:

- Improve leadership
- Ensure drivers are in place to support implementation of national guidance
- Strengthen service monitoring
- Support better commissioning and planning of services, through the provision of evidence and guidance, and in particular strengthening workforce planning so that sufficient skilled professionals are available to deliver high-quality Parkinson's care.

These recommendations are set against the background of a large and rapidly growing neurological sciences evidence base and an increasing number of medical and surgical interventions for people with Parkinson's, some of which are very expensive and only available to a limited number of people with the condition.

The guidelines also note there is currently no comprehensive, standardised, occupational therapy assessment/measurement tool specific to Parkinson's that can be used by occupational therapists in the UK.

#### 4.18. UK: Best practice guideline for dieticians on the management of Parkinson's<sup>35</sup>

Produced by the British Dietetics Association in association with Parkinson's UK, the guidelines are aimed at dieticians working with PwP. The guidelines include information about the nutritional consequences of Parkinson's, as well as strategies for managing a variety of nutrition-related symptoms. The key recommendations are:

- The risk of malnutrition and body weight must be **routinely monitored as the condition progresses**.
- Worsening motor symptoms e.g. dyskinesias should also be monitored to prevent or reverse weight loss in people living with Parkinson's.
- Dieticians have the skills to help people living with Parkinson's to optimise their nutritional status and manage nutrition-related symptoms at all stages of the condition.

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<sup>34</sup> [www.cot.co.uk/publication/cot-publications/occupational-therapy-people-parkinsons-disease](http://www.cot.co.uk/publication/cot-publications/occupational-therapy-people-parkinsons-disease)

<sup>35</sup> [www.parkinsons.org.uk/content/best-practice-guideline-dietitians-management-parkinsons](http://www.parkinsons.org.uk/content/best-practice-guideline-dietitians-management-parkinsons)

#### 4.19. UK: Consensus guideline on the medication management of adults with swallowing difficulties<sup>36</sup>

The 2006 guideline, supported by an educational grant from Rosemont Pharmaceuticals Ltd., sets out recommendations that HCPs should always ask if a patient has difficulty swallowing medication. This advice comes in light of evidence that almost 60% of older people have experienced problems taking solid medicines<sup>37</sup>. The guideline highlights that many physicians are unaware of the scale of the problem, and fail to take steps to check that a patient is actually able to swallow the medicine prescribed. However, it cautions that many patients continue to open capsules or crush tablets to make them easier to swallow – unaware that they may experience an adverse reaction as a result of crushing a non-crushable tablet. David Wright, senior lecturer in pharmacy at the University of East Anglia, UK, and chair of the working party for the guideline, explains: “Many drugs are now given in a slow-release format. Crushing or opening means that the drug is released quicker than it is designed to be, and this can cause side effects.”<sup>38</sup>

Patients with swallowing difficulties present a drug management challenge since:

- Therapeutic outcomes may be affected in those not adhering to prescribed medications
- Tablets or capsules may cause choking with consequent risk to the airway
- There may be an increased risk of a tablet or capsule becoming lodged in the patient’s throat or oesophagus, resulting in incorrect drug dispersal and subsequent changes in efficacy and/or tolerability, and possible oesophageal damage
- Altering the formulation of a medicine has important medical and legal implications.

The guideline recommends that improved communication between healthcare providers and patients is essential to avoid complications for the patient and the risk of litigation for the prescriber due to negligence.

A review<sup>39</sup> of the guideline two years on further recommends:

- Prescribers need to be aware of the presence of dysphagia to ensure that the most appropriate formulations are selected for the patient
- Community pharmacists and carers have a responsibility to report any identified dysphagia to a patient’s general practitioner
- Dysphagia should be noted on all written communications between primary and secondary care
- Where patients can still receive medicines orally, have a long-term problem and are unable to take tablets or capsules, a liquid formulation should be prescribed
- Liquid medicines are designed to maximise patient acceptability and improve dosage reliability
- Crushing tablets and opening capsules can affect dosing, reduce patient acceptability, and leave prescribers open to litigation.

<sup>36</sup> Wright D, Chapman N, Foundling-Miah M et al. Consensus guideline on the medication management of adults with swallowing difficulties. In: Foord-Kelcey G, editor. Guidelines - summarising clinical guidelines for primary care. 30th ed. Berkhamsted: Medendium Group Publishing Ltd; October 2006. p. 373 - 376

<sup>37</sup> Strachan I and Greener M. “Medication-related swallowing difficulties may be more common than we realise.” Pharmacy in Practice 2005; 15 (10): 411-414.

<sup>38</sup> Rosemont Pharmaceutical Ltd news. (<http://bit.ly/1rwLZUJ>)

<sup>39</sup> Dr David Wright, University of East Anglia Chair of the Guideline Development Group - “Dysphagia should always be considered when prescribing” (<http://bit.ly/109CsNS>)

## 5. MULTIDISCIPLINARY TEAM (MDT) AND COLLABORATIVE CARE

Healthcare in Europe today is defined by an ageing population, complex health challenges, national economic deficits coupled with increasing societal and governmental demands for a more efficient yet effective healthcare system. This can only be achieved through consensus among the health payers and decision makers, together with HCPs and agreement with the patient and their families.

In 2008, Margaret Richardson, Parkinson's disease clinical nurse specialist at the Mid-Western Regional Hospital in Limerick, Ireland, wrote: *"In 2002 the Global Parkinson's Disease Survey identified several factors other than medication and severity of the condition that influenced quality of life for people with the condition. One major factor highlighted was the importance of a multidisciplinary team approach to managing the care of people with PD, their carers and families. Sometimes management focuses so much on the medical aspects that other issues and the important roles of other professionals in managing PD are often neglected."*<sup>40</sup>

There was a large body of academic literature around multidisciplinary teams identified by the academic search strategy. The majority of the evidence came from the Netherlands in relation to multidisciplinary care.

A recent article published in the BMJ (2014)<sup>41</sup> highlighted the value of the Dutch ParkinsonNet which established regional networks of selected and highly motivated healthcare professionals to whom patients are referred for long-term care. Whilst they initially focused on training and developing guidelines for physiotherapists, the networks have now developed further to include other therapists and has nationwide coverage (since 2010). A second important feature of ParkinsonNet has been the establishment of an information technology platform. This includes a dedicated website<sup>42</sup> with a search engine<sup>43</sup> and web based communities<sup>44</sup> for both patients and health professionals where they can talk to each other.

