




SUPER

**Supporting professionals working with and people
living with Parkinson's disease through an
integrated care approach: a digital training
program**



Project result 1 - An ecosystem mapping and training
methodological framework: Integrated Care for Parkinson
disease

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1. Introduction

Parkinson's Disease (PD), is a progressive neurodegenerative condition that impacts the lives of those living with the condition and their loved ones in various areas of daily life, affecting about 2 to 3 percent of the population aged 65 or older [1].

The main symptoms are related to motor disorders, particularly tremor, rigidity, bradykinesia (slowing of voluntary movements) or akinesia (reduction or loss of ability to perform automatic movements) and postural instability. The full clinical picture also includes other motor symptoms and non-motor symptoms. Non-motor symptoms, in PD, involve many functions leading to various disorders [2], including:

- Sleep-wake cycle regulation disorder
- Cognitive impairment: executive function dysfunction, memory deficits, dementia and hallucinations
- Mood and affect disorders: depression and anxiety, for example, are present
- Dysautonomia: dysfunction related to autonomic nervous system malfunction, such as orthostatic hypotension, hypotension, constipation, and hyperhidrosis
- Sensory symptoms: most present is hyposmia (decreased sense of smell)
- Pain

The symptomatology is related to neurocognitive degeneration, due to the loss of dopaminergic neurons in the substantia nigra (particularly in the pars compacta, dorsolateral portion of the substantia nigra with a high density of dopaminergic neurons) [3]. For this reason, most interventions designed for PD are targeted in the management of dopamine deficits. The main interventions are:

- Pharmacological treatments: mainly dopaminergic drugs; although they are helpful in improving motor function, over time they can lose their effectiveness and cause greater side effects than actual benefits.
- Deep Brain Stimulation (DBS): this type of therapy uses an implantable medical device, similar to a pacemaker, to send electrical stimulation to specific areas of the brain. Stimulation of these areas allows better functioning of the brain circuits responsible for movement control.

Some research stress the importance of having to complement these types of therapy with treatments based on motor exercise [4]. This is because treatments aimed at curbing neuronal degeneration lose effectiveness as they are maintained over time.

For this reason, care is also being imprinted on the management of motor deficits and in the creation of exercise-based coping strategies: indeed, it has been seen how neuroplasticity and potential neuroprotective effects from exercise can be harnessed to improve patients' quality of life [5].

The complex, unpredictable and fluctuating nature of the condition means that people living with PD must adapt and adjust every aspect of their lives continuously. Currently, models of care have many drawbacks, such as a lack of multidisciplinary collaboration, a lack of access to care delivery at home or in the community, and a failure to take the social needs of patients and families into account [6].

To address these gaps, the SUPER project focused on improving the competences, skills and knowledge of multidisciplinary care team member and co-designing a sustainable, tailored and integrated care digital training program to address the patient's needs.

To ensure an integrated care approach there must be “a coherent set of methods and models on the funding, administrative, organizational, service delivery and clinical levels designed to create connectivity, alignment, and collaboration within and between the cure and care sectors” [7].

As highlighted in the World Health Organization's global strategy on people-centred and integrated health services, integrated care considers various aspects of care delivery “in a way that ensures people receive a continuum of health promotion, disease prevention, diagnosis, treatment, disease management, rehabilitation, and palliative care services, at different levels and sites of care within the health system, and according to their needs throughout the life course” [8].

At this early stage of the project, the partners considered a co-design approach and made the focus of the design process not only the experiences of patients, but also the approach to the work of health and social workers in their specific field.

The aim of this project result is to provide a deeper understanding of the exact training needs, gaps and requirements of health and social care professionals have regarding the Integrated Care (IC) on PD and also, to create the basis of the training curriculum that will be developed in the second project result.

Our approach consisted of three linked steps that were coordinated among four partner countries: (1) A literature review about available training opportunities and programs for professionals in each partner country; (2) Capture patients and caregivers' experiences by using a focus group approach and understand the patients' trajectory to better conduct the focus group with professionals and help them to reach an integrated care approach; (4) Co-produce solutions by identifying key requirements for designing an integrated care digital training initial draft.

The aim of our co-design approach was not only to collect contextual information or describe patient experiences, but also to 'make sense together' and co-produce knowledge for the digital learning training for the health and social care professionals.

From the perspective of patients, our focus is on better information on self-management, sufficient interdisciplinary collaboration between different health care professionals, ample time to discuss possible future scenarios, and an individual health care professional guiding and supporting them. To address these needs, multiple different integrated care models have been established worldwide, but all aiming to offer PD patients structured and tailor-made comprehensive care programs. So far, there is limited consistency across these programs in terms of settings, team composition, or level of clinical integration.

2. Integrated Care for Parkinson Disease and available training opportunities for health and social professionals in each country

It is now clear how both motor and non-motor symptoms contribute to the disease, from premotor symptoms to the more advanced stages of the disorder. The complexity of this disease requires a multicomprehensive treatment approach individualized to the needs of the individual patient. Therefore, pathways of physiotherapy, occupational therapy (aimed at the development, improvement or maintenance of daily living and cognitive skills for people with physical disabilities) and psychotherapy should be considered along with medical treatment (drug therapy and DBS) to consider and improve the quality of life of patients and caregivers [9]. From the patient's perspective, the needs that are most reported are related to more information about self-management, more collaboration (interdisciplinary) among different caregivers, times to discuss the evolution of the disease, and a professional who can support and guide them through the disease [10]. To meet these often-disparate needs, many models have been created, varying profoundly in degree and intensity, but all aimed at offering comprehensive and tailored care programs to patients with Parkinson's. Inevitable within these models, however, are issues related to setting, team composition or levels of integration with the clinic. For this reason, there is no common method of care but very heterogeneous models [11].

There tend to be 3 models related to care and disease management (Fig. 1)

- Monodisciplinary (or consultative): is the classic, evidence-based method of care in which the patient refers to multiple but independent figures making communication between them limited.
- Multidisciplinary: involves several professionals working independently not collaborating and in parallel each is responsible for the patient's different needs.
- Interdisciplinary: uses a patient-centred perspective where assessments (on medium- and long-term goals) are conducted and carried out by a team of professionals working together with the patient.
- Transdisciplinary: Care services based in this model are more family oriented, coordinated and integrated to face complex needs. This model looks for sharing roles for maximizing communication, interaction and cooperation between member of different teams.

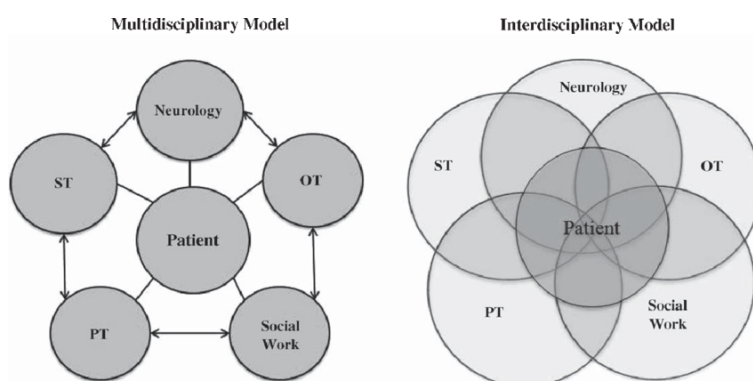


Fig 1. Multidisciplinary vs Interdisciplinary models of care

Some multidisciplinary models are useful in fostering communication among the professionals involved in care, but the interdisciplinary model promotes open and continuous communication between the patient and all professionals involved [12].

Very little research exists in reference to integrated care models, but those that have been done [13; 14] have shown how multidisciplinary models improved motor and non-motor symptoms and, consequently, the patient's quality of life; in the same research, another key finding also emerged: it was noted that, compared with those in control groups, caregivers involved in multidisciplinary care not only did not worsen but, in some cases, even improved their scores related to mood and experienced stress.

The 2018 work by Schrag et al. [15] investigated how the experience of care was perceived in Parkinson's patients in 11 European states (Denmark, France, Germany, Hungary, Ireland, Italy, the Netherlands, Slovenia, Spain, Sweden, and the United Kingdom).

