












# Exploring health and social services in Denmark, Norway, Spain and the United Kingdom for the development of Parkinson's care pathways. A document analysis

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## Abstract

People with Parkinson's disease (PD) may find it difficult to identify and access the wide number of services they need and are entitled to along their complex PD journey. As part of the project OPTIM-PARK – Optimisation of community resources and systems of support to enhance the process of living with Parkinson's Disease, document analysis was developed to create overviews of existing resources and systems of support in Denmark, Norway, Spain and the United Kingdom. Documents on community resources, policies, guidelines and professional recommendations were the main sources of information. They were sought systematically at official websites of the public sector (national and regional levels) and websites of non-governmental organisations and scientific societies; searches were performed in October 2020 and updated in September 2021. A higher-level cross-national content analysis integrated all the country-specific information. Data- and concept-driven coding frames were developed; trial coding and peer review strengthened face validity and reliability. The analysis led to overviews of: (1) Key aims at patient and societal levels. (2) Key elements in form of professional approaches. (3) Community resources. (4) Legally

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anchored services. In general, clear descriptions of how to implement care pathways and tools to facilitate delivery were missing in the included documents, and pathways and guidelines did not include referral to general social support, social security support or labour and employment support. The results shed light on the complex support systems and resources and can inspire the planning of more comprehensive care pathways for people with PD and other long-term conditions.

#### KEYWORDS

care pathways, chronic disease management, delivery of healthcare, health service research, Parkinson's disease, social welfare

## 1 | INTRODUCTION

Parkinson's disease (PD) is a long-term neurodegenerative condition with an estimated prevalence of 0.3% in the general population and 3% in people >80 years (Balestrino & Schapira, 2020). Motor and nonmotor symptoms may cause a profound, life-altering decline in all aspects of everyday life and lead to increasing needs for healthcare and social services (Ambrosio et al., 2019; Haahr et al., 2021; Radder et al., 2017). People with PD (PwPD) and their family carers are eligible to receive healthcare, social and labour market services, according to national and regional legislation. These services are included in the International Classification of Functioning, Disability and Health (ICF), in the descriptions of *Environmental factors: services, systems and policies* and are found to be important influencers on people's health, activity and participation (World Health Organisation WHO, 2001). However, PwPD and their carers can find it difficult to navigate and understand what services are available (Lökk, 2011; Read et al., 2019; Schrag et al., 2018). In addition, PwPD is often not referred to allied healthcare due to professionals' lack of knowledge or time (Nijkrake et al., 2009). In addition, professionals attending PwPD are not always up-to-date concerning the treatment and available services/support, and cross-sectoral professional communication can be a challenge (Nijkrake et al., 2009; Schrag et al., 2018; Thompson et al., 2013). Consequently, the needs of PwPD are not consistently and effectively met, with possible detrimental effects on health and quality of life.

A survey amongst PwPD in 11 European countries, including Denmark, Spain and the United Kingdom (UK), showed a lack of satisfaction amongst the participants regarding: their care (37%), their involvement in decisions (38%), communication with professionals (43%), information received (46%), availability and accessibility of treatment (52%), and collaboration between healthcare professionals (59%) (Schrag et al., 2018). This highlights the importance of an ongoing need for quality management and improvements in relation to the management of PD along each individual's illness trajectory.

A way of establishing how to sequence and deliver healthcare, social and labour market services, including which resources to allocate, is to develop evidence-based care pathways and clinical practice guidelines (European Pathway Association EPA, n.d.). A care

### What is known about this topic

- People with Parkinson's disease (PwPD) experience all-encompassing challenges in their everyday lives.
- Multiple community resources and recommendations concerning services for people with long-term conditions exist in Denmark, Norway, Spain and the United Kingdom.
- PwPD, their family carers and professionals have difficulty finding, navigating, and making use of the complex systems of support despite the existence of multiple (but not coherent) care pathways and guidelines.

### What this paper adds

- Key aims and elements regarding Parkinson's disease management to consider in future care pathways.
- Overviews of community resources and services to include in future care pathways.

pathway is defined as *a complex intervention for the mutual decision-making and organisation of care processes for a well-defined group of patients during a well-defined period. Goals and key elements to be described include communication, coordination, roles, sequencing the activities of the multidisciplinary team, patients and relatives, documentation, monitoring, evaluation, and the identification of the appropriate resources* (EPA, n.d.). The aim of a care pathway is to enhance the quality of care across the continuum of care by improving patient outcomes, promoting patient safety, increasing patient satisfaction and optimising the use of resources (EPA, n.d.). Clinical practice guidelines may contain the same elements as above, yet they may be less comprehensive and with a narrower scope (Lohr & Field, 1990). Over the years, there have been national and cross-national attempts at creating guidelines for PD management and recommendations on their content (e.g., NICE, 2017; Keus et al., 2014; Vanhaecht et al., 2006). Whilst these guidelines seem to mainly guide activities within the health system with a focus on diagnosing and symptom treatment, including mid- and long-term complications, there is a

lack of more comprehensive guidelines on how to develop and navigate existing resources and parallel systems of support within both health and social care services through patients' and family carers' trajectory of living with PD.