In a Netherlands-based non-randomised, controlled trial<sup>45</sup> on integrated multidisciplinary care in Parkinson's, the study found a third of eligible patients declined to visit the expert centre established by the programme. The report said that this was partly because the patients perceived it as having no benefit, although this perception may be peculiar to PwPs in the Netherlands. Nevertheless, it was concluded that integrated intervention within an expert centre environment offered only little benefit compared with multidisciplinary care delivered in the traditional way, that more work is needed to investigate how separate interventions are best bundled into a multidisciplinary approach, and that a better approach might be to not routinely offer multidisciplinary intervention to all patients, but reserve this for patients with the highest need. In a more recent review by the same authors<sup>46</sup>, the researchers concluded that an individually tailored approach seems preferable over a one-size-fits-all approach, but there is no evidence to support this assumption. Their other conclusions found that allied healthcare can complement standard medical management, even for symptoms that are largely resistant to pharmacotherapy or surgery. There is increasing evidence (largely from outside the field of Parkinson's) that active involvement of patients helps to improve the quality of care and to reduce healthcare costs. Empowering patients by self-management support and

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<sup>40</sup> Richardson, "Working together" WIN 2008;16(9): 31-32 ([www.inmo.ie/tempDocs/parkinsons\\_Oct08.pdf](http://www.inmo.ie/tempDocs/parkinsons_Oct08.pdf))

<sup>41</sup> Bloem, B. R., & Munneke, M. (2014). Revolutionising management of chronic disease: the ParkinsonNet approach. *BMJ*, 348. doi: <http://dx.doi.org/10.1136/bmj.g1838> (Published 19 March 2014)

<sup>42</sup> [www.ParkinsonNet.nl](http://www.ParkinsonNet.nl)

<sup>43</sup> [www.ParkinsonZorgzoeker.nl](http://www.ParkinsonZorgzoeker.nl)

<sup>44</sup> [www.MijnParkinsonzorg.nl](http://www.MijnParkinsonzorg.nl)

<sup>45</sup> van der Marck, Marjolein A., et al. "Integrated multidisciplinary care in Parkinson's disease: a non-randomised, controlled trial (IMPACT)." *The Lancet Neurology* 12.10 (2013): 947-956.

<sup>46</sup> van der Marck, Marjolein A., and Bastiaan R. Bloem. "How to organize multispecialty care for patients with Parkinson's disease." *Parkinsonism & related disorders* 20 (2014): S167-S173.



shared decision-making improves self-efficacy, quality of life, treatment compliance and patient satisfaction, according to the researchers.

Despite the benefits that can be achieved from taking this multidisciplinary team approach, the reviewers warned that offering a comprehensive multidisciplinary approach to only the patient might paradoxically create more stress among carers, because of the greater organisational demands that more intensive treatments bring to them. Therefore, dedicated attention to carers should be considered, and may alleviate this concern; for example, by asking occupational therapists to help caregivers gain more competence when assisting the patient could help them to maintain their own independence.

While an increasing number of HCPs and patients agree that the patient voice is key in realising optimal care and disease management, and that patients should be active partners with HCPs<sup>47</sup>, in practice, there are unmeasured or unspoken aspects that play a part in whether this ideal is achievable. For example, there will always be those (including doctors and patients) who feel the patient should not have any say in their disease management. There will also be PwPs, family members and/or carers who do not want to – or are reluctant to – look beyond the disease from the present stage; and there are PwPs who, as a result of negative social interactions and/or structural barriers, manifest self-imposed discrimination and stigma and become isolated<sup>48 49</sup>. These factors are unpredictable but should not be a barrier to effecting change; instead they should be seen as a challenge to overcome.

In Britain, the Parkinson's Excellence Network was launched by Parkinson's UK on Feb 3rd 2015<sup>50</sup>. The aim of the network is to bring together health and social care professionals to transform care for people affected by Parkinson's - a one-stop-shop for collaboration, evidence, education and resources to drive real improvement in health and care services. The Network offers resources to support service improvement and engage people affected by Parkinson's, comprehensive information about education and training and collaboration opportunities.

### 5.1. Evidence-based analysis of physical therapy in Parkinson's disease with recommendations for practice and research<sup>51 52 53</sup>

In the Netherlands, a large cluster randomised control trial has been established. This ParkNet trial includes the creation of regional networks of expert physiotherapists with specific training in Parkinson's to evaluate the implementation of ParkNet recommendations. Following this trial, a joint collaboration among 19 European physiotherapy associations has led to a European guideline for physiotherapy in Parkinson's disease.

<sup>47</sup> van der Eijk, Martijn, et al. "Moving from physician-centered care towards patient-centered care for Parkinson's disease patients." *Parkinsonism & related disorders* 19.11 (2013): 923-927.

<sup>48</sup> Simpson, Jane, Helen McMillan, and Donna Reeve. "Reformulating psychological difficulties in people with Parkinson's disease: the potential of a social relational approach to disablism." *Parkinson's disease* 2013 (2013).

<sup>49</sup> C. S. Hurt, J. Weinman, R. Lee, and R. G. Brown, "The relationship of depression and disease stage to patient perceptions of Parkinson's disease," *Journal of Health Psychology*, vol. 17, no. 7, pp. 1076–1088, 2012.

<sup>50</sup> [www.parkinsons.org.uk/professionals/news/3-february-2015/excellence-network-revolutionise-parkinsons-care](http://www.parkinsons.org.uk/professionals/news/3-february-2015/excellence-network-revolutionise-parkinsons-care)

<sup>51</sup> S. H. J. Keus, L. B. Oude Nijhuis, M.J. Nijkrake, B. R. Bloem, and M. Munneke, "Improving Community Healthcare for Patients with Parkinson's Disease: The Dutch Model," *Parkinson's Disease*, vol. 2012, Article ID 543426, 7 pages, 2012. doi:10.1155/2012/543426

<sup>52</sup> Keus, S. H.J., Bloem, B. R., Hendriks, E. J.M., Bredero-Cohen, A. B. and Munneke, M. (2007), "Evidence-based analysis of physical therapy in Parkinson's disease with recommendations for practice and research." *Mov. Disord.*, 22: 451–460. doi: 10.1002/mds.21244

<sup>53</sup> Bloem, B. R., & Munneke, M. (2014). Revolutionising management of chronic disease: the ParkinsonNet approach. *BMJ*, 348. doi: <http://dx.doi.org/10.1136/bmj.g1838> (Published 19 March 2014)

By integrating the best available research evidence with clinical expertise and patient values, the authors have developed clinical practice recommendations that facilitate evidence-based healthcare for physiotherapy in Parkinson's.

Furthering the success of the trial, in 2004 ParkinsonNet was established as a model where care is delivered by a network of specially trained professionals who collaborate through a dedicated online platform to which patients also have access. It has since expanded to 66 regional networks and almost 3000 trained experts from 15 different disciplines covering the whole of the Netherlands.

It was developed to tackle concerns of insufficient training for health professionals and poor communication between health professionals and patients.

Through the platform, patients can find information about treatment options and the trained professionals they need to help them. They are also given the option of having consultations in their own homes through secure video links.

## 5.2. Neurological Disorders – public health challenges<sup>54</sup>

This 2006 document, produced by the World Health Organisation (WHO), provides the public health perspective for neurological disorders, including Parkinson's disease, and presents estimates and predictions of the global burden borne by them. Its aim was to provide comprehensive information on neurological disorders to policymakers; the document was also aimed at being used as an awareness-raising tool.

Its recommendations include:

- Gaining commitment from decision makers
- Increasing public and professional awareness
- Minimising stigma and eradicating discrimination
- Strengthening neurological care within the existing healthcare systems
- Incorporating rehabilitation into the key strategies
- Developing national capacity and international collaboration
- Establishing links to other sectors
- Defining priorities for research

## 5.3. Parkinson's integrated care pathway<sup>55 56</sup>

In the UK, Neurological Commissioning Support (NCS) Limited – a joint initiative of the MS Society, the MND Association and Parkinson's UK – have developed a Parkinson's Care Pathway model.

The model covers primary, secondary, tertiary and social care, mapping out which health and social care professionals the patients should see, what the referral processes between them should be, and suggested governance arrangements to make things run smoothly. The model was developed together with the NHS and has been implemented across multiple sites including Cornwall, Kernow, Norfolk, Great Yarmouth, Waveney and South Tees Hospitals as integrated care pathways (ICPs).