This research found that satisfaction related to the care received was greater the more involved the patient and their caregivers were in decisions related to treatment and the way communication about their condition was approached. Despite these findings, it was noted that only 63 percent of patients were involved in decision-making processes as the importance of involvement (and, therefore, the fundamental difference between evidence-based and value-based care) was only recently understood.

Nearly half of the study participants emphasized the impact of a lack of resources to provide regular check-up particularly in the more advanced stages of the disease, a lack of access to therapists to address individual needs to prevent deterioration, and the absence of a personalized and responsive service to address complications when they arise.

Lower scores are present when investigating how professionals work together; this is relevant because it demonstrates a serious deficiency with regard to the emphasis on the concept of integrated care. A lack in this aspect leads to less patient-centeredness and, therefore, a lack of emphasis on the needs of patients and caregivers.

From this analysis, it is clear that there is still no clearly defined plan or model for how to best address -- on a value-based basis -- Parkinson's disease. But first and fundamental changes in the approach to care but, more importantly, to the patient are beginning to take place in Europe, especially in those states that have always conceived of care as resolution or stabilization of a disorder rather than care as improvement of the patient's quality of life.

2.1. Results from each country

This chapter describes the activities carried out by each partner in the framework of the project result 1 "An Ecosystem Mapping and training methodological framework Integrated Care for PD". Part of this outcome PR1/A1 is the analysis of an advanced literature review of the training opportunities on IC for PD for professionals in each country (M1-M3).

For conducting the review, ISRAA prepared a document for the methodological analysis with the following elements to be considered (Fig. 2 and Fig. 3):

Country	Title of training or program	Area/s covered	Training provider	Public/private	Open access/ under payment	Type of care	Target group	Training modality
Training content (agenda, topics, units, modules)			Duration of training	Training material used	Useful links	Comments/additional information		

Fig. 2 Training research requirements

Country	Project title	Type of project	Area covered	Target group	Short description of the project/summary
Results/Training material		Useful links	Comments/additional information		

Fig. 3 Projects research requirements

All these elements were collected both for trainings and projects analysis and all the partners started with the research. In Annex I, all results from each country can be consulted.

2.2. Discussion of the results

Mainly ISRAA, APM and IFIC found something interesting. ISRAA found a lot of information regarding trainings for professionals working with patients suffering from Parkinson's disease, both private and public. Most of these educational trainings, especially in Italy, were aimed at professionals such as physiotherapists, practitioners, occupational therapists, geriatrics or nurses, and are composed by modules dedicated to the treatment of Parkinson's disease in all its manifestations. Considerable importance is given to the ability of the professional to empathize with the patient and how the importance of properly treating motor function leads the patient to a recovery of autonomy. Trainings are divided into modules and are delivered in-person or online depending on the organizing institution, which may be centres specialized in treatment of patients with Parkinson's or Universities with a less practical and more theoretical approach. For example, the Parkinson's Wellness Recovery (PWR) is delivered by the European Parkinson Training Centre, the Fresco Parkinson Institute and also some Italian associations as the Italian Physiotherapy Association. The PWR is a training that can be used by professionals which can be practiced in multiple positions, made progressively more physically and cognitively challenging, and be used differently to target each person's unique symptoms individually. Trainings for family members and caregivers were also identified in the research. In Italy the courses are principally promoted by the Fresco Parkinson Institute located in Tuscany region. Attention is given on how to recognize motor and non-motor symptoms, how to recognize and manage behavioural and psychiatric disorders, the importance of a proper lifestyle (nutrition and physical activity) and what motor activities are indicated at home.

The first that APM took was to find organisations, websites and sources in general where they could find courses/training on Parkinson Disease and also on Integrated Care. After that we researched in each of them those courses or activities on the subject and filtered those that fit the criteria of our project. APM prepared the contents and incorporated it into the excel tables provided by ISRAA.

APM had some localised articles and studies on integrated care and have incorporated into the table three projects in which APM is involved. As for the trainings identified in Spain, they are structured mainly only for specific profile of professionals, as clinic assistant, geriatric staff, nurse, socio-health care professionals and neurologists. They are focused on symptomatology not treatment/interventions and most of them fee-based. Course modules last hours, weeks or are annual and are delivered both in-person and remotely. Much emphasis is placed on the

clinical aspects of the disease, functional, social and cognitive transformations and what tools are needed to best cope with the various stages of the disease. The courses introduce what it can be like to live with the disease and mentions rehabilitative therapy but without any integrated care concept or holistic perspective of the patient.

Instead, IFIC has provided many trainings that focus on integrated care, but geographically are delivered mainly in the UK, specifically IFIC itself provides a certificate in Integrated Care using IFIC's 9 Pillars of Integrated Care as a module-based course of online learning. The accessible, high-quality programme is offered through a digital, innovative and dynamic online learning platform. This comprehensive introductory level self-managed Certificate in Integrated Care is accredited by CPD Standards UK and delivered online. This course is an introduction to the subject and is therefore accessible to all those with an interest in integrated care principles, but will be particularly relevant to those working within healthcare, social care, community and other public service design or delivery from public and private sector. This kind of inputs can help the SUPER partners to develop an e-learning platform based on Integrated Care principles to help professionals in Parkinson Disease to better respond Parkinson's Patient's needs. The Integrated Care Systems (ICSs) Learning network is also another interesting model that introduces care coordination strategies; establishing new ways of working in and with general practice; implementing governance mechanisms; overcoming workforce issues; establishing strategies for population health. The network offers opportunities to join peers facing similar issues and to learn from successful examples both from England and internationally. We are so much interested in internationally opportunities to spread the Integrated Care approach among Parkinson's professionals. This will be a relevant element of innovation for the e-learning platform that will be developed by the French partner of SUPER consortium (Interactive 4D). In France, instead the France Parkinson association is a training organisation, it has a training activity number and meets the quality criteria of the training organisations that can be taken into account in the framework of the continuous professional training plans. France Parkinson has also put online a distance learning platform 'Forma Parkinson' for patients and their families, but also for professionals. There is one module that is divided into lectures of 15 to 45 minutes that deal mainly with the characteristics of the disease; symptoms: the potential warning signs, those that enable the diagnosis to be established, and all those that can occur from the very beginning, but also as the disease progresses; treatments: the different types of treatment that exist for optimal management of symptoms and to combat Parkinson's disease, the course of the disease and research. The contents have been validated by healthcare professionals specialised in Parkinson's disease, but the division of contents also remains very fragmented and poorly integrated into the different fields of action.

Concerning projects across Europe there are lots of examples about how to develop models based on Integrated Care. Partners in iCare-PD, an EU Joint Programme - Neurodegenerative Disease Research, has started to develop innovative sustainable care models shifting from "(in)outpatient care" to "home-based and integrated health care" that focus on Integrated Care, Self-management support and Technology-enabled Care using a patient-centred approach. This set of interventions can play a critical role in a solution to the challenges of complex care in PD, enhancing patient dignity and care equity. ICT4Life, a Horizon 2020, aims to provide new services for integrated care employing user-friendly ICT tools, ultimately increasing patients with Parkinson's, Alzheimer's and other dementias and their caregivers' quality of life and autonomy at home. TeNDER is a Horizon 2020 project that will develop an integrated care model to manage multi-morbidity in patients with Alzheimer's disease (and other forms of dementia), Parkinson's disease, and cardiovascular disease.

Another Horizon 2020 is PROCare4Life that aim to facilitate and improve care management for older adults living with neurodegenerative and other chronic conditions by creating an interactive, personalised model, developed to meet users' needs, to adopt healthy habits, maintain a daily routine and follow advice from care teams and enabling communication across sectors and disciplines to improve time and cost-efficiency, and communication with and across users to strengthen support.

Not much has been found on e-learning training platform for Professionals in Parkinson Disease also considering the following elements (Fig. 6):

E-learning trainings criteria							
Name of the taining	Methodology	Programme	Learning material	Duration	Learning outcomes	Add others criteria from the analysis	Target

Fig. 6 *e-learning trainings*

2.3. Conclusions/Summary

On the basis of this initial advanced literature review, the SUPER project partners will develop a first draft of the training curriculum for social and health care professionals in Parkinson Disease and of the e-learning platform. After the PR1/A1 results, ISRAA and all the partners prepared the co-design session methodology to be carried out together with Parkinson Disease Patients and social and health care professionals to better respond to patient's needs and to support an integrated approach in care.