By unfolding existing care pathways, guidelines and other recommendations on the utilisation and roles of community resources within both health and social services, and by mapping legally anchored services, this study aims to provide a broader knowledge base for the design and implementation of future comprehensive care pathways for PwPD. It may also provide important knowledge for the development of care pathways for people with long-term conditions (PwLTCs) in general.

The following review questions were posed:

1. What do existing Danish, Norwegian, Spanish and the UK policy and guidelines advise regarding the organisation of healthcare and social services aimed at enhancing the process of living with PD? What are the key aims, key elements and proposed community resources?
2. Which legally anchored healthcare, social and labour market services relevant to PwPD exist in Denmark, Norway, Spain and the UK?

## 2 | MATERIALS AND METHODS

This study is part of the European project OPTIM-PARK—Optimisation of community resources and systems of support to enhance the process of living with Parkinson's Disease, involving research teams from Denmark, Norway, Spain, and the UK, and the results will be used to develop and establish the feasibility and acceptability of a care pathway that will enhance the process of living with PD for patients and family-carers by building multisectoral care pathways (OPTIM-PARK, *n.d.*).

### 2.1 | Study design

A document analysis was developed specifically for the OPTIM-PARK project to find and analyse evidence-based care pathways, clinical practice guidelines and national/regional policies from Denmark, Norway, Spain and the UK. Document analysis has been deemed particularly relevant to qualitative analysis of statutory documents and non-technical grey literature, such as documents from the public domain (Bowen, 2009). Analyses were performed at national and cross-national levels. The review questions, the study design and the analyses were discussed in national patient and public involvement (PPI) groups in each country, consisting of PwPD, family carers, healthcare professionals and stakeholders involved in service provision, policy design and decision-making. PPI representatives were recruited through PD associations and amongst staff and decision-makers at different organisational levels of health and social care services.

### 2.2 | Search and appraisal strategy

Relevant documents were expected to be found through web-based searches mainly at official websites. Eligible documents targeted PwPD, PwLTCs and their family carers and all citizens when relevant to the process of living with PD.

- For Question 1, we included current national and regional care pathways, clinical practice guidelines and policies, and professional recommendations for practice produced by PD associations, scientific societies and other professional associations.
- For Question 2, we included current national and regional documents on legally anchored healthcare, social and labour market services meeting the needs of individuals.

Detailed guidelines were developed for search, documentation and recordkeeping, inspired by Stansfield et al. (2016). This ensured a uniform approach, aiming for transparency, accountability and reproducibility. The searches were performed in the national languages. The review questions were operationalised into two typologies (Tables 1 and 2) that set out the focus of the searches in relation to the questions and the most relevant types of sources; the typologies allowed room for documentation to ensure homogeneity, transparency and reproducibility (Stansfield et al., 2016). The approach was introduced and discussed with all the national teams, and the teams worked closely together in the process of gathering data, to ensure mutual understanding and homogeneity in the process.

Searches were performed in October 2020 and updated in September 2021 by researchers with professional knowledge of health and social care services, relevant legislation, organisations, policies and structures at national and regional levels as well as their national use of relevant terms and local idioms. Focused searches were performed on official webpages where guidelines, policy papers, legislative documents, service mapping reports and other official documents were available to the public. A strategy was applied to search at least seven regions in each country using a principle of diversity. When using search engines, the researchers in each country screened the first 50 results produced by each search and only proceeded if they still found relevant material at that point (Stansfield et al., 2016). When necessary, a peer reviewer was involved in screening for relevance. Websites and documents were evaluated and appraised with emphasis on accuracy, authority, objectivity, currency and coverage, using the quality criteria from Monash University (*n.d.*). The reference management programme Zotero was used to transparently organise and share the records. The numbers of references included in the national reports are shown in Table 3.

### 2.3 | Data management and analysis

Due to the complex process of this document analysis at national and cross-national levels, different steps took place during the analysis as presented below.

**TABLE 1** Typology concerning guidelines and policy on utilisation and roles of community resources and working relationships between sectors in relation to PD management

<p>1. Which care pathways<sup>a</sup>, clinical practice guidelines<sup>a</sup>, and other professional recommendations describe the utilisation and roles of community resources and working relationships between sectors in relation to services aimed at PwPD (or PwLTCs that include PD)?</p> <p>2. Which national or regional policies describe the utilisation and roles of community resources<sup>b</sup> and working relationships between sectors<sup>c</sup> when organising services aimed at PwPD (or PwLTCs that include PD)?</p> <p><i>Write a short summary of each finding in English. Report key elements relevant to PD management, use of community resources, communication, coordination within and across sectors, and the roles of involved professionals.</i></p>		
What to search for ➔	1	2
Where to search ↓	Care pathways, clinical practice guidelines, and other professional recommendations	Policies
National level, public sector		
Regional level, public sector		
Non-governmental organisations: PD associations etc.		
Scientific societies /professional associations		
Other sources, specify		

Abbreviations: PD, Parkinson's disease; PwPD, people with Parkinson's disease; PwLTCs, people with long-term conditions.