The pathways are tailored for each region and is intended as a complete pathway, mapping the route that a PwP might take through the different services available to support them, from diagnosis through to the end of life.

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<sup>54</sup> WHO: Neurological Disorders - public health challenges (<http://bit.ly/ZVOPwn>)

<sup>55</sup> [www.ncssupport.org.uk/parkinsons-care-pathway](http://www.ncssupport.org.uk/parkinsons-care-pathway)

<sup>56</sup> [www.ncssupport.org.uk/wp-content/uploads/2012/08/Integrated\\_care\\_pathway\\_for\\_Parkinsons.pdf](http://www.ncssupport.org.uk/wp-content/uploads/2012/08/Integrated_care_pathway_for_Parkinsons.pdf)

It is possible to focus on specific areas of the pathway, showing individual services and how they link together. There is also information on what pathways should develop, and why.

ICPs for Parkinson's disease scenarios have also been mapped out across Teesside, County Durham and North Yorkshire. These are aimed at classifying Parkinson's patients who are admitted to hospital with particular complexities, disease-specific issues or disease-stage issues such as deep brain stimulation, dementia, duodopa, hip fractures (basic and complex), psychosis and more.

This Parkinson's pathway service aims to provide a coordinated and accessible service for PwPs, their family and carers.

#### 5.4. Parkinson Lab 360

Parkinson Lab 360 in Catania, Italy, is a pilot programme that launched on 11 April (World Parkinson's Day) 2014 by the University Gabriele D'Annunzio Chieti-Pescara, Marche Polytechnic University and several hospitals in Sicily and Marche, with national Parkinson's organisations Azione Parkinson Catania and Parkinson Italia.

It is the first multidisciplinary project in Italy to offer PwPs an MDT of neurologists, psychiatrists, neuro-psychologists, speech therapists, physiotherapists and nutritionists. The MDT monitors the patients for 24 hours throughout the duration of the programme.

The programme is still live. Once it has been completed, it is hoped that the analysis of the progress of the programme will drive improvements MDT care in Parkinson's.

#### 5.5. Country examples of MDT care

**Czech Republic:** In the Czech Republic, it is reported that PwPs have access to psychologists, family counselling, and psychotherapy. However it is unclear how wide spread this is across the country.

**Denmark:** A trial has been established across three municipalities in which nurse visits are available soon after diagnosis to give advice and counselling to PwPs and their families – no results have been published yet

**Ireland:** The Parkinson's Association of Ireland was established in 1987 and one of its objectives is to facilitate easy access to all appropriate services for people with Parkinson's and to lobby to improve those services. It has worked to help establish a network of PD Nurse Specialists within a multidisciplinary setting.

**The Netherlands:** Patients at the Netherland's Parkinson Centre (ParC), Nijmegen, are routinely invited to provide feedback about what is important for them in their Parkinson's treatment. Because this process is carried out before the actual visit to the centre, the centre can adjust the MDT team according to the unique priorities identified by the patient themselves. This client-centred approach improves the quality of care, while reducing the amount of redundant attention to issues that are less relevant for patients. The purpose of the park is to optimize the quality of life for Parkinson's patients and relatives. This applies to patients with Parkinson's disease, and in patients with a form of atypical parkinsonism.

Also across The Netherlands, the ParkinsonNet is a national network of health care providers who specialise in treating and guiding patients with Parkinson's and atypical parkinsonism. More than 2,700 health care providers (including neurologists, physiotherapists, occupational therapists, speech therapists and nurses) are members of this network. Taking this further, ParkinsonNet also monitor and present utilisation of care for various disciplines in the ParkinsonAtlas [www.parkinsonatlas.nl]. The ParkinsonAtlas also provides information on healthcare outcomes and health care costs of Parkinson's patients and compares the quality of the 66 regional ParkinsonNet networks. By making quality transparent, the belief is that this will make better healthcare.

**Malta:** There are multidisciplinary team offering: physiotherapy, speech therapy, a falls prevention programme, nutrition and occupational therapy. There is also access to complimentary medicine such as hydrotherapy and dance classes.

**Portugal:** In the *Residencial Mar Hospital* an individual neurological rehabilitation plan is outlined after a patient is seen by a multidisciplinary team. The plan is developed in collaboration with patients and their families. These teams include physiotherapy, speech and occupational therapists.

**Slovenia:** Multidisciplinary care is offered mainly through Ljubljana Neurological Clinic (based in the capital city). Involved in the treatment are: neurologists, physicians and specialist nurses.

**UK:** Rehab units and multidisciplinary Parkinson's clinics are available at some NHS hospitals (Nottinghamshire, Derby to name two). These offer MDT care through weekly clinics and virtual clinics. Services include physiotherapy, occupational therapy, speech and language therapy etc.

**US:** The team approach is widely recognised and practiced in the US. A good example is the University of North Carolina Center for Movement Disorders, which has been recognized as a National Parkinson Foundation Center of Excellence. A movement disorders multidisciplinary team offers patients comprehensive consultations from a team of experts specialising in Parkinson's. This team includes neurologists, neurosurgeons, physiotherapists, occupational therapists, speech and language pathologists, sleep specialists, counsellors and social workers.

In some of the other countries, although currently multidisciplinary care is not available (or just available in the capital/main cities), it should be noted that dedicated health professionals and third sector organisations are lobbying government to try and introduce the approach. For example:

**Bosnia:** it is reported that there is currently no access to multidisciplinary teams. However in an interview Professor Dzelilovic-Vranic MD, he recommends that in addition to neurologists, depending on the symptoms, "*the therapy treatment should involve social workers, physical therapists, psychiatrists*"<sup>57</sup>.

**Belgium:** There are plans for a new Parkinson's network called the "PARKINSON ZORGIJZER VLAANDEREN" that will support the creation of different centres across Belgium where patients can be supported by a multi-disciplinary team.

**Romania:** The national patient organisation, Asociatia Antiparkinson, has been lobbying for development of multidisciplinary teams across the country.

## 5.6. Neurodegenerative Diseases Research lab, Spain

The Neurodegenerative Diseases Research Group ([www.vilalab.org](http://www.vilalab.org)) at the Vall d'Hebron Research Institute (Barcelona) was created in January 2006 with the support of the Catalan Institution for Research and Advanced Studies (ICREA) and the European Commission's Marie Curie Excellence Grants Program. The group is part of the Spanish Network of Excellence on Neurodegenerative Diseases (CIBERNED).

The research conducted in this group is geared toward elucidating the molecular mechanisms of neuron cell death that occurs in neurodegenerative disorders. Its aim is to find a cure for disabling, currently incurable, neurological diseases. Most of their work focuses on Parkinson's.

Elucidating the molecular mechanisms that underlie neurodegeneration in Parkinson's disease should allow the development of new therapeutic strategies aimed at blocking neuronal death in this disorder; it should also elicit important clues to identifying molecular pathways that might be common to other neurodegenerative conditions.

## 5.7. Remaining knowledge gaps

Although the academic literature suggested the benefits of a multidisciplinary approach, there is no accepted standard for organising these team models of healthcare. The evidence thus far points in favour of team/specialist intervention, but does not offer the final answer on how to optimally design multidisciplinary team-based care in the

<sup>57</sup> Novovrijeme.ba, (2014, Apr 18) [online] <http://novovrijeme.ba/neurodegenerativna-obiljenja-parkinsonova-bolest/> (Accessed: September 2014)

management of Parkinson's. This is an important knowledge gap, in particular when a couple of studies from the Netherlands have highlighted the possible added strain a multidisciplinary approach can put on the carers.