3. Health and social professionals' needs and shortages about Integrated Care for Parkinson

3.1. Methodology (guidelines) for the co-design sessions

After the literature review, the SUPER Project consortium started with the PR1/A2 activity by designing the co-design guidelines based on the PR1/A1 results in support to the focus group activities to be carried out with PD patients, caregivers and health and social care professionals. ISRAA prepared the document considering the PR1/A1 literature review.

These are the co-design guidelines that partners from Spain, UK and Ireland follow in order to complete the PR1/A3 activity of the project.

Co-design pilots: ISRAA – PR1 coordinator (Italy), APM together with UVEG (Spain), and IFIC (Netherlands).

OBJECTIVE OF THE R1/A2-A3 CO-DESIGN ACTIVITIES: The co-design sessions with professionals and PPD/relatives/caregivers in all partner's countries is addressed to promote the direct involvement of the target population in the creation process the SUPER project curriculum and to a better understanding of PD professionals' needs. This is planned to be done not only with social and health professionals but also with some relevant stakeholders such as PD patients and their relatives to encourage their empowerment and their sense of responsibility at the centre of the IC practice.

TARGET GROUP (I focus group/Interviews session): PD patients and relatives/caregivers.

TARGET GROUP (II Focus group/Interviews session): Social and Health professionals (e.g., general practitioner, neurologists, geriatricians, psychiatrists, nurses, speech therapists, psychologists, physiotherapists, social workers).

MATERIAL: A paper or a computer to collect feedbacks from participants + Sociodemographic template (Annex II) + Informed consent template (Annex III).

I Focus Group sessions/Interviews

METHOD: Focus group with PD patients and relatives/caregivers online or face-to-face

- 2 or 3 focus group with 5 participants
- 10 ISRAA and 15 (IFIC, APM + UVEG)
- Duration: 1.15 hours per Focus Group

Each participant has to complete the socio-demographic template and the informed consent attached to the guidelines.

Partner's staff members: 2, one main trainer and one supporter

OBJECTIVES: The main objective of the I Focus Group session is to better understand PD patients' needs and difficulties and their caregivers' way to support them with the disease. The final result of three sessions is the development of 3 different "Personas" with their attributes, attitudes, behaviours and characteristics and PD stage that will be used in the II Focus Group session with professionals who will be the main user of the SUPER e-learning platform.

STEP ONE - Focus Group Questions:

On set stage (PD patients and relatives/caregivers)

1. When you were diagnosed with the disease what aspect did you find most difficult to cope with??
2. What kind of help you would have liked to receive?
3. What do you think you missed in the assistance from professionals during the initial phase of the disease?

Progression of the disease (PD patients)

1. How long have you been living with Parkinson's? What is your actual stage of the disease?
2. Do you have/need a caregiver? If yes who is yours?
3. Which activities you find most difficult in your everyday life?
4. What are your daily exercises?
5. Where did you find the information about how to overcome PD?

Progression of the disease (Relatives/Caregivers)

1. What kind of support you think you need the most as a caregiver?
2. Would you say that you are stressed? If yes Why?
3. What you would like to know more about the disease?

STEP TWO - Personas

Develop your own three personas

What is a Persona? - A persona is a fictional archetype of the actual target (or indirect target) of the project. For the SUPER project we want to develop various type or Personas as PD patients with different characteristics and needs to better respond to them with a good e-learning training toolkit that will be used by the social and health professionals through an integrated care approach. The Personas represent the lived experiences and specific characteristics of PD patients interviewed from previous Focus Groups and are intended to promote empathy among program designers and create a clinical case for professionals to analyse during the II Focus Group sessions.

To develop the avatar the SUPER Project partners used the free website named "Make My Persona" (https://www.hubspot.com/make-my-persona?utm_source=toolbaseio), following the instructions given in the website. Firstly, you decide these elements:

- Name:
- Age:
- Educational level:

Secondly, you can skip other cells by leaving them blank, deleting them at the end of the creation process, and, after completing the first sections, you can delete the pre-set boxes and add new ones by titling them like those written below and then add the specific text.

- Personal Story:
- Health concerns:
- Daily living:
- Needs:
- Treatments, therapy:
- Assistance received:
- What is important:

Finally fill in the blanks with your organization info's then Download your Persona (Annex IV).

II Focus Group sessions/Interviews

METHOD: Focus group with Social and Health Professionals (e.g., general practitioners, neurologists, geriatricians, psychiatrists, nurses, speech therapists, psychologists, physiotherapists, social workers).

- 3 focus group with 5 participants
- Total: 15 participants for each partner country
- Duration: 1.15 hours per Focus Group

Each participant has to complete the socio-demographic template and the informed consent attached to the guidelines.

STEP ONE - Focus Group Questions:

1. Do you know what does it mean an Integrated Care approach?
2. How do you try to adopt a person-centred approach in your professionals' activities?

3. What do you think about settings, team composition, and levels of clinical integration in your daily activities with you patients? Would you like to change something to improve the health-related quality of life of your patients?
4. Try to identify key components or resources of a tailored integrated care for people living with PD taking into account the local realities
5. Which kind of tools you think you need to better manage with other colleagues and PD patients?
6. Have you ever benefited from a professional training? If so, how was it structured?
7. What kind of training do you think would be useful to improve your work with PD patients?
8. Do you think that a training Platform could help you to better respond to PD patient's needs? If yes, how do you imagine it?

STEP TWO – Personas – What this Patient need?

Use your 3 Personas to start a conversation with professionals about how to better treat the patients considering all the care aspect and all the care pathways needed that are emerged during the Focus Group sessions with PD patients and relative/caregivers and for knowledge to be improved and how to do it (Annex IV).

3.2. Focus groups with patients and caregivers in each country

As mentioned in the previous paragraph the Focus Group of the PR1/A3 activity included three target groups: PD patients and their caregivers and adults from different professional profiles dealing with patients with Parkinson disease, such as physiotherapists, educators, social workers, nurses, psychologists, speech therapists, gerontologists and general practitioners.

In Italy, ISRAA reached 5 PD patients, 5 caregivers and 15 professionals.

In Spain APM and UVEG reached 8 PD patients, 9 caregivers and 16 professionals.

IFIC reached 1 professional from Italy, 3 professionals from Ireland and 1 professional from the United Kingdom.

A total number of 13 PD patients, 14 caregivers and 36 professionals (Fig. 7, Fig. 8 and Fig. 9) participated in the focus group sessions or interviews from the different partner countries in order to receive the necessary information to develop the first draft of the SUPER training curriculum and e-learning platform.

3.3. Results of the co-design sessions

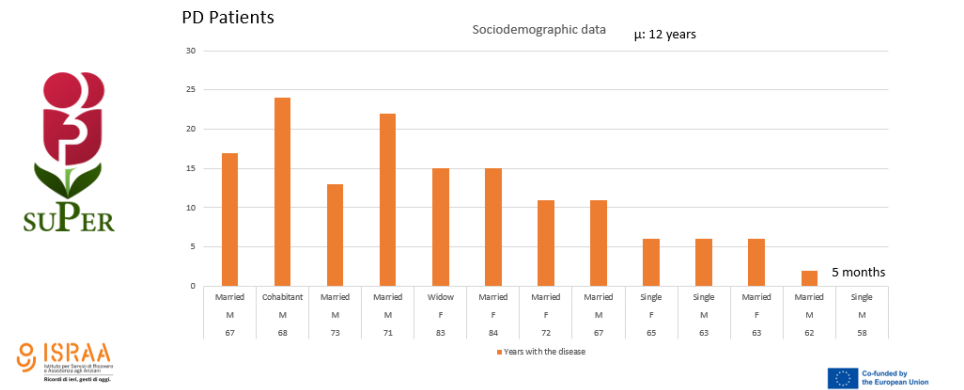
ISRAA compiled all the results from the co-design sessions carried out by partners and presented them during the 2nd Transnational Project Meeting (15th & 16th December, Treviso) in order to discuss with partners.

In the following pages, a set of slides used during the meeting for the mentioned purpose are presented.