<sup>a</sup>Care pathways and clinical practice guidelines: For this study, care pathways may be aimed at PwPD or, more generally, at PwLTCs that include PwPD. Goals and key elements to be described include communication, coordination, roles, sequencing the activities of the multidisciplinary team, documentation, monitoring, and evaluation. Clinical practice guidelines may be less comprehensive; they may contain the same elements as above.

<sup>b</sup>Community resources: Community resources can be run or funded by the government, businesses, non-profit groups, or even individuals and serve the community in a variety of ways. Hospitals, community clinics, and public health organisations are all considered community resources regardless of funding.

<sup>c</sup>Working relationships between sectors: The roles and cooperation between the primary health and social care sector (general practitioners and community services), the secondary sector (hospitals and specialists), and the private sector that provide services and advocate for PwPD.

**TABLE 2** Typology concerning specific national and regional legislation pertaining to health service policy, social policy and labour market policy

<p>1. Which health service policy<sup>a</sup> exists in your country relevant for PwPD?</p> <p>2. Which social policy<sup>b</sup> exists in your country for relevance for PwPD?</p> <p>3. Which labour market policy<sup>c</sup> exists in your country relevant for PwPD?</p> <p><i>Report type of document, target group, problems addressed and policy instrument</i></p>			
What to search for ➔	1	2	3
Where to search ↓	Health service policy	Social policy	Labour market policy
National level, public sector			
Regional level, public sector			
Notes, e.g., findings from other areas of legislation			

Abbreviation: PwPD, People with Parkinson's disease.

<sup>a</sup>Health service policy: legislation (statutory documents) and principles to grant health services of relevance to PwPD.

<sup>b</sup>Social policy: legislation (statutory documents) and principles concerning social services of relevance to PwPD.

<sup>c</sup>Labour market policy: legislation (statutory documents) and principles to help people with disabilities maintain their labour market affiliation.

### 2.3.1 | Step 1. Content analysis and report at the national level

To ensure consistency, the national teams used common extraction templates to summarise and conclude upon the national documents. Codes and concepts were predefined in the main OPTIM-PARK project plan.

- For each document related to Question 1, the teams summarised and reported what was prescribed or recommended for PD management (or long-term conditions that included PD), covering the following codes: key aims, key elements, use of community

resources, communication and coordination (working relationships) within and between sectors and roles and activities of involved professionals.

- For each category related to Question 2, the teams summarised and reported existing national and regional legally anchored services covering the codes of health service policy, social policy and labour market policy.

The national reports, written in English, were shared amongst the teams; this led to the refinement of document searches and revision of reports to more comprehensively cover the review questions.

**TABLE 3** Numbers of references included in the national reports

	Denmark 22 documents	Norway 30 documents <sup>a</sup>	Spain 35 documents	UK 47 documents <sup>a</sup>
National level, public sector <sup>b</sup>	Q1: 7	Q1: 11	Q1: 9	Q1: 12
	Q2: 8	Q2: 19	Q2: 9	Q2: 23
Regional level, public sector <sup>c</sup>	Q1: 3	Q1: 2	Q1: 10	Q1: 3
	Q2: -	Q2: 2	Q2: 2	Q2: 4
Non-governmental organisations <sup>d</sup>	Q1: 2	Q1: 2	Q1: 3	Q1: 4
	Q2: -	Q2: -	Q2: -	Q2: -
Scientific societies/ professional associations <sup>e</sup>	Q1: 2	Q1: 2	Q1: 2	Q1: 5
	Q2: -	Q2: -	Q2: -	Q2: -

Abbreviations: Q1, Review question 1; Q2, Review question 2; UK, United Kingdom.

<sup>a</sup>Some documents delivered information for both Q1 and Q2.

<sup>b</sup>National guidelines, quality standards, policy and legislative documents about health and social services and their organisation.

<sup>c</sup>Regional policy and legislative documents about health service provision and organisation, guidelines for policy implementation and service mapping overviews.

<sup>d</sup>Service evaluations and proposals from organisations for people with PD and other long-term conditions.

<sup>e</sup>Documents on the development of care pathways, guidelines, professional approaches in healthcare and professional training.

### 2.3.2 | Step 2. Content analysis and report at the cross-national level

A cross-national (higher level) analysis was performed on the four national reports with the intention to bring forth commonalities and differences. Qualitative content analysis ad modum Schreier was used (Schreier, 2012). The Danish team led this analysis and used data-driven and concept-driven strategies (see below) to build valid coding frames that included the aspects necessary to answer each review question (Schreier, 2012). A trial coding (Schreier, 2012) was performed by the Danish and Norwegian teams and later reviewed by all teams. Face validity and feasibility of the coding frames were improved through structural changes and restrictions in the use of lower level ICF codes (WHO, 2001). Consistency and, therefore, reliability (Mayring, 2010) were improved by reaching consensus about the understanding of terms and applying this to the final coding, for instance, establishment of mutual understanding regarding how to separate policy (adopted and pursued the cause of action) and legally anchored services granted to individuals (e.g., free healthcare, physiotherapy or home help).