Another important knowledge gap is in relation to the exact type of therapy that should be given. A 2009 review concluded that, although there is strong evidence to support physiotherapy, it remained unclear as to which physiotherapy techniques are the most effective<sup>58</sup>. A COCHRANE<sup>59</sup> review detailed similar findings in relation to speech therapy.

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<sup>58</sup> Tomlinson, C.L., Herd, C. et al. Physiotherapy for Parkinson's disease: A comparison of techniques. Editorial Group: Cochrane Movement Disorders Group Published Online: 17 JUN 2014  
DOI: 10.1002/14651858.CD002815.pub2

<sup>59</sup> Herd, C.P., Tomlinson, C.P., et al. Comparison of speech and language therapy techniques for speech problems in Parkinson's disease. Published Online: 15 AUG 2012. Accessed at:  
<http://onlinelibrary.wiley.com/doi/10.1002/14651858.CD002814.pub2/full#CD002814-bbs2-0030>

## 6. TECHNOLOGY, TOOLS AND MEASUREMENT

The advent of the Apple iPhone in 2007 with its refined touch responsive interface, brought about a revolution in the use of smartphones and smart-enabled peripherals from Apple and its competitors, and a sea-change in the public attitude toward the use of technology, which, until then, was considered expensive and cumbersome by today's standards. In less than five years, smartphones, tablets and smart-enabled devices have become ubiquitous with modern living and permeate almost every aspect of work and play.

Mobile apps have given patients and HCPs access to technology that had previously been considered specialist or required dedicated hardware. This new format can be updated to accommodate new hardware and/or changes to the operating systems easily and at reduced cost and risk.

A 2013 study<sup>60</sup> by the IMS Institute for Health Informatics included the analysis of the 40,000+ healthcare apps available for download from the US Apple iTunes app store, and assessed the potential value they provide throughout a patient's journey. The report concluded that physicians – while seeing the potential benefits of mobile healthcare apps – remain wary of formally recommending apps to patients. This is due to the current lack of evidence of their benefit, clear professional guidelines regarding their use in practice, and confidence in the security of personal health information that may be generated or transmitted by the app. Payers and employer wellness programmes also want clear evidence of benefit before considering reimbursement or promoting the use of apps.

However, the continued growth of the smart device and app industry does not appear to be slowing down, and it is inevitable that consumer-oriented devices will continue to develop and mature with each new version of the technology. Recognising this, the European Commission launched a public consultation in April 2014, alongside its Green Paper<sup>61</sup> on mobile health (mHealth), to help identify the right way forward to unlock the potential of mobile health in the EU. mHealth includes medical and public health practices that are supported by mobile devices, such as mobile phones, patient monitoring devices, personal digital assistants, and other wireless devices. mHealth can also include lifestyle and wellbeing apps that may connect to medical devices or sensors (e.g. bracelets or watches). It can also include personal guidance systems, health information and medication reminders (delivered wirelessly by sms and telemedicine).

Together with the Green Paper, the Commission published a Staff Working Document on the existing EU legal framework applicable to lifestyle and wellbeing apps<sup>62</sup>. This provided legal guidance on EU legislation to app developers, medical device manufacturers and digital distribution platforms. In the US, the Food and Drug Administration (FDA) have implemented procedures to regulate mobile medical apps<sup>63</sup>.

### 6.1. Nintendo Wii and Microsoft Kinect

The Nintendo Wii Balance Board is a balance board accessory, shaped like a household body scale, for the Nintendo Wii and Wii U video game consoles. Along with Wii Fit – an exercise game consisting of activities using the balance board – the system has been widely used for physiotherapy rehabilitation<sup>64</sup> and Parkinson's research<sup>65 66 67 68 69 70</sup>.

<sup>60</sup> Patient Apps for Improved Healthcare: From Novelty to Mainstream. Report by the IMS Institute for Healthcare Informatics. (<http://bit.ly/1azGqhd>)

<sup>61</sup> EU Green Paper on mobile health ("mHealth") - <http://bit.ly/1hvoThV>

<sup>62</sup> Commission Staff Working Document on the existing EU legal framework applicable to lifestyle and wellbeing apps (<http://bit.ly/1tBPr5Z>)

<sup>63</sup> U.S. Food and Drug Administration (FDA): Mobile Medical Application (<http://1.usa.gov/1iRgN2N>)

<sup>64</sup> "Nintendo Wii Fit for physiotherapy". Wellsphere. 2008-10-29. Retrieved 2014-04-23.

Kinect(r), produced by Microsoft enables users to control and interact with their console/computer without the need for a game controller.

The system uses technology that facilitates depth sensing, HD video, skeleton tracking, motion capture, gesture recognition, facial recognition and voice recognition. Originally developed as a gaming peripheral for the Microsoft Xbox 360 and Xbox One video game consoles and Windows PCs, the Kinect system is finding increasing traction in Parkinson's-related physiotherapy, rehabilitation and telemedicine <sup>71 72 73 74 75</sup>.

These studies and examples demonstrate that tailored use of these technologies are a feasible intervention to augment traditional physiotherapy and the rehabilitation of motor symptoms in PwPs. It can also offer a low-cost tool for telehealth and remote patient monitoring that can facilitate exercise compliance and motivation in the home.

## 6.2. Country examples of Nintendo Wii and Microsoft Kinect use

**Israel:** Multiple research projects investigating the use of the Microsoft Kinect system:

- Automatic analysis and classification of Parkinson Disease patients using Kinect device
- Motion Analysis Using Kinect for Monitoring Parkinson's Disease

**Italy:** Italian researchers have carried out studies to determine if home-based training with Nintendo Wii Fit and balance board could provide a self-management tool for people living with Parkinson's. The trial of 20 patients found significant psychological and physical improvements compared to the control group. They suggest there were clear benefits from the visual feedback, continuous reinforcement and results provided by these games <sup>76</sup>.