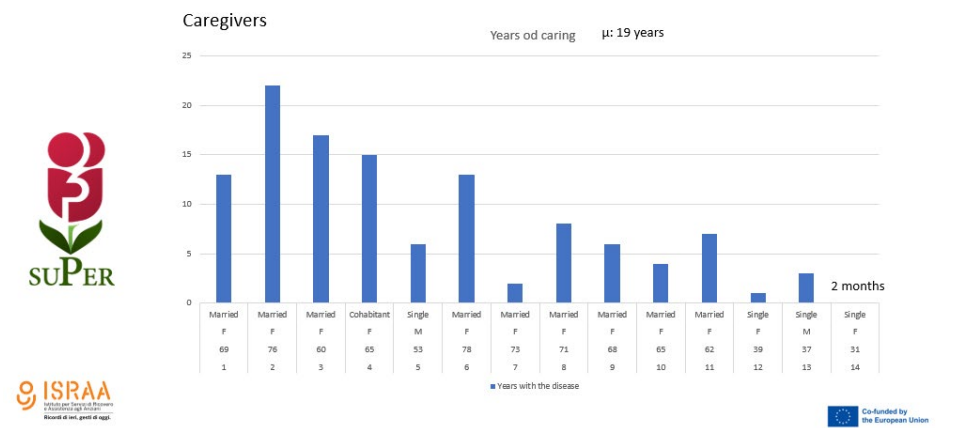
Results from PD patients and Caregivers

PR1 – An Ecosystem Mapping and training methodological framework
Integrated Care for PD

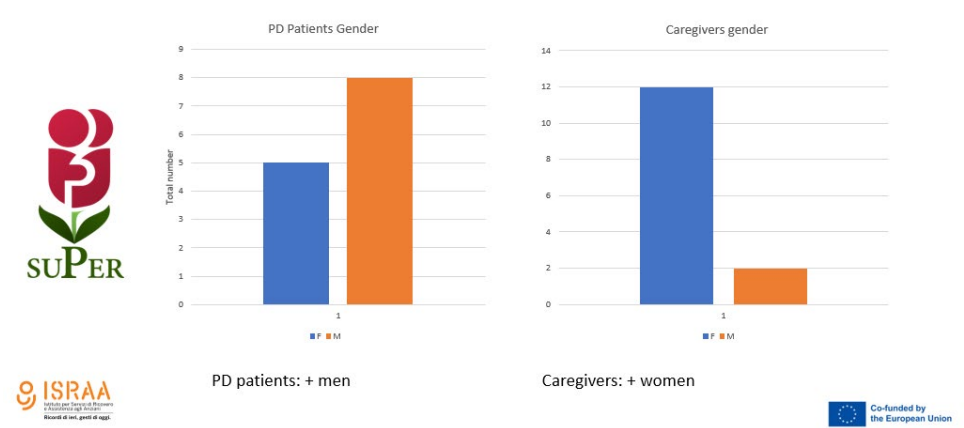
Results from the co-design activities



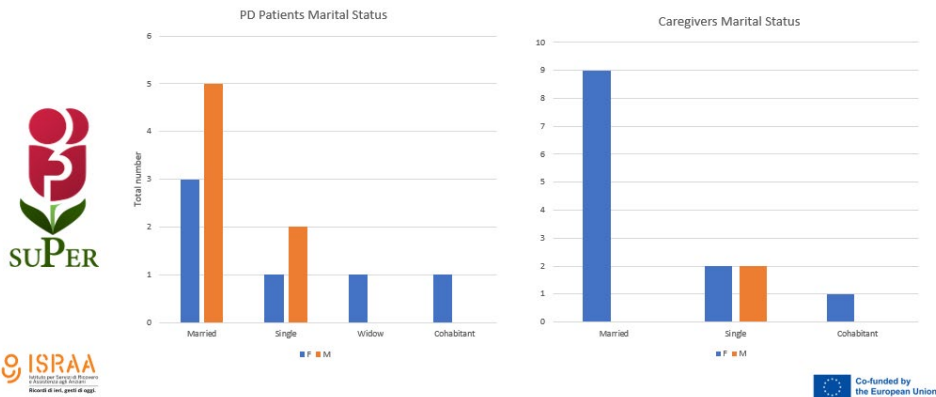
PR1 – An Ecosystem Mapping and training methodological framework
Integrated Care for PD



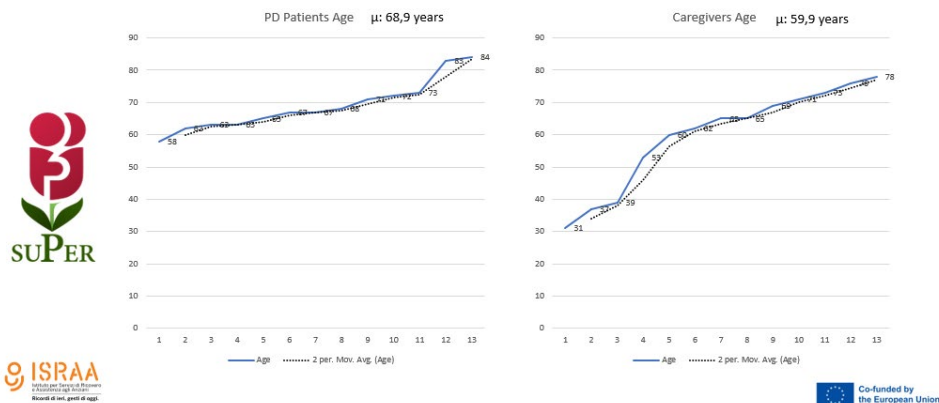
PR1 – An Ecosystem Mapping and training methodological framework
Integrated Care for PD



PR1 – An Ecosystem Mapping and training methodological framework Integrated Care for PD



PR1 – An Ecosystem Mapping and training methodological framework Integrated Care for PD



PR1 – An Ecosystem Mapping and training methodological framework Integrated Care for PD

ONSET STAGE 1. Aspect most difficult to cope with; 3. Help would you like to receive; 4. Rating of the assistance received from professionals.

PD Patients

- The uncertainty of not knowing what is going to happen.
- Lack of empathy from professionals in the diagnosis communication.
- The transition period to admitting that something is wrong with your health.
- Coping with health worsening.
- Assuming that abilities are going to get worse and get dependent.

Caregivers

- Not knowing how to handle the patient's reaction.
- Poor dialogue and poor listening by professionals.
- Poor support in being informed about the about the disease and how it will/may evolve.
- The disease that is not considered by professionals in all its social aspects, but only clinical and symptomatic aspects.
- The thought of having to care for a dependent person.
- Psychological support for the carer.
- Missed having a place to call to resolve situations, support for the carer.

PR1 – An Ecosystem Mapping and training methodological framework Integrated Care for PD

PROGRESSION OF THE DISEASE 1. Years of the disease Actual stage; 2. Help of a caregiver (who); 3. Most Difficult everyday activities; 4. Sources of information to overcome PD disease;



PD Patients

- Between 6 months and 24 years.
- Symptoms that were not there suddenly appears.
- More falls.
- Medication has less effect.
- Trouble sleeping.
- Changes in nutrition.
- Help from Associations and wives.
- Thinking of professional support in the short to medium term.
- Less motivation.
- More difficult to go out from the comfort zone. Feeling insecure.
- Less concentration (i.e., drive) and more forgetfulness.
- Fatigue.
- Mobility (i.e., play with grandchildren, cutting up food, carry out physiotherapy exercises, dressing, reading, writing, getting up and sitting on a sofa/bed, cleaning themselves, going shopping)
- Help from family members (internet), neighbours and people with the disease.
- Help from neurologists and nurses. People in the Healthcare system and associations



PR1 – An Ecosystem Mapping and training methodological framework Integrated Care for PD

PROGRESSION OF THE DISEASE 1. The most needed support; 2. Level of stress and reason; 3. Desire/need to know more about the disease



Caregivers

- Hard to be 24 hours caring (i.e., having to remind the person you love of the things they have to do, having to do things for them).
- Accepting that in certain cases the roles in the couple have changed.
- A team of same professionals that generate trust.
- Specific spaces for carers where have a coffee and talk.
- High level of stress because of lack of time and few resources.
- Advice on nutrition for drug absorption.
- Not having other people/resources to rely on for care, not being able to switch off, not being valued in what they do for the patient.
- Evolution of the disease to be better prepared. Every day is different.
- How to manage complex situations as the disease progresses (i.e., stiffness, anger, obsessions, sleeping problems, blocking, choking).
- Difference between Parkinson and other Parkinsonism.
- Medication.
- Advances in treatments and research.