- The final coding frame for Question 1 exploring the organisation of services had three concept-driven main categories also used in the national reports: Key aims, Key elements, and Community resources used to manage PD. Data-driven codes and sub-codes are seen in Tables 4–6. They were created cooperatively after a thorough reading of all the material (Schreier, 2012).
- The final coding frame for Question 2, which unfolded specific legally anchored services aimed at individuals, had four concept-driven main categories related to health, social- and labour market aspects as predefined in the main OPTIM-PARK project plan. To provide a more detailed analysis, codes and sub-codes

**TABLE 4** Key aims of care pathways, clinical practice guidelines, other professional recommendations and national and regional strategies and policies

Health outcomes	<ul style="list-style-type: none"> <li>• Neuroprotection, good brain health throughout the life span. Prevention and health promotion (ALL)</li> <li>• High quality of diagnosing and medication (ALL)</li> <li>• Patient safety, reduction of complications (DK,N,SP)</li> <li>• Adequate palliative care (ALL)</li> </ul>
Psychosocial outcomes	<ul style="list-style-type: none"> <li>• Autonomy, empowerment, coping with disease (ALL)</li> <li>• Quality of life. Reduce the burden of disease (N,SP,UK)</li> <li>• Activity and participation: support living as normal a life as possible (DK,N,SP)</li> <li>• Carer support and empowerment (ALL)</li> </ul>
Organisation	<ul style="list-style-type: none"> <li>• Coherent, coordinated health services within and between all involved sectors and settings (ALL)</li> <li>• Coherent, coordinated healthcare and social services (ALL)</li> <li>• Timely access to services and resources (ALL)</li> </ul>
Health economy	<ul style="list-style-type: none"> <li>• Effective use of resources, reduce the need for health services, avoid unnecessary hospitalisation (DK,N,UK)</li> </ul>
Health equality	<ul style="list-style-type: none"> <li>• Reduced health inequalities including territorial /geographic inequalities (ALL)</li> </ul>

Note: References are found in Appendix S1.

Abbreviations: ALL, DK,N,SP,UK; DK, Denmark; N, Norway; SP, Spain; UK, United Kingdom.

were created, building on the International Classification of Functioning, Disability and Health (ICF) coding: e580 Health services, systems and policies; e575 General social support services, systems and policies; e570 Social security, services, systems and

**TABLE 5** Key elements of care pathways, clinical practice guidelines and other professional recommendations and national and regional strategies and policies

Person-centred, comprehensive approaches
<ul style="list-style-type: none"> <li>• Person-centred health and care services, individualised care (ALL)</li> <li>• Holistic approach, comprehensive care (ALL)</li> <li>• Comprehensive assessment (ALL)</li> <li>• Specialised treatment (ALL)</li> <li>• Rehabilitation/training (ALL)</li> <li>• Regular reviews. Follow-up on changes in needs. Structured GP reviews (DK,N,UK)</li> </ul>
Cross-sectoral and local approaches
<ul style="list-style-type: none"> <li>• High-quality services and pathways within and across sectors/ other boundaries (ALL)</li> <li>• Referral pathways in place for diagnosis, management, and palliative care (ALL)</li> <li>• Local approach. Community participation is integrated into health and welfare actions (DK,N,SP)</li> </ul>
Professional coordination
<ul style="list-style-type: none"> <li>• Multidisciplinary/interdisciplinary approach (ALL)</li> <li>• Partnership work between primary and secondary care and the third/voluntary sector (ALL)</li> <li>• Professional teams (ALL)—see details in <a href="#">Table 6</a></li> <li>• Specialised coordinators (ALL)—see details in <a href="#">Table 6</a></li> </ul>
Information and knowledge sharing
<ul style="list-style-type: none"> <li>• Information for PwPD at all stages including kinds of services available. Written information after an appointment. Feasible ways of communication between PwPD and professionals (ALL)</li> <li>• Caregiver support and training (ALL)</li> <li>• Training of professionals: Skills development; Knowledge sharing between professionals and sectors; Learning networks (ALL)</li> <li>• Method handbooks and other explicit guidelines on treatment and treatment coordination (DK,N,UK)</li> <li>• Individualised care plans (ALL)</li> <li>• New technologies: IT systems across sectors, shared electronic health records, comprehensive monitoring systems, telemedicine/tele-assistance, multichannel information platforms (ALL)</li> </ul>

Note: References are found in Appendix [S1](#).

Abbreviations: ALL, DK,N,SP,UK; DK, Denmark; N, Norway; SP, Spain; UK, United Kingdom.

policies, and e590 Labour and employment services, systems and policies (WHO, 2001) ([Table 7](#)).

The Danish team performed the final coding. The interpretations were discussed between the coders (Schreier, 2012); when doubts arose, the original references or the authors of the national reports were consulted. Tables and narrative summaries were constructed and included in a cross-national report; this was read and validated by all national teams.