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- (www.wellsphere.com/general-medicine-article/nintendo-wii-fit-for-physiotherapy/460917)
- <sup>65</sup> Mhatre, Priya V., et al. "Wii fit balance board playing improves balance and gait in Parkinson Disease." *PM&R* 5.9 (2013): 769-777.
- <sup>66</sup> Herz, Nathan B., et al. "Nintendo Wii rehabilitation ("Wii-hab") provides benefits in Parkinson's disease." *Parkinsonism & Related Disorders* 19.11 (2013): 1039-1042.
- <sup>67</sup> "Wii May Help Balance in Parkinson's" Published: Jun 24, 2011 (www.medpagetoday.com/MeetingCoverage/MDS/40058)
- <sup>68</sup> Esculier JF, Vaudrin J, Beriault P, Gagnon K, Tremblay LE. "Home-based balance training programme using Wii Fit with balance board for Parkinson's disease: a pilot study." *J Rehabil Med* 2012, 44:144-150.
- <sup>69</sup> Barry, Gillian, Brook Galna, and Lynn Rochester. "The role of exergaming in Parkinson's disease rehabilitation: a systematic review of the evidence." *Journal of neuroengineering and rehabilitation* 11.1 (2014): 33.
- <sup>70</sup> Mhatre, Priya V., et al. "Wii fit balance board playing improves balance and gait in Parkinson Disease." *PM&R* 5.9 (2013): 769-777.
- <sup>71</sup> Takac, Boris, Wei Chen, and Matthias Rauterberg. "Toward a domestic system to assist people with Parkinson's." (www.spie.org/documents/Newsroom/Imported/004884/004884\_10.pdf)
- <sup>72</sup> Alvarez, Maria, and Patrick Grogan. "Connecting with Kinect (R) To Improve Motor and Gait Function in Parkinson Disease." *Neurology*. Vol. 78. 530 WALNUT ST, PHILADELPHIA, PA 19106-3621 USA: LIPPINCOTT WILLIAMS & WILKINS, 2012.
- <sup>73</sup> Galna, Brook, et al. "Accuracy of the Microsoft Kinect sensor for measuring movement in people with Parkinson's disease." *Gait & posture* 39.4 (2014): 1062-1068.
- <sup>74</sup> Galna, Brook, et al. "Retraining function in people with Parkinson's disease using the Microsoft kinect: game design and pilot testing." *Journal of neuroengineering and rehabilitation* 11.1 (2014): 60.
- <sup>75</sup> Vyšata, Oldrich, et al. "Quantitative gait analysis in Parkinson's disease using MS Kinect: Entropy and fractal dimension." *Journal of the Neurological Sciences* 333 (2013): e67-e67.
- <sup>76</sup> Abstracts of the Third World Parkinson's Conference (Montreal, October 1-4, 2013) *Journal of Parkinson's*

**Spain:** Spanish firm Virtualware has developed the VirtualRehab(r) platform based on Microsoft's Kinect system, which has won the scientific endorsement<sup>77 78</sup> of the Spanish Neurological Society (SEN) as well as recognition by the European Commission at the 2014 Enterprise Europe Network Awards.

VirtualRehab(r) comprises nine games based on Kinect technology and is aimed at rehabilitating patients with degenerative neurological diseases or suffering from cerebrovascular accidents (strokes).

The tool stimulates affected functions in patients (motor, coordination and, to a lesser extent, cognitive) suffering from degenerative neurological diseases (multiple sclerosis, Parkinson's, ALS, Alzheimer's), neuromuscular disorders and brain damage. The exercises and movements have been specifically designed to work on different functions such as equilibrium, coordination and strength. It also lets physical therapists remotely monitor their patients.

VirtualRehab(r) is the first<sup>79</sup> virtual rehabilitation software to be classified as a medical device and has been issued with more than 1,000 patients with degenerative neurological diseases in Spanish hospitals and in Moscow's largest rehabilitation center.

Spain's La Roda Parkinson's Association opened a new physiotherapy unit at the Center for Integrated Rehabilitation for Neurological Chronic Illness (CIRENC) in the city of La Roda. The centre became the first such place in Spain to introduce the VirtualRehab(r) rehabilitation videogame system – it was an additional service for the 180 users in the area, alongside magnetic therapy, electrotherapy and physiotherapy equipment.

ORPEA Ibérica, which operates care homes for the elderly across Spain, has recently introduced<sup>80</sup> the VirtualRehab(r) rehabilitation system in its centres in Madrid.

**Sweden:** Swedish-based consultant Softronic are conducting patient trials in collaboration with Karolinska University Hospital, in a project called Kinecting Parkinson's<sup>81 82</sup>.

The project aims to demonstrate how Kinect for Windows is a cost-effective way for patients with the disease to do rehab exercises at home and to help physicians follow up with their patients more often through remote monitoring.

The technical platform and software supports five movements based on the standardised Unified Parkinson's Disease Rating Scale (UPDRS). Data from the movements are analysed and presented in an interface that the doctor can use to make an assessment of the patient. The solution can also be used to educate neurologists specialising in Parkinson's and for second opinions.

**UK:** Parkinson's UK has put together guidelines for PwPs with regards to the use of the Wii Fit for exercise ([www.parkinsons.org.uk/content/parkinsons-and-wii](http://www.parkinsons.org.uk/content/parkinsons-and-wii)). A team in Newcastle also designed and tested an Xbox Kinect game to encourage people with Parkinson's to take part in exercise in a new and innovative way<sup>83</sup>.

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<sup>77</sup> Sociedad Española de Neurología: Videojuego SEN para conocer el trabajo del neurólogo: En la reunión de la Sociedad ([www.sen.es/noticias/110-noticias-sen/vocalia-de-cultura/595-videojuego-sen-para-conocer-el-trabajo-del-neurologo-en-la-reunion-de-la-sociedad](http://www.sen.es/noticias/110-noticias-sen/vocalia-de-cultura/595-videojuego-sen-para-conocer-el-trabajo-del-neurologo-en-la-reunion-de-la-sociedad))

<sup>78</sup> <http://virtualwaregroup.com/en/portfolio/neurology-educational-game>

<sup>79</sup> [www.virtualrehab.info/virtualrehab-receives-first-medical-device-ce-mark-approval-for-motion-capture-physical-rehabilitation-software-in-europe/](http://www.virtualrehab.info/virtualrehab-receives-first-medical-device-ce-mark-approval-for-motion-capture-physical-rehabilitation-software-in-europe/)

<sup>80</sup> [www.virtualrehab.info/orpea-centres-in-sanchinarro-and-las-rozas-have-introduced-the-virtualrehabilitation-system/](http://www.virtualrehab.info/orpea-centres-in-sanchinarro-and-las-rozas-have-introduced-the-virtualrehabilitation-system/)

<sup>81</sup> Gustaf von Dewall – a business developer with the Swedish-based consultant Softronic, Microsoft Health blog article: "Kinecting" to telemedicine (<http://bit.ly/1w7xSgl>)

<sup>82</sup> Softronic Health Partner: Vi presenterade Kinecting Parkinson på Health 2.0 Stockholm (<http://bit.ly/1FATvbP>)



The VirtualRehab(r) system is currently being used in the Neurorehabilitation unit of the National Hospital for Neurology & Neurosurgery (NHNN) Queen Square in London, part of University College London Hospitals NHS Trust.

**US and Canada:** The National Parkinson's Foundation research report on the Nintendo Wii and PD (<http://bit.ly/1zIGaDz>)

McMaster University – Combining dance and technology for Parkinson's therapy (using Microsoft Kinect) (<http://bit.ly/1vRG42Q>)

### 6.3. Objective measurement in Parkinson's disease management

Typically, clinical assessment, professional evaluation, and patient feedback are subjective, dependent upon human observation and interpretations off the patient, the doctor and HCP during the consultation and treatment process. Adverse factors such as personal and environmental stresses and strains will often skew or distort the real picture before, during and after a consultation/appointment with the PwP. Additionally, Parkinson's patients' symptoms can change within minutes and this will affect the accuracy of any professional assessment of the disease symptomatology.

This can make accurate assessment of disease progression difficult resulting in a prolonged cycle of adjustment and re-adjustment before the patient and doctor/HCP feel the treatment path is having a positive beneficial impact on managing the disease symptoms or whether they feel it is as good as it gets. In a study<sup>84</sup> comparing subjective self-reports with objective performance ratings of activities of daily living (ADLs) and instrumental ADLs (IADLs) to identify variables associated with discordance of ratings between these two methods, significant differences were found between patients and clinicians' ratings on all tasks except walking. Patients overestimated their function on four of five tasks.