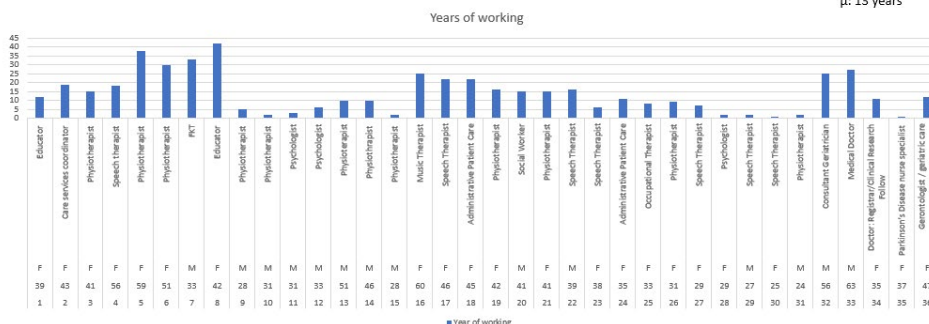
PR1 – An Ecosystem Mapping and training methodological framework Integrated Care for PD

Results from the co-design activities

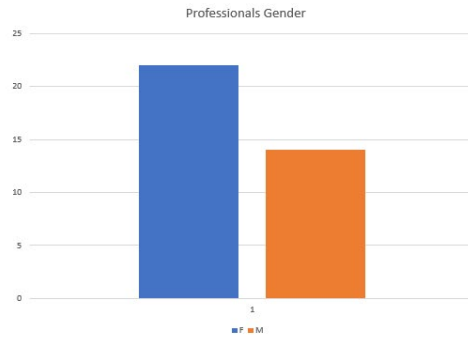


Professionals

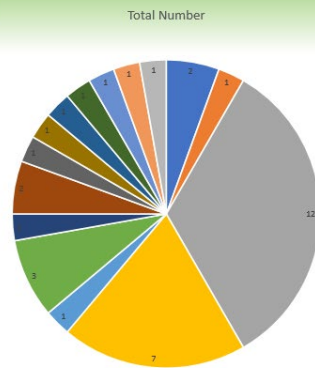
μ: 13 years



PR1 – An Ecosystem Mapping and training methodological framework Integrated Care for PD



PR1 – An Ecosystem Mapping and training methodological framework Integrated Care for PD



PR1 – An Ecosystem Mapping and training methodological framework Integrated Care for PD

Level of knowledge about integrated care approach.

The professionals from **Italy** asked to have more info about the Integrated Care approach strategies and later they said they already use them in their daily work activities but would like to have more trainings on that.

All the professional from **Spain** said they were aware of what is meant by the use of an Integrated Care approach and defined it in the second question when asked about the integrated care strategies they use.

Professionals interviewed by **IFIC** answered:

- Having a team talking to each other, communicating
- Ways of communication among different professionals
- ICT tools for better communication among professionals
- Multidisciplinary team.
- Avoiding duplication
- Understanding of team members doing to the members
- Weekly meeting
- Established care pathway, person centredness, coordination.
- Collaborative work considering patients and their contexts, and caregivers.



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Person-centred strategies they adopt

- No decision of me, without me.
- What is the priority? when I have so many different needs from patients, how can I priorities?
- Giving patients the tools for self-management
- Resourcing patients with resources that they need in their journey
- Patient initiative follow-up – lowering patient resources
- Balance waiting lists – meetings
- Someone who informs them (benefits, insurance...)
- Addressing newly diagnosed cases with training (different topics)
- Face to face meetings
- Patients involved in research too
- Shared goals
- Catching up with preferences and needs of patients.
- Working with the expectations in the treatments
- Asking goals & doubts and listening
- Asking for preferences and priorities for patients by writing.
- Adapting and individualising the intervention according to the needs of the person.
- Looking for their interests, expectations, trying to analyse their close environment.
- Involving the person concerned in all interventions (e.g., decision-making; design and adoption of resources...)



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Person-centred strategies they adopt

- Working in an interdisciplinary way
- Taking into account the needs of people in the patient's context. Involving the family and other professionals in the process, depending on what the person affected decides.
- Paying attention to what is most important to the patient, and how he or she is feeling.
- Taking into account the life history of each person, so that the intervention goes according to the person's life plan.
- Adopting a good communication.
- Trying to accompany in the empowerment of those areas that the person wants to change/improve.
- Avoiding having a paternalistic or "I know what you need" posture. In the same way, with caregivers trying to give them guidelines, recommendations or to teach them tools (communication, environmental and sensory) that involve the least possible use of restraints if the person has dementia, neuropsychiatric and behavioural alterations, etc.

Aspects they would change to improve the integration of care and QoL

- Reinforce the importance of interdisciplinarity within care teams and their internal communication.
- More access to information from other professionals in the team.
- Knowledge of tools such as sensory tools (music therapy) for the improvement of neuropsychiatric symptomatology (agitation, aggressiveness, anxiety, compulsive behaviours...) in people affected by advanced Parkinson's disease or parkinsonism with dementia.



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- More collaboration inside teams in drawing up joint care plans or contrasting the therapeutic plan of those affected (there is hardly any time for the team to meet).
- Greater cohesion and information, and offer more resources and tools to each patient's environment.
- An ongoing and updated training on the disease and the different therapies (new techniques for example).
- More material resources, technologies to the intervention in therapies.
- Still providing quality care for people with advanced stages of Parkinson
- Community geriatrics for people who cannot reach the clinic
- Care homes don't know much more about Parkinson – many complains about lack of knowledge
- How we provide advanced care planning and palliative care
- Accessibility by phone line - reinsurance for patients
- Written guidelines for patients when they go to hospital, they got delayed – pharmacy department
- Important information sharing tools is very important to know, what other professionals have done and what other patients have seen when visit a patient.
- Mental health systems integrated in the overall
- Environments really clinical, design of environments no friendly with patients
- Same clinic = more integration (data sharing), but if they change centre information flow is lost.
- GP is the centre, services are commissioned. Fragmentation among sectors.





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Key components or resources of IC for PPD



- Transdisciplinarity
- From general social services by district to primary health care, through work with the intervention teams at the municipal councils.
- Networks with different medical centre and Parkinsons' Associations.
- Guidelines about the legal rights and the procedure to be done in case of Parkinson disease.
- A connection also with the social services.
- At the speech therapy level, platforms such as arasaac for those people who may need a speech therapist. SAAC, as for other CEAPAT resources (helps to adapt and create alternative and augmentative communication systems).
- The economic aids of the dependency law, which allow patients to have from therapies to help in their ADLs.
- The solidarity fund, which allows members with fewer resources to access therapies that would otherwise be impossible.
- Gerontologist coordinate the work of different professionals by sharing data.
- Community-oriented Multidisciplinary centers, with data sharing
- Connecting centres
- Professionals with holistic approach (geriatricians)
- Empowering patients in condition.
- There have recently been positive representations of Parkinsons in the Irish media ie Paxman 'it hasn't got me yet'; this may lead to less stigma and more understanding surrounding the disease.



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Relevant tools to improve the management



- Communication with the different professionals and information exchange.
- It could be interesting to improve technological channels of rapid communication so that the patient and family can have quicker contact with the professional and in this way also strengthen their trust in the organisation and strengthen their adherence to treatment.
- A meeting place and a way to collect information of common use.
- Have a stricter estimate of the number of hours involved in carrying out each activity.
- "Time" as a tool: to communicate.
- To have a basic understanding of the other disciplines
- Face-to-face and online training, articles, courses, etc. meetings to deal with clinical cases by a multidisciplinary departments.
- Social and empathic skills
- Empowering patients in condition.
- Communication and conflict resolution skills.
- Resources information reaching patients and families.
- Shared records.
- Email, online meetings.
- A unique platform.



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Results from the PERSONAS – How to better provide care and treatment

- Better communication of the diagnosis.
- A broader explanation of Parkinson disease.
- Experience of multidisciplinary teams available.
- Suggest a psychological support for PD patients and the family member.
- Personalised integrated care plan (developed together with the professionals).
- Need to share concerns.
- Need to be recognised.
- Training that includes space to talk within the disciplines. Communication skills between disciplines in order to address integrated care between professionals.
- Training in transfers, nutrition and feeding, adaptation of spaces.
- Training about PD management with family members also to better manage patients with cognitive difficulties (existence of hallucinations, disorientation).
- Training that includes space to talk within the disciplines. Communication skills between disciplines in order to address integrated care between professionals.
- Training in technology. Teaching professionals to innovate.