### 3 | RESULTS

The cross-national analysis is built on the national typologies and reports (Denmark: 32 pages, Norway: 14 pages, Spain: 39 pages, and the UK: 45 pages). Below, country-specific summaries of

**TABLE 6** Community resources used to manage Parkinson's disease

Healthcare and social service professionals (by job title; different titles used in the four countries)
<ul style="list-style-type: none"> <li>• Audiologists; Dieticians; Doctors including Physicians, General practitioners/family doctors, Neurologists, PD specialists, and Geriatricians; Mental health professionals including Psychiatrists and Psychologists; Nurses including PD nurse specialists, Falls specialist nurses, Community nurses, and Specialised care nurse; Pharmacists and pharmacologists; Social workers/social services professionals; Therapists and Rehabilitation specialists including Community PD therapists, Movement disorders consultants, Occupational therapists, Physiotherapists, Specialised physiotherapists, and Speech therapists (ALL)</li> </ul>
Coordinators within healthcare and social services (different titles used in the four countries)
<ul style="list-style-type: none"> <li>• Care coordinators; Case manager nurse; Disability coordinators; Exercise coordinators; General practitioners; Key workers from the multidisciplinary team; Link workers; Parkinson coordinators; PD nurse specialist/case manager; Personal coordinators; Process coordinators for PwLTCs. (ALL)</li> </ul>
Organisational entities within healthcare and social services (different designations used in the four countries)
<ul style="list-style-type: none"> <li>• Specialised health services: Call centres; E-clinics; Falls clinics; Healthy life centrals; Memory service; Mental health services; Multidisciplinary cross-sectoral health professional services; Municipal health and care services; Neurology services; Palliative care units; Rehabilitation services; Specialised care; Specialist health services; Specialised hospital treatment (ALL)</li> <li>• Professional healthcare teams: Community mental health team; Community neurorehabilitation team; Interdisciplinary Parkinson treatment team; Palliative care team; Primary care team (ALL)</li> </ul>
Nonprofit organisations
<ul style="list-style-type: none"> <li>• PD associations (main organisations/local branches) and other patient associations; Local community and voluntary organisations (ALL)</li> </ul>
Professional networks
<ul style="list-style-type: none"> <li>• Networks of interdisciplinary expertise; ParkinsonNet Norway; UK Parkinson's Excellence Network (N,UK)</li> </ul>

Note: References are found in Appendix [S1](#).

Abbreviations: ALL, DK,N,SP,UK; DK, Denmark; N, Norway; SP, Spain; UK, United Kingdom.

policies and practices are presented, followed by results of the detailed cross-national content analyses pertaining to review questions 1 and 2 ([Tables 4–7](#)). For table references, see Appendices [S1](#) and [S2](#).

#### 3.1 | Country-specific summaries of policies and practices

In Denmark, The Local Government Reform stresses that treatment, rehabilitation and patient-directed prevention are a shared responsibility between regions and municipalities (Sundhedsministeriet, 2007). A generic model provides a framework for health programs for PwLTCs including early detection and diagnostics, treatment, rehabilitation, follow-up, and self-care

**TABLE 7** Legally anchored health services, social security services and labour market services relevant to people with Parkinson's disease

Health services, systems and policies (ICF code e580) addressing needs for healthcare, rehabilitation, and environmental adaptations
<ul style="list-style-type: none"> <li>• Universal and free healthcare (ALL)</li> <li>• Free choice and use of general practitioner (ALL)</li> <li>• Rehabilitation (including both rehabilitation and maintenance training by relevant professionals) (ALL)</li> <li>• Assistive devices, home modifications to improve activity and participation (ALL)</li> </ul>
General social support (ICF code e575) addressing needs for personal assistance, practical help and psychosocial support
<ul style="list-style-type: none"> <li>• Primary care (including Continuing healthcare; Day centres; Home care; Respite care, Nursing homes, Personal and practical [home-] help; Tele-assistance) (ALL)</li> <li>• User-controlled personal assistant including accompanying schemes (ALL)</li> <li>• Health promotion related to patients' and carers' well-being (UK)</li> <li>• General carer support (N,SP,UK)</li> </ul>
Social security service, financial (ICF code e570) addressing disease-related financial challenges
<ul style="list-style-type: none"> <li>• State pension (ALL)</li> <li>• Unemployment/Sickness benefits (ALL)</li> <li>• Financial support home and housing (mortgage, social housing, protected housing) (N,SP,UK)</li> <li>• Tax reduction and VAT relief (N,SP,UK)</li> <li>• Early retirement pensions (ALL)</li> <li>• Financial support related to daily living if the person has additional expenses related to impaired functioning (e.g., meals at home, personal hygiene remedies, transportation, practical tasks) (ALL)</li> <li>• Financial support related to leisure activities (cultural activities, tickets, travel) (N,SP)</li> </ul>
Labour and employment services (ICF code e590) addressing impaired the ability to work
<ul style="list-style-type: none"> <li>• Support to people who have special needs for help in obtaining and keeping employment (ALL)</li> <li>• Improvements in physical working conditions e.g. special aids and equipment (ALL)</li> <li>• Working flexible hours or part-time (DK,N,UK)</li> </ul>

Note: References are found in Appendix S2.