Objective measurement employing devices such as Global Kinetics Corporation's Personal KinetiGraph™ (PKG™), and Great Lakes NeuroTechnologies Kinesia™ provide a way of measuring and recording clinical movement data to provide quantitative and objective information. This objective movement data can be used to assist doctors when determining objective clinical status about each patient, as well as monitoring disease progression and quantifying treatment response across non-specific medication and non-medical treatments.

The technologies provide a fuller and more objective picture of the severity of disease symptoms and its impact on the patients' quality of daily living. It offers a complementary and supportive view of the disease that is more realistic and less affected by short term or immediate adverse factors. Increasingly, objective assessment data is being used to provide a detailed insights into symptom fluctuation in the context of daily living, provide greater test-retest reliability and sensitivity to change than conventional clinical ratings for measuring bradykinesia, hypokinesia, and dysrhythmia in PwP<sup>85</sup>, effectively predict or provide accurate measures of overall dyskinesia severity<sup>86 87 88</sup>,

<sup>83</sup> Developing movement based computer games for Parkinson's - research project summary ([www.parkinsons.org.uk/sites/default/files/k-1106\\_rochester\\_plain\\_english\\_summary.pdf](http://www.parkinsons.org.uk/sites/default/files/k-1106_rochester_plain_english_summary.pdf))

<sup>84</sup> Shulman, Lisa M., et al. "Subjective report versus objective measurement of activities of daily living in Parkinson's disease." *Movement Disorders* 21.6 (2006): 794-799. doi: 10.1002/mds.20803

<sup>85</sup> Heldman, D. A., Espay, A. J., LeWitt, P. A., & Giuffrida, J. P. (2014). Clinician versus machine: Reliability and responsiveness of motor endpoints in Parkinson's disease. *Parkinsonism & related disorders*, 20(6), 590-595. doi:10.1016/j.parkreldis.2014.02.022

<sup>86</sup> Mera, T. O., Burack, M. A., & Giuffrida, J. P. (2012, August). Quantitative assessment of levodopa-induced dyskinesia using automated motion sensing technology. In *Engineering in Medicine and Biology Society (EMBC), 2012 Annual International Conference of the IEEE* (pp. 154-157). IEEE. Doi: 10.1109/EMBC.2012.6345894

<sup>87</sup> Mera, T. O., Burack, M. A., & Giuffrida, J. P. (2013). Objective Motion Sensor Assessment Highly Correlated

and assist in programming DBS parameters to better identify stimulation parameters in order to achieve optimal improvement across multiple motor symptoms<sup>89</sup>. The value of objective assessment is well demonstrated in one study<sup>90</sup> that looked at objective assessment of fall risk in Parkinson's. The study concluded that a body-fixed sensor worn continuously can evaluate fall risk in Parkinson's and was able to identify transition from non-faller to faller, whereas many traditional metrics were not successful. The researchers added that this approach may facilitate earlier detection of fall risk and could, in the future, help reduce high costs associated with falls and furthermore may assist in the evaluation of disease progression.

In the US, a collaboration<sup>91</sup> between Intel (NASDAQ: INTC), a world leader in computing innovation, and the Michael J Fox Foundation is leading the way in a multiphase research study using a new big data analytics platform that detects patterns in participant data collected from wearable technologies used to monitor symptoms. This effort is an important step in enabling researchers and physicians to measure progression of the disease and to speed progress toward breakthroughs in drug development. The project will use a device similar to FitBit's<sup>92</sup> wristband activity monitoring.

The PKG™, has recently been given approval<sup>93</sup> by the U.S. Food and Drug Administration (FDA) for market access within the US. In Europe, the company have been granted a long-term patent covering its Parkinson's Kinetigraph technology in the European Union<sup>94</sup> having obtained its CE Mark and TGA registration for the PKG™. The company recommends<sup>95</sup> the use of their device:

- At patient presentation to
  - Establishing the nature of reported symptomatology
  - Identifying unreported Bradykinesia or Dyskinesia
- Establishing if bradykinesia or dyskinesia are either dose related or unpredictable
- As a guide to therapy success and whether advanced therapy is required
- As a guide to disease progression
- Establishing an initial baseline measurement for a new patient for comparison with future consultations

with Scores of Global Levodopa-Induced Dyskinesia in Parkinson's Disease. *Journal of Parkinson's disease*, 3(3), 399-407. doi: 10.3233/JPD-120166

<sup>88</sup> Pulliam, Christopher L., et al. "Motion Sensor Dyskinesia Assessment During Activities of Daily Living." *Journal of Parkinson's disease* (2014). Doi: 10.3233/JPD-140348

<sup>89</sup> Mera, T., Vitek, J. L., Albers, J. L., & Giuffrida, J. P. (2011). Kinematic optimization of deep brain stimulation across multiple motor symptoms in Parkinson's disease. *Journal of neuroscience methods*, 198(2), 280-286. doi:10.1016/j.jneumeth.2011.03.019

<sup>90</sup> Weiss, A., Herman, T., Giladi, N., & Hausdorff, J. M. (2014). Objective Assessment of Fall Risk in Parkinson's Disease Using a Body-Fixed Sensor Worn for 3 Days. *PloS one*, 9(5), e96675. doi: 10.1371/journal.pone.0096675

<sup>91</sup> Intel Press release: The Michael J. Fox Foundation and Intel Join Forces to Improve Parkinson's Disease Monitoring and Treatment through Advanced Technologies - <http://intel.ly/1usy6gX>

<sup>92</sup> [www.fitbit.com](http://www.fitbit.com) (Accessed 17 Dec 2014)

<sup>93</sup> Global Kinetics Corporation Announces FDA Clearance of the Personal KinetiGraph™ for Assessment of Parkinson's Disease Symptoms - <http://prn.to/1At3Lie>

<sup>94</sup> Global Kinetics Corporation Secures Key European Union (EU) Patent for Parkinson's Kinetigraph™ Technology - <http://bit.ly/16vBDSr>

<sup>95</sup> When is the PKG™ movement recording useful? - <http://bit.ly/1AiDhSc>

- As a means to engage patients
  - Communicate the impact of compliance
  - Present information in a format that assists health care professionals to communicate with patients

## 7. MUSIC, DANCE AND EXERCISE

### 7.1. Music

Studies show that music therapy and music-based movement can help improve the quality of life for people with Parkinson's by:

- Promoting a sense of wellbeing
- Reducing stress, anxiety, depression and feelings of isolation
- Improving movement, breathing
- Improving verbal and non-verbal communication
- Promoting self-expression
- Improving memory.

Rhythm also seems to improve tremor and dyskinesia by providing a template or pattern that allows movement to be synchronised and controlled again. Not only is there improvement of general gait patterns (including postural control)<sup>96</sup>, but also in the ability to generate complex coordinated movement sequences combining upper and lower limbs. The study<sup>97</sup> notes that rhythms should be designed effectively as they appear to lose therapeutic value when they are not tuned to the individual's pace, or when they become more cognitively demanding.

The Ronnie Gardiner Rhythm and Music (RGRM™) Method showed promising results in both motor and cognitive functions as well as quality of life in PwPs with moderate Parkinson's and the adherence level was high. The results<sup>98</sup> suggested that the RGRM™ Method could be used by physiotherapists, occupational, speech and music therapists in neurological rehabilitation.