PR1 – An Ecosystem Mapping and training methodological framework Integrated Care for PD

Results from the PERSONAS

Ada



Age
68
years



Personal history

In the summer of 2012, after a treatment for insomnia, he experienced stiffness in his right leg, slight tremor in his hand on the same side and widespread difficulty in movement. The diagnosis was 'extra-pyramidal syndrome, to be treated with muscle relaxants'. For about two years I had alternating disorders, until a neurologist diagnosed Parkinson's disease with certainty. That evening, at home, we all cried. After an initial moment of denial and demoralisation, I accepted the disease and its treatment.

Health status

A decade on, I do not suffer from any particular motor problems. I can be self-sufficient and lead an almost normal life. I realised that this pathology, although evolving slowly, does not only present motor symptoms, but also neurovegetative disorders, such as problems with my sound, joint pain, excessive sweating, mood swings, widespread stiffness, and more. Today, at 68, I cultivate my lifelong interests: reading, music, dancing, art, new technologies. For the past two years, I have been a member of an association and I assiduously and enthusiastically follow the initiatives they propose, which allow me to socialise, keep fit, and be constantly informed about the latest research findings.

Assistance received

I got on quite well with the doctors and the various operators, except at the beginning when I was given an incorrect diagnosis, after which we found a welcoming environment, nurses who were all in all helpful, and the doctor who looked after me proved to be a person of great humanity. However, a lady I know told me one day that their doctor, after so many years of her husband suffering from Parkinson's disease, dismissed them by simply saying: "Your husband is not recovering any more anyway, we have to give way to others!" I have to say that from the accounts of other people I know, I have come across the perception of a lack of sensitivity on the part of the health personnel. I repeat, I was fine, but many people I spoke to were not. Maybe it is because they cannot make their voices heard so much out of fear or because they think they are powerless in the face of the care system.

Treatment

Levodopa, physiotherapy and I go to a yoga class. Sometimes I also use herbal products that I see work even though my doctor says they are not needed. I have noticed over the years that few Parkinson's patients undertake therapy for psychological support. I started it almost immediately and it has helped me a lot in coping with difficult times.

Daily routine

I have problems with sleep. When I take the medication then I feel much better but I spend a lot of money on all these treatments and there are not many concessions.



PR1 – An Ecosystem Mapping and training methodological framework Integrated Care for PD

Results from the PERSONAS

Fabrizio



Age
70
years



Personal history

Fabrizio does not speak easily so he tells his wife instead. Fabrizio was diagnosed with the disease about six months after his first hand tremors. You see him like this now, but he was a person full of energy, he liked to help others and make himself available for anything. As soon as he was diagnosed with the disease, he struggled to accept the assisted condition and it was also difficult for me, for us, to change our balance as a couple. Thanks to Fabrizio, many initiatives and conferences were born, which he planned among the various activities he did, in addition to work, to talk about the disease all together, the sick and the caregivers. For many years he lived without too many problems and now some of his symptoms have totally disappeared with the therapy, however, as we know, the drugs he takes make him not very responsive and participative in daily life.

Health status

Today, living with the disease maintains a fair balance: he has no dyskinesias, no excessive tremors, no hallucinations. However some disturbances persist: he falls asleep easily in the evening, but then at night he spends hours with crossword and sleeps little. He has some salivorrhoea (hypersalivation), excessive night sweating and other minor complaints.

Assistance received

I personally informed myself on how I could best assist him, but the doctors were also helpful, even though many are not informed on, for example, the correct diet for Parkinson's sufferers. We, for example, have both become vegans, and this has improved our health a lot, of course it's a radical choice that we don't want to impose on anyone, but in our opinion it works. Fabrizio also needs better to medication and is less burdened, we have been doing this for two years now.

Treatment

Levodopa, physiotherapy and then we use a device that very often not even the doctors know about, which helps Fabrizio to move better. He wears three of them, although they are very expensive. It is a neurotechnological medical device that looks like a rigid disc and is applied to the skin by means of a patch tape. The device is applied to nerve/ganglia points of the body and their stimulation by photons acts to improve the brain's proprioception and thus improve postural instability.

Daily routine

I always drive him around even though I'm a bit worried that they might take away my licence too because of some vision problems. Luckily I can still drive at the moment because in many couples we know, the wife doesn't have a licence. I've taken care of him a lot in the last three years because the disease has gotten so bad. We don't have too many difficulties, we have many loved ones who support us, but for many it is not like that, it feels so lonely and if you are not even lucky enough to have the support of a group close to you who share the same things, everything becomes even more difficult.



PR1 – An Ecosystem Mapping and training methodological framework Integrated Care for PD

Results from the PERSONAS

John



Age
65
years



Personal history

I was diagnosed with Parkinson's at the age of 50. At first, the doctors I went to thought I had a brain tumour, but after the various specialist visits I was told in a very cold and detached manner that I had Parkinson's and that all the symptoms I reported were very normal for someone with Parkinson's. I remember that day the neurologist only looked at my wife when he spoke as if I were invisible or yet another case to be prescribed medication. I was humiliated. I have to say that during the first few years of the disease, no one gave us the necessary guidance to understand it in all its developmental stages, and as a result we did not really know what to do. Mainly because of this, my wife and I felt very lonely, without an adequate support network even to share our experience with people in the same situation.

Health status

I am still autonomous, but I find it hard to accept that my wife has to take care of me, especially I am worried about how the disease will evolve in the future. I feel helpless and I experience the need for care badly. My wife recently decided to go to therapy to be able to support me better. In my opinion she is right to be supported by a psychologist and often this is not recommended by doctors, she has to learn not to feel guilty when she decides to take some space for herself which I think is fundamental otherwise she cannot help me as she would like.

Assistance received

We received little assistance from the social and health services with regard to how to behave, for example, when there are seizures at night, hallucinations. In addition, we did not receive technical information about the disease that would have been very useful to us.

Treatment

Levodopa and assisted physiotherapy

Daily routine

At the moment I am quite independent, but I am afraid for when they tell me that I can no longer use the car.




PR1 – An Ecosystem Mapping and training methodological framework Integrated Care for PD

Results from the PERSONAS

Grupos discusión - Profesionales

SEGUNDO PASO: Personas | Paciente 2 | ¿Qué creéis que necesita?



Nombre
Juan

Puesto
Ingeniero Telecomunicac

Edad
49 años

Nivel de educación más alto
Doctorado

Industria
Tecnología

Tratamientos y Terapias

- Manejo correcto con medicación y terapias (Fisioterapia)
- Masajes puntuales
- Pensando en apuntarse al Equipo Deportivo de APM más adelante

Asistencia que recibe

Seguimiento en Centro de Especialidades
Primera visita Atención Sociosanitaria y pendiente evaluación Atención Terapéutica APM

Otros datos importantes

- Iniciado proceso de separación
- Hijo único
- Padres mayores (Padre con Alzheimer)




PR1 – An Ecosystem Mapping and training methodological framework Integrated Care for PD

Results from the PERSONAS

Grupos discusión - Profesionales

SEGUNDO PASO: Personas | Paciente 3 | ¿Qué creéis que necesita?



Nombre
Pedro

Puesto
Escribe aquí

Edad
73 años

Nivel de educación más alto
Secundario no finalizado

Industria
Comercial (jubilado)

Historia Personal

- Casado
- Su mujer es la cuidadora familiar principal
- 1 hijo de 49 años que vive en el extranjero (Italia)
- Reside en vivienda propia en Madrid capital
- Nivel socioeconómico medio bajo

Preocupaciones sobre Salud

Posible diagnóstico Parkinsonismo (2 años)
Preocupación por caídas recurrentes. Utiliza bastón para caminar
Preocupación por deterioro cognitivo de evolución rápida

Necesidades

- Dificultades para realizar tareas dentro y fuera de casa.
- A nivel motor: Rigidez, bradicinesia e inestabilidad de la marcha
- A nivel no motor: Deterioro cognitivo fluctuante con periodos de coherencia y otros de confusión. Disfunción ejecutiva. Manifestaciones psiquiátricas con alucinaciones amenazadoras. Problemas del sueño




PR1 – An Ecosystem Mapping and training methodological framework Integrated Care for PD

Results from the PERSONAS

Grupos discusión - Profesionales

SEGUNDO PASO: Personas | Paciente 3 | ¿Qué creéis que necesita?