Abbreviations: ALL, DK,N,SP,UK; DK, Denmark; N, Norway; SP, Spain; UK, United Kingdom.

support (Sundhedsstyrelsen, 2008). No comprehensive care pathway exists for PwPD. A clinical practice guideline on PD describes the process of diagnosis, individually tailored treatment from an early stage, patient information, interdisciplinary contact, and involvement of caregivers (Karlsborg & Møller, 2017), another guideline, that builds on a European guideline, provides practical and evidence-based recommendations for specialised physiotherapy for PwPD (Danish Physiotherapists, 2006; Keus et al., 2014). Other professional recommendations aim to achieve coherent health systems and better help for PwPD and PwLTCs. Healthcare, social and labour market services are legally anchored at the national level; they aim at the general population or specifically at PwLTCs.

In Norway, The Coordination Reform and the right to an individual plan and a personal coordinator for PwLTCs aim to include and provide the follow-up needed through the different stages of illness and ensure cross-sectoral cooperation (LOVDATA, 2011; Norwegian Ministry of Health, 2009). In addition, a National Brain Health Strategy acknowledges that people with brain diseases have particular needs for comprehensive patient care and care pathways (Norwegian Ministry of Health, 2018). Whilst no comprehensive care pathway exists for PwPD at the national level, the government plans to develop care pathways for people with similar symptoms and functional difficulties (Norwegian Ministry of Health, 2018). A guideline from the Norwegian Centre for Movement Disorders (2010) concerns diagnosis, treatment, rehabilitation and general follow-up through the trajectory of living with PD. To ensure that PwPD receives better care in the municipality, ParkinsonNet aims to give PwPD the best possible follow-up through networks of interdisciplinary expertise (Norwegian Parkinson Association, n.d.). Healthcare, social and labour market services are legally anchored at the national level; they aim at the general population or specifically at PwLTCs.

In Spain, national and regional policies prescribe that service development for PwLTCs should take an intersectoral approach to achieve coordination between primary care, specialised care and social service. Continuity of care, integrated care processes and comprehensive care of PwLTCs are emphasised. Another key element is promoting self-care, co-responsibility and healthy lifestyles amongst PwLTCs. Community orientation should be promoted in the organisation of all services for PwLTCs and their family carers (Cassetti et al., 2018; Ministerio de Sanidad, Consumo y Bienestar social, 2019; Ministerio de Sanidad, Servicios Sociales e Igualdad, 2012). No comprehensive care pathway exists for PwPD at the national level. A White Book points out community resources to manage PD and emphasises communication and coordination between professions, sectors, patients, family-carers, and patient associations (Domingo, 2015). Several clinical practice guidelines and other professional recommendations exist. Some address organisational issues in relation to PwLTCs/PwPD and their families, others aim to promote comprehensive care, reduce health inequalities and promote autonomy. Healthcare, social and labour market services are legally anchored at national and regional levels; they aim at the general population or specifically at PwLTCs or PwPD.

In the UK, national policies and National Institute for Health and Care Excellence (NICE) guidelines emphasise multidisciplinary teams and partnerships between the primary, secondary and tertiary healthcare sectors, to provide holistic and personalised healthcare to PwLTCs/PwPD (National Health Service NHS, 2019; NICE, 2017). The need for a key worker role is stressed, to assist PwPD and their relatives in navigating care and understanding the available resources (Department of Health, 2012). The UK is the only participating country where PD care pathways exist that explicit the trajectory of PwPD from diagnosis to end-of-life care, including descriptions of key elements, referral to community resources, working relationships with other services, and the roles and activities of involved

professionals, patients and relatives (NHS, 2019; NICE, 2017). A pathway also exists to support carers of PD (James Parkinson Centre, 2006). Practice guidelines and other professional recommendations cover a broad spectrum of clinical and non-clinical management issues. Moreover, the voluntary sector constitutes a key element in supporting PwLTCs from diagnosis to end of life (Buck & Wenzel, 2021). Healthcare, social and labour market services are legally anchored at the national levels; they aim at the general population or specifically at PwLTCs (people with mental and physical impairments) or PwPD. Specific legally anchored services for PwPD mainly focus on treatment, management of symptoms and referral pathways.

### 3.1.1 | Review question 1

The cross-national analysis of question 1 concerning policy and guidelines on the organisation of healthcare and social services built on the national summaries of six care pathways (all from the UK, two specifically for PwPD), 17 clinical practice guidelines (from all countries, 10 specifically for PwPD), 20 other professional recommendations (from all countries, 13 specifically for PwPD and mainly issued by PD or neurological associations) and 45 national and regional strategies and policies (from all countries, one specifically for PwPD).