Music therapy was successful in significantly enhancing facial expression<sup>99</sup>, speech intelligibility and vocal intensity<sup>100</sup>. It is estimated that almost 90% of PwPs have speech and voice disorders but studies suggest that only 3-4% of PwPs receive speech treatment<sup>101</sup>.

The Lee Silverman Voice Treatment (LSVT), which evolved into LSVT-Loud™, can be effective in reducing some of the speech abnormalities experienced by PwPs<sup>102 103 104</sup>. Its counterpart, LSVT-BIG™, has demonstrated

<sup>96</sup> Nombela, Cristina, et al. "Into the groove: Can rhythm influence Parkinson's disease?." *Neuroscience & Biobehavioral Reviews* 37.10 (2013): 2564-2570.

<sup>97</sup> Thaut, Michael H., and Mutsumi Abiru. "Rhythmic auditory stimulation in rehabilitation of movement disorders: a review of current research." (2010): 263-269.

<sup>98</sup> Pohl, Petra, Nil Dizdar, and Eva Hallert. "The Ronnie Gardiner Rhythm and Music Method-a feasibility study in Parkinson's disease." *Disability & Rehabilitation* 35.26 (2013): 2197-2204.

<sup>99</sup> Elefant, Cochavit, et al. "Effects of music therapy on facial expression of individuals with Parkinson's disease: A pilot study." *Musicae Scientiae* 16.3 (2012): 392-400.

<sup>100</sup> Haneishi, Eri. "Effects of a music therapy voice protocol on speech intelligibility, vocal acoustic measures, and mood of individuals with Parkinson's disease." *Journal of Music Therapy* 38.4 (2001): 273-290.

<sup>101</sup> Wan, Catherine Y., et al. "The therapeutic effects of singing in neurological disorders." *Music perception* 27.4 (2010): 287.

<sup>102</sup> Ramig, Lorraine O., et al. "Changes in vocal loudness following intensive voice treatment (LSVT®) in individuals with Parkinson's disease: A comparison with untreated patients and normal age - matched controls." *Movement Disorders* 16.1 (2001): 79-83.

benefits that address gait, balance and bed mobility<sup>105 106</sup> although long-term effects of the system still need to be established<sup>107</sup>.

## 7.2. Dance

It is recognised among HCPs that medication and pharmacology alone cannot always fully address motor, cognitive and psychosocial symptoms. Various studies<sup>108 109 110 111</sup> have demonstrated or suggest that, at the very least, dance is an effective psychotherapeutic adjunct therapy for Parkinson's that has the potential to improve health-related quality of life (HRQoL) and influence health behaviours of PwPs.

As a regular exercise, dance is shown<sup>112</sup> to have positive effects on motor deficits, especially on the rigidity of the limbs as well as on fine motor skills, facial expression; it can also improve mobility, balance and gait function. Furthermore, the quality of life of PwPs and their caregivers is seen to improve in parallel: as social dances, Tango<sup>113</sup> and Irish set dancing<sup>114</sup> are prominent expressions of dance that have found widespread popularity. It is not known whether other dance genres or styles are more or less effective compared to one another but this point is considered academic given the evidence that point to their benefits.

During the EPDA's Learning in Partnership workshops, members within the central/eastern Europe group said that they often hear of innovative projects in western Europe such as dancing or drama clubs etc – they considered these important because they can evidently improve the quality of life by increasing self-assurance.

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- <sup>103</sup> Dumer, Aleksey I., et al. "Effects of the Lee Silverman Voice Treatment (LSVT® LOUD) on Hypomimia in Parkinson's Disease." *Journal of the International Neuropsychological Society* 20.03 (2014): 302-312.
- <sup>104</sup> Ramig, L. O., et al. "Intensive voice treatment (LSVT®) for patients with Parkinson's disease: a 2 year follow up." *Journal of Neurology, Neurosurgery & Psychiatry* 71.4 (2001): 493-498.
- <sup>105</sup> Ebersbach, Georg, et al. "Comparing exercise in Parkinson's disease—the Berlin BIG Study." *Movement Disorders* 25.12 (2010): 1902-1908.
- <sup>106</sup> Janssens, Jorina, et al. "Application of LSVT BIG Intervention to Address Gait, Balance, Bed Mobility, and Dexterity in People With Parkinson Disease: A Case Series." *Physical therapy* (2014).
- <sup>107</sup> Fox, Cynthia, et al. "LSVT LOUD and LSVT BIG: behavioral treatment programs for speech and body movement in Parkinson disease." *Parkinson's disease* 2012 (2012).
- <sup>108</sup> Shanahan, Joanne, et al. "Dance for people with Parkinson's disease: what is the evidence telling us?." *Archives of physical medicine and rehabilitation*(2014).
- <sup>109</sup> Sharp, Kathryn, and Jonathan Hewitt. "Dance As An Intervention For People With Parkinson's Disease: A Systematic Review And Meta-Analysis." *Neuroscience & Biobehavioral Reviews* (2014).
- <sup>110</sup> Earhart, Gammon M. "Dance as therapy for individuals with Parkinson disease." *European journal of physical and rehabilitation medicine* 45.2 (2009): 231.
- <sup>111</sup> Hackney, M. E., and C. G. Bennett. "Dance therapy for individuals with Parkinson's disease: improving quality of life." *Journal of Parkinsonism and Restless Legs Syndrome* 4 (2014): 17-25.
- <sup>112</sup> Heiberger L, Maurer C, Amtage F, Mendez-Balbuena I, Schulte-Mönting J, Hepp-Reymond M-C and Kristeva R (2011) "Impact of a weekly dance class on the functional mobility and on the quality of life of individuals with Parkinson's disease." *Front. Ag. Neurosci.* 3:14. doi: 10.3389/fnagi.2011.00014
- <sup>113</sup> McKee, Kathleen E., and Madeleine E. Hackney. "The effects of adapted tango on spatial cognition and disease severity in Parkinson's disease." *Journal of motor behavior* 45.6 (2013): 519-529.
- <sup>114</sup> Volpe, Daniele, et al. "A comparison of Irish set dancing and exercises for people with Parkinson's disease: A phase II feasibility study." *BMC geriatrics*13.1 (2013): 54.

### 7.3. Boxing, yoga and tai chi

Some experts believe that non-contact boxing-inspired fitness training (sometimes known as boxercise) can help improve PwPs' physical performance and daily living activities <sup>115 116</sup>.

Researchers from the University of Luxembourg (LCSB) have begun offering PwPs boxing training at Parkinson Luxembourg's centre "La Tulipe" in Leudelange. Though limited within Europe, boxercise for PwPs is more common and well organised in the US <sup>117 118</sup>.

Tai chi is practiced widely as a complementary exercise that can improve balance and posture for PwPs. Numerous researches into the benefits of tai chi on balance and fall prevention point to the effectiveness of the practice. Again, the US appears to lead the way with the adoption of organised classes and information by its national patient groups.

Yoga focuses on building strength and flexibility. Research <sup>119 120 121</sup> shows that the benefits of yoga for movement disorders include improved strength, flexibility, balance, and overall fitness. Research also cites improvements in relation to fatigue, anxiety, depression and difficulty sleeping – all important factors in boosting psychological well-being and overall quality of life.

There is some indication from patient organisations in Israel, the UK and the Netherlands – as well as independent health centres – that dedicated classes for yoga and tai chi are beneficial for PwPs.