Nombre
Pedro

Puesto
Escribe aquí

Edad
73 años

Nivel de educación más alto
Secundario no finalizado

Industria
Comercial (jubilado)

Tratamientos y Terapias

Reajustes frecuentes tratamiento dopaminérgico
Terapias: Fisioterapia, logopedia y terapia ocupacional en APM

Asistencia que recibe

- Seguimiento Unidad Trastornos Movimiento - Hospital General Universitario Gregorio Marañón
- Seguimiento Atención Sociosanitaria y Atención Terapéutica APM

Otros datos importantes

Cuidadora principal preocupada por gestionar el avance y compensar deficiencias funcionales. Preocupan fundamentalmente los cambios de humor, los problemas de sueño.



3.4. Conclusions/Summary

As we can see from the results of the co-design activities many patients and their caregivers need more support from professionals regarding the characteristics of the disease, so there is an informational need, and how to intervene during the course of the disease, which changes as the disease progresses and worsens. All the professionals from the different countries have knowledge about the Integrated Care approach but is still needed to know and learn more about this perspective applied to Parkinson Disease. The SUPER project partners discussed about the results above from the co-design activities with PD patients, caregivers and PD professionals and it emerged the need to create a curriculum divided into three modules, each one with specific learning units to be completed from professionals to improve their knowledge and quality of care with the Integrated Care approach on Parkinson Disease. The first Module will be about the necessary information on Parkinson Disease, the second one will be about the meaning and practice of Integrated People Centred Care (IPCC) and the third one will be about Integrated People Centred Care applied to Parkinson Disease.

4. First draft of the training course and e-learning platform requirements

In the basis of the results presented during the meeting in Treviso, partners discussed and agreed on a first structure of the training course contents, and also they discussed about the e-learning platform features.

Afterwards, a document with that first draft was circulated across the consortium members for refining and completing the training curriculum. The final version of training curriculum was the following:

Introduction to the training course

1. General explanation of the training course and its content
2. Target group
3. General objectives of the course
4. Competences to be acquired

Module 1. Parkinson disease

Unit 1. Clinical aspects

1. What is Parkinson? Causes, types.
2. Symptomatology and expected evolution
3. Assessment process (tools), detection and diagnosis

Unit 2. Health and social care

1. Pharmacological
2. Surgical

3. Non-pharmacological (therapeutical and rehabilitative therapies such as psychotherapy, physiotherapy, speech therapy, occupational therapy, music therapy, nutritional care, tai-chi, Pilates...).
4. Social support (such as home care services, tele assistance, day care centers)

Unit 3. Resources for dealing better with the disease

1. Communication of the disease (Buckman six-step protocol for breaking bad news)
2. Legislative regulations (country specific based)
3. Support and referral resources: Associations/institutions (Europe and country specific based).
4. Digital tools (Europe and country specific based). Life-style apps, Self-care, patient-Care team communication

Module 2. Integrated Care (IC)

Unit 1. A new care model focused on the person

1. Changes in the health and care model (transformation towards IC)
2. Principles (person centred...) and types of the IC model
3. Benefits of the IC model
4. Applications and benefits of the different IC models (cost effective, improve health outcomes...)

Unit 2. New roles and professional skills for the IC

1. New ways of relating with the person, family and professional teams (multidisciplinary, transdisciplinary and interdisciplinary).
2. Professional competences to provide IC: 1) patient-centred care, 2) teamwork and collaboration, 3) evidence-based practice, 4) quality improvement, 5) informatics and 6) safety.

Unit 3. Digitalization in the health sector

1. Towards the digitalization of the care
2. Benefits of the digitalization and its relation with IC (effect on professionals, patients & caregivers)
3. Barriers and drivers of the digitalization
4. How to promote digitalization on patients and caregivers?
5. How to encourage digitalization in professionals?

Module 3: Integrated care applied to Parkinson disease

Unit 1. Working with a person with PD from the IC

1. Knowing the person
2. Promoting autonomy
3. Individualisation
4. Privacy

Unit 2. Communication skills

1. How to effectively communicate with the person with PD and their families/caregivers
2. How to effectively communicate between members of professional teams?

Unit 3. How to manage complex situations with the PD patient and families/caregivers

1. How to cope with health worsening (e.g., on-off, choking, sleeping problems, end of life...)
2. Neurotic & psychotic symptomatology (e.g., depression, anxiety, obsessions, hallucinations, delusions...).

Unit 4. Professional self-care in the PD context

1. Health promotion: What self-care mean? And self-care practices
2. Self-awareness and self-esteem
3. Resilience (how to build and develop?)
4. Crisis (and coping strategies)
5. Physical and psychological stress (and coping strategies)
6. Grief (and coping strategies)

Regarding the e-learning platform, partners agreed on the following:

- The platform will be open access but the user will have to create an account. In this way, the course could be carried out in different times and the results will be storage.
- The platform will be intuitive and easy to use.
- The online training will be adapted to the end-user: available 24 Hours a day, 365 days a year.
- FAQ or an area where the user can consult doubts and receive technical support.
- Platform accessible from any device: computer, mobile or tablet.
- Sharing space. A sort of forum where someone from each country check the content before being published. It would be active during the project lifetime.
- Links to official colleges, where there are working groups.
- A certificate (not officially) will be issued after the completion of the course.

5. Validation of the training curriculum with professionals

In order to check if the training contents and structure were appropriate and covered the professionals needs and preferences, partners performed an additional validation through an online survey (EUSurvey) addressed to health and social professionals.

Professionals involved in this validation received an email with the final structure of the course together with a link to the survey (Annex V) to get their feedback about it.

A total of 49 professionals participated in the validation, 25 from Spain, 21 from Italy, 1 from Ireland, 1 from Canada, and 1 from Belgium.

There was a common agreement about the usefulness of the 3 modules: 100% of the respondents reported that the content of such modules will be useful for their daily practice.

Regarding module 1, 91.8% of the respondents would not include, modify or remove any topic from this module, while four people would: 1 person would add the neuropsychology area, 1 person would add "Social services: home care services, tele assistance are not social. Social services can be home adaptations, support/activity groups (of which the exercise and art/music/pet therapy are part of rather than being considered rehabilitative in a progressive disease - rehabilitation is a word that gives false hope); financial assistance, etc.", 1 person "Caring for immigrants with Parkinson's - language & cultural norms" and 1 person would include a focus on gender differences.

Regarding module 2, 93.9% of the respondents would not include, modify or remove any topic from this module, while three people would: 1 person would include a focus on gender differences, and 2 people would replace the word "patient" by user and/or person with PD.

Regarding module 3, 95.9% of the respondents would not include, modify or remove any topic from this module, while two people would: 1 person would add "cooperation" of team and 2 people eliminate the word "patient".

Additionally:

- 100% of the respondents informed that the content of the training will cover their training needs.
- 79.6% reported that the training course could improve their provision of care.
- 100% stated that the training course could improve the quality of care offered to people with PD.
- 91.8% said that the content of the training course is innovative.
- 100% of the respondents would like to take the course.