## 3.2 | Cross-national analysis: Key aims and key elements of care pathways, clinical practice guidelines, recommendations, strategies and policies

The key aims highlighted in the analysed documents address PwLTCs/PwPD and carer outcomes, organisational matters, health economy and health inequalities (Table 4). Many similarities were found across countries. The aims emphasise coordinated, timely and safe healthcare and social services of high quality throughout an individual's life with PD and other LTCs, as well as promotion of autonomy, quality of life, activity and participation. The key elements highlighted in the analysed documents (Table 5) refer to aspects that indicate how to achieve the key aims. A holistic, comprehensive and person-centred approach is recommended, as well as specialised services delivered in a multidisciplinary context. More investment towards healthcare in the community is recommended, as an alternative to hospital-based care. A key element not directly mentioned in the reports is evidence-based practice; this element is inherent in the included care pathways and clinical practice guidelines since they build on thorough literature searches and appraisals/audits.

### 3.3 | Cross-national analysis: Community resources used to manage PD

This theme captures the large variety of professions, specialists and other community resources involved in and recommended for the

management of PD/LTCs (Table 6). General practitioners are consistently ascribed a key coordinating role, the same applies to PD nurse specialists/case managers and other PD coordinators employed within the public healthcare system or by private organisations. Organisational entities offering specialised health services cover uni-sectoral services (hospital-based or community-based) and cross-sectoral services. Some entities focus on very specific problems, e.g. falls clinics, others are broader in scope. Non-profit organisations include community organisations, PD- and other patient organisations; their roles are mainly highlighted in Spanish and UK documents. The organisations voice the needs of PwPD and their carers, offer emotional support to promote autonomy, provide information, advice and peer support, deliver education and training programs and promote research participation. Professional PD networks, present in Norway (ParkinsonNet) and the UK (UK Parkinson's Excellence Network), provide information about PD, participate in healthcare development, advocate for PwPD and offer education to professionals, PwPD and family carers.

### 3.3.1 | Review question 2

The cross-national analysis of question 2 concerning legally anchored services is built on the national summaries of 51 legislative documents from all four countries.

## 3.4 | Cross-national analysis: Legally anchored services

This theme represents the legally anchored healthcare, social and labour market services relevant to PwPD (Table 7). Most services exist in some form in all four countries, although the criteria to be fulfilled in order to benefit from the services and the level of service inevitably vary between countries and in some cases between regions. Some services are available to the general population (universal and free healthcare, unemployment benefits and state pension), others are specifically targeting people in need due to impaired health and functioning.

## 4 | DISCUSSION

The present study analysed existing policy and guidelines regarding the organisation of healthcare and social services aimed at enhancing the process of living with PD, including their key aims, key elements and proposed community resources. Also, legally anchored healthcare, social and labour market services relevant to PwPD were described. This provided new knowledge that could constitute a common basis for a care pathway for PwPD and other PwLTCs.

The study identified some pathways and clinical guidelines that met the definition of a care pathway from the EPA (n.d.). Important similarities were found in the content of these documents, especially



their focus on diagnosis and medical treatment. Several other documents included professional recommendations of a broader scope, e.g., reports from PD organisations. No single document addressed all the recommended components of a care pathway (EPA, n.d.); therefore, we are proposing that an ideal care pathway should combine the content of existing pathways, clinical practice guidelines and other professional recommendations, as this has brought forward not only elements generally considered important to care pathways but also additional elements of special importance to PwPD.

Our findings point out the need to ensure high-quality services within and across agencies, and they highlight the importance of a community approach when feasible. PwPD and their family carers need health and social care from many different service providers to be easily accessible and well-coordinated, and travelling long distances for help may complicate their everyday lives. Consistent with this, a panel of PD experts from nine western countries, including Norway and the UK, concluded that an outpatient setting is the preferred setting to organise care for the majority of PwPD, with healthcare professionals skilled in treating PD (Radder et al., 2020). We, therefore, recommend the incorporation of high-quality local initiatives in future care pathways for PwPD. This could also be reflected as a strategy to implement a multiagency collaboration policy at local, regional and national levels (WHO, 2018).

Our overview of community resources for PwPD highlights the many different services, professionals, coordinating bodies, organisations and networks involved in PD management. Emerging evidence shows that multidisciplinary or interdisciplinary teams may improve PD management (e.g. Post et al., 2011; Qamar et al., 2017). Radder et al. (2020) developed a set of recommendations and considerations for optimal multidisciplinary care for PwPD. We found large overlaps with our own findings, yet our analysis led to some aims and elements not described in Radder's work, for instance, *reduced health inequalities, the involvement of patient associations, other local community and voluntary organisations and networks of interdisciplinary expertise*. These aims and elements reflect the specific focus of the OPTIM-PARK project on developing cross-sectoral pathways accessible to all PwPD including those from disadvantaged populations and areas; we deem them also to be of relevance regarding other LTCs. As the voluntary sector has a privileged position to voice the needs of PwPD and carers and, in some countries, is a key element in supporting people from diagnosis to end of life, their services should be emphasised in care pathways. Likewise, the voluntary sector should participate in the development and assessment of care pathways.