### 7.4. Country examples of dance, music and exercise

**Australia:** Dance for Parkinson's Australia [<http://danceforparkinsonsaustralia.org/>]

**France:** The Parkinson's Dance Project / Parkinson en Mouvement [<http://parkinsonenmouvement.com/>]

**Germany:** FunTango [[www.funtango.de/de/26249-Parkinson](http://www.funtango.de/de/26249-Parkinson)]

**Iceland:** Parkinsonsamtökin á Íslandi Parkinson's organisation dance therapy classes

**Malta:** FlexFit dance-based exercises [[www.livelifecom.mt/site/care-and-recovery/flexfit-classes](http://www.livelifecom.mt/site/care-and-recovery/flexfit-classes)]

**Netherlands:** Parkinson Vereniging: Dance for Health [[www.danceforhealth.nl](http://www.danceforhealth.nl)] and Salsa [<http://klipdans.weebly.com/>]

**Portugal:** Dancing with Parkinson – joint Associação Portuguesa de Doentes de Parkinson (APDPk) and Santa Casa da Misericórdia de Lisboa (SCML) project [[www.portugalsenior.org/?p=12143](http://www.portugalsenior.org/?p=12143)]. These programmes were

<sup>115</sup> Diehl, D., S. Combs, and B. Staples. "Comparison of boxing training and traditional exercise on balance and quality of life outcomes in persons with Parkinson's disease: A pilot study." MOVEMENT DISORDERS. Vol. 26. COMMERCE PLACE, 350 MAIN ST, MALDEN 02148, MA USA: WILEY-BLACKWELL, 2011.

<sup>116</sup> Combs, Stephanie A., et al. "Boxing training for patients with Parkinson disease: a case series." Physical therapy 91.1 (2011): 132-142.

<sup>117</sup> [www.rocksteadyboxing.org](http://www.rocksteadyboxing.org)

<sup>118</sup> [www.punchingoutparkinsons.org](http://www.punchingoutparkinsons.org)

<sup>119</sup> Moriello, Gabriele, et al. "Incorporating yoga into an intense physical therapy program in someone with Parkinson's disease: A case report." Journal of bodywork and movement therapies 17.4 (2013): 408-417.

<sup>120</sup> Yvonne Searls, Colgrove. "Effect of Yoga on Motor Function in People with Parkinson's Disease: A Randomized, Controlled Pilot Study." Journal of Yoga & Physical Therapy (2012).

<sup>121</sup> Roland, Kaitlyn P. "Applications of yoga in Parkinson's disease: a systematic literature review." Journal of Parkinsonism and Restless Legs Syndrome 4 (2014): 1-8.

inspired by the Mark Morris Dance Group/Brooklyn Parkinson Group methodology, Dance for PD® (see US and Canada).

**Slovakia:** Tango can benefit treatment of Parkinson's disease [<http://gancho.info/tango-can-benefit-treatment-of-parkinsons-disease/>]

**Switzerland:** Parkinson Schweiz Tango courses: Tangotänzen für Parkinsonbetroffene [[www.parkinson.ch/index.php?id=374](http://www.parkinson.ch/index.php?id=374)]

**UK (including Ireland):** Dance for Parkinson's Network [[www.danceforparkinsonsuk.org](http://www.danceforparkinsonsuk.org)]

English National Ballet – Dance for Parkinson's [[www.ballet.org.uk/learning/dance-parkinsons/](http://www.ballet.org.uk/learning/dance-parkinsons/)]

**US and Canada:** Dance for PD [<http://danceforparkinsons.org/>]

Yogadopa [<http://kaitlynroland.wordpress.com/2013/04/04/dance-for-parkinsons-tango/>]

**US only:** The Institute for Music and Neurologic Function (IMNF) offers music therapy to patients with Parkinson's disease [<http://musictherapy.imnf.org/services/category/inpatient-parkinsons-disease>]

## 8. ACCESS TO THERAPIES

While it is beyond the scope of this report to determine which European countries PwPs have access or lack of access to particular medication, surgical treatment or other therapy, many patient organisations from across Europe have highlighted their concerns relating to a lack of treatments or therapies (or difficulties in accessing particular modes of treatments and/or therapies).

### 8.1. Deep brain stimulation (DBS)

One therapy in particular – deep brain stimulation (DBS) – is often mentioned as being costly and not accessible within many healthcare environments. Unfortunately there are very few recent studies in Europe that directly support this anecdotal feedback or can provide strong enough qualitative evidence around the extent to which DBS and other “advanced” treatments are difficult to access or the factors that are limiting their access. What data and studies that have been carried out are primarily US-based<sup>122 123 124</sup>.

Nevertheless, recent studies do suggest that DBS is a cost-effective intervention in patients with advanced Parkinson's who are eligible for surgery, would provide good value for money to healthcare payers<sup>125</sup>, and offers a value-for-money profile comparable to other well-accepted healthcare technologies<sup>126</sup> (costs in this study were assessed within the German healthcare system).

A review<sup>127</sup> of the current application of DBS in Parkinson's highlights that the therapy is typically performed in late-stage Parkinson's, a mean of 14 to 15 years after diagnosis. It also suggests that the criteria within current guidelines for determining when a PwP should be referred to, or given the option to have DBS, are inadequate; the review suggested that by the time medical treatment options have been exhausted, the disease has progressed to the point where the patient may no longer be fit for neurosurgical intervention.

The EARLYSTIM study<sup>128</sup> found evidence to support the use of DBS in less-advanced Parkinson's (motor complications for less than three years) and advocated that the therapy may be appropriate for people in the earlier stages of the disease. However, a later review<sup>129</sup> concluded that the most relevant issue is not when to operate but on whom and that early is not always better.

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<sup>122</sup> Willis, Allison W., et al. "Disparities in deep brain stimulation surgery among insured elders with Parkinson disease." *Neurology* 82.2 (2014): 163-171.

<sup>123</sup> Chan, Andrew K., et al. "Disparities in Access to Deep Brain Stimulation Surgery for Parkinson Disease: Interaction Between African American Race and Medicaid Use." *JAMA neurology* 71.3 (2014): 291-299.

<sup>124</sup> Hariz, Gun-Marie, et al. "Gender distribution of patients with Parkinson's disease treated with subthalamic deep brain stimulation; a review of the 2000–2009 literature." *Parkinsonism & related disorders* 17.3 (2011): 146-149.

<sup>125</sup> Eggington, Simon, et al. "The cost-effectiveness of deep brain stimulation in combination with best medical therapy, versus best medical therapy alone, in advanced Parkinson's disease." *Journal of neurology* 261.1 (2014): 106-116.

<sup>126</sup> Dams, Judith, et al. "Cost-effectiveness of deep brain stimulation in patients with Parkinson's disease." *Movement Disorders* 28.6 (2013): 763-771.

<sup>127</sup> deSouza, Ruth - Mary, et al. "Timing of deep brain stimulation in Parkinson disease: a need for reappraisal?." *Annals of neurology* 73.5 (2013): 565-575.

<sup>128</sup> Schuepbach, W. M. M., et al. "Neurostimulation for Parkinson's disease with early motor complications." *New England Journal of Medicine* 368.7 (2013): 610-622.

<sup>129</sup> Mestre, Tiago A., et al. "Subthalamic nucleus - deep brain stimulation for early motor complications in Parkinson's disease—the EARLYSTIM trial: Early is not always better." *Movement Disorders* (2014).