Through the documents included in our cross-national analysis, care coordinators were strongly recommended. These initiatives for PwPD have previously been explored and implemented (Connor et al., 2020; Lidstone et al., 2020), aiming for a more individualised assessment and identification of problems in care management. However, PwPD has rated having a personal coordinating healthcare professional as one of their top 4 unmet needs (Vlaanderen et al., 2019).

In the reviewed documents we did not find clear, practical descriptions regarding how to implement a care pathway and tools to

facilitate delivery, including how to achieve coordination amongst all the agents that provide care throughout the different phases of the disease. However, this gap has formerly been addressed, and pathway facilitator tools have been developed. An example is The 7-phase Method to Design, Implement and Evaluate Care Pathways by Vanhaecht et al. (2012). This method emphasises the importance of an implementation plan that describes a clear division of roles, centrally monitored feedback on the practical usability and communication problems when using the pathway, information sessions and communication plans. Moreover, evaluation and continuous follow-up should take place and include assessments of usability, compliance, outcome and process indicators. Monitoring processes should be set up and deviations from the plan are registered and analysed (Vanhaecht et al., 2012).

Regarding the second review question, legally anchored services were found, including healthcare and some social services of relevance to PwPD. The included care pathways and clinical guidelines all failed to present the possibilities of receiving general social support, social security support, and labour and employment support, including income support and financial support for other more specific needs in relation to everyday living with PD. According to webpages of PD associations, these services are highly relevant to PwPD (e.g., Parkinson's UK, n.d.) and should therefore also be included in future care pathways so that health professionals are aware of them and inform and help PwPD with referrals. As most of the identified legally anchored services were found to exist in all four countries, they could with reason be included in a common care pathway for PwPD.

Strengths and study limitations. As we found a gap in the literature on conducting qualitative document analysis, we developed a tailored, systematic approach specifically for the OPTIM-PARK project with tools for planning and executing comprehensive web-based searches and for managing the results. This was found to accommodate the complexity of the review tasks. The similar structure and rigorous data extraction at the national level ensured that our analyses were built on relevant, sound, consistent and updated information, reflecting the different welfare systems of the four countries. The close cooperation across countries, including a final process of validation and update of the national information, helped prevent inclusion bias. The combination with Schreier's qualitative content analysis (Schreier, 2012) for the cross-national analysis, including trial coding, peer review and other processes involving all authors, strengthened face validity, content validity and reliability of the coding frames and the analyses. Involvement of PPI groups in discussions ensured relevance and helped substantiate the implications of our results (Mathie et al., 2014). Data was, to a high degree, collected at official national and regional websites, and this excluded exhaustive internet searches; as an implication, we cannot guarantee that this method led to all relevant material being identified, including cross-national documents (Stansfield et al., 2016). However, the experienced researchers used multiple search strategies by combining the use of search engines with websites of pre-known official bodies; this improved

their chances of finding the relevant material. The international team included researchers from a number of health professional backgrounds; our different specialties and experiences with the phenomenon under study clearly helped broaden the searches and analyses thus highlighting more facets relevant to PD management. Involving a social worker in future work might help broaden the literature search and analysis even more due to the specialised knowledge of this discipline.

In conclusion, the findings illustrate the complexity of PD management through an overview of important aims, elements, community resources and services recommended for and used in practice amongst PwPD. It is important that roles and responsibilities within a care pathway are clear, in all sectors involved and across all levels of care. The clarity in how to deliver a care pathway, tools to facilitate its delivery and descriptions of how to implement and evaluate its efficacy are paramount and missing in care pathways for PwLTCs/PD and relevant policy. Likewise, highly relevant types of social support are most often not described in care pathways or clinical guidelines. This underlines the need for the development of comprehensive guidelines for PwPD and other LTCs. The findings have broad relevance in countries, within and outside Europe, that aim to organise and allocate welfare resources to people with PD and other LTCs. Attention should be drawn to variations in the organisation, levels of service and service provision within and across countries and to the possible need for local adaptations. Whilst countries with relatively less health and social care resources cannot be expected to follow all the given recommendations, the recommendations may help prioritise and substantiate the efforts.

#### AUTHOR CONTRIBUTIONS

TLN, NBK, AH, LKB, EGH, MVNS and MCP contributed to the conception and organisation of the study. TLN, NBK, EGH, LKB, MVNS, APS, APM and SBP contributed to the execution of the document search. All authors contributed to the analysis of national documents and to writing the national reports. TLN, NBK, AH, LKB and EGH contributed to the design of the cross-national analysis. TLN and NBK performed the cross-national analysis and all authors contributed to reviewing it. TLN wrote the first draft of the article assisted by NBK, AH and MCP. All authors contributed with review and critique and read and approved the final manuscript.

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#### CONFLICT OF INTEREST

No conflict of interest has been declared by the authors.

#### DATA AVAILABILITY STATEMENT

The national reports that support the findings of this study are available from the corresponding author upon reasonable request.

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#### SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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