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7. Annexes

7.1. Annex I: Results of the literature review from each country

Trainings

Country	Title of training or program	Area/s covered	Training provider	Public/private	Open access/under payment	Type of care	Target group	Training modality	Training content (agenda, topics, units, modules)	Duration of training	Training material used	Useful links	Comments/additional information
Italy and others	PWR! Moves - Parkinson Wellness Recovery	Science of movement, control, and motor learning.	European Parkinson Training Centre; Fresco Academy; Regen Centre and European Parkinson Disease Association, Cure Parkinson's Trust, Oxford Brookes University, Parkinson's people e Becky Farley	Private	Under payment	Physical therapy	Physiotherapists, doctor, geriatrics,	face to face; 4 days 13.00-16.00; 4 Modules: 1.	<ol style="list-style-type: none"> 1. To provide skills and methodology in rehabilitation treatment planning; 2. Accompany the skills learned with a new perspective: it is not just the application of techniques but the importance of empathy in treating them; 3. Explain the importance of movement as it is an essential pillar in maintaining the quality of life of a person with Parkinson's; 4. Learn about the rehabilitation approach founded by Becky Farley Chief Scientific Officer" of Parkinson Wellness Recovery PWR! - transnational movement - axial mobility - weight shifting - antigravity extension 	30 hours		https://formazioneparkinson.com/calendario_corso/corso-post-laurea-intensivo-sul-trattamento-della-malattia-di-parkinson-per-fisioterapisti-power-moves/	



Italy	Training Course for Family Members and Caregivers Living with People with Parkinson.	Every area in global	www.frescoparkinsoninstitute.com	Private	Free	General	Caregivers	Face to face; 1 day different sessions	Parkinson's M.: how to recognize motor and non-motor symptoms 1. Behavioral and psychiatric disorders: how to recognize and manage them 2. Drug therapy: the importance of proper management 3. How to manage advanced therapies 4. The importance of a proper lifestyle (nutrition and physical activity) 5. Speech disorders: how to recognize and manage them 6. How to correctly perform postural transitions and transfers? 7. What motor activities are indicated at home?	7 hours			https://www.frescoparkinsoninstitute.com/exploratory-pilot-ars-pd-study/?lang=en
SPAIN	Parkinson's specialist course: specialist in attention, care and treatment of Parkinson's disease in the elderly.	1) Aging and knowledge on PD The objectives of this Parkinson's Specialist Course are: - Describe the general notions of the ageing process. - To learn about Parkinson's disease,	Euroinnova	Private	Under payment	General	Clinic assistant, geriatric staff or nurse.	Online	MODULE 1. GENERAL NOTIONS OF AGEING DIDACTIC UNIT 1. AGEING DIDACTIC UNIT 2. GERONTOLOGICAL CLASSIFICATION DIDACTIC UNIT 3. CHANGES IN AGEING: NORMAL AGEING, COGNITIVE IMPAIRMENT AND DEMENTIA MODULE 2. PARKINSON'S DISEASE DIDACTIC UNIT 4. CLINICAL ASPECTS OF PARKINSON'S DISEASE DIDACTIC UNIT 5. FUNCTIONAL, SOCIAL, COGNITIVE AND MOBILITY ASSESSMENT DIDACTIC UNIT 6. TREATMENT OF PARKINSON'S DISEASE DIDACTIC UNIT 7. TOOLS NECESSARY FOR COPING WITH THE CHANGES CAUSED BY PARKINSON'S DISEASE DIDACTIC UNIT 8. THE IMPORTANCE OF NUTRITION IN PARKINSON'S DISEASE DIDACTIC UNIT 9. HYGIENE HABITS	200 hrs	Course in SCORM format	https://www.euroinnova.edu.es/curso-tratamiento-parkinson?matctype=&device=c&lv=1&promo=default&gclid=Cj0KCQjwzL CVBhD3ARIs APKYTcQaxZm E TR 67 o45Zu7TSXU j2qmLzd0hw 9b68ICBFHD Q4CdVVEA W0aAkmueA Lw wcb#sec	Double Degree awarded by EUROINNOVA BUSINESS SCHOOL and accredited by the Higher School of Professional Qualifications.

		its symptoms , the problems associated with it and its treatment. - To determine the changes that occur in the lives of people with Parkinson's disease.							DIDACTIC UNIT 10. THE FAMILY AND CARERS			cion- titulacion	
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SPAIN	Training in semiology of parkinson's disease	1) Knowledge on PD: Semiology of Parkinson's disease and parkinsonisms	Vivactis Lexic	Private	Info not available in web	Specialized	Neurologists	Online	<p>6 training modules. Each module includes presentations and videos of patients given by leading neurologists in this disease. All the presentations are accompanied by explanatory videos in order to provide highly visual material when dealing with movement disorders. At the end of the training the student will be able to:</p> <p>Conduct an appropriate clinical interview (anamnesis and physical examination) to define and identify relevant symptoms and signs that allow differentiating PD from other parkinsonisms.</p> <p>Interpret the data from the physical examination and the symptoms reported by the patient in order to formulate a syndromic diagnosis and determine the most appropriate therapeutic interventions.</p> <p>Establish efficient communication with the patient and caregiver.</p> <p>Module 1: Cardinal signs of Parkinson's disease .</p> <p>Module 2: Differential diagnosis of PD: atypical and secondary parkinsonisms.</p> <p>Module 3: Non-motor symptoms of parkinson's disease.</p> <p>Module 4: Phenomenology of motor fluctuations in PD.</p> <p>Module 5: Phenomenology of dyskinesias in PD.</p> <p>Module 6: Non-motor fluctuations in PD</p>	3 weeks (between 03/02/22 - 02/02/2023)	Each module includes patient presentations and videos made and taught by leading neurologists in this disease.	https://semilogiaep.es/	1,1 credits ; 7 Lective hours; With the scientific endorsement of the Spanish Society of Neurology
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SPAIN	Parkinson's disease	1) Knowledge on PD: Anatomical and functional review of PD disease PD disease	ASISPA	Private	50 Euros This training can be 100% subsidised through FUNDAE credit.	General	Socio-health care professionals and other professionals	Online	<p>Unit 1.- Anatomical and functional review of the nervous system. Function and structure of the nervous system. Brain organisation at motor level. Associated pathologies: extrapyramidal and pyramidal symptoms.</p> <p>Unit 2.- Parkinson's disease (PD). Incidence and aetiopathogenesis. Diagnosis: Parkinsonian syndrome, exclusion criteria and diagnostic aids. Main clinical signs and symptoms. Stages of the disease: Hoehn-Yahr scale, evolution and complications. Pharmacological treatment: preventive, symptomatic, surgical and restorative. Non-pharmacological treatment: physiotherapy. Living with Parkinson's disease.</p>	Open all year	Interactive content: videos, text, images, animated activities, downloadable files, practical exercises, etc.	https://asispa.org/formacion/curso/la-enfermedad-de-parkinson/	<p>Compulsory assessment at the end of each module. The student will take a final assessment covering all the contents. It is necessary to pass all the evaluations, carry out the activities and visualise all the contents in order to obtain the accredited diploma.</p>
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SPAIN	Course on Attention, Care and Treatment of Parkinson's Disease in the Elderly	1) Knowledge on aging and PD	IPFAP Formación	Private	170 euros	General	Different profiles	Online Virtual Platform OR book format for 40 euros more.	<p>Module 1. General notions of ageing</p> <p>Didactic unit 1. Ageing</p> <p>Definition of ageing</p> <p>Active ageing</p> <p>Theories of ageing</p> <p>Stochastic Theories</p> <p>Non-stochastic theories</p> <p>Important disciplines in ageing</p> <p>Geriatrics and gerontology</p> <p>Psychogerontology</p> <p>Longevity</p> <p>Cellular and molecular ageing</p> <p>Modifications of ageing by organs and systems</p> <p>Higher mental functions and the ageing process</p> <p>Didactic unit 2. Gerontological classification</p> <p>Introduction to geriatrics and gerontology</p> <p>Classification of the elderly</p> <p>Healthy elderly person</p> <p>Sick or dependent elderly person</p> <p>Geriatric patient</p> <p>Frail or high-risk elderly</p> <p>Didactic unit 3. Changes in ageing: normal ageing, cognitive impairment and dementia</p> <p>Normal ageing and pathological ageing</p> <p>Impairment in old age</p> <p>Mild cognitive impairment</p> <p>Dementias</p> <p>Diagnostic criteria for dementia</p> <p>Module 2. Parkinson's disease</p> <p>Didactic unit 4. Clinical aspects of Parkinson's disease</p> <p>What is Parkinson's disease?</p> <p>Causes of Parkinson's disease</p> <p>Types of Parkinson's disease</p> <p>Characteristics for detection.</p> <p>Symptomatology</p> <p>Parkinson's in the elderly</p> <p>PD assessment tests</p>	380 hours	Downloadable files, practical exercises..	https://www.educaweb.com/curso/atencion-tratamiento-enfermedad-parkinson-mayores-distancia-366898/	Diploma awarded by Clea University.
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									<p>Diagnosis of the disease</p> <p>Aims of comprehensive assessment and main areas of assessment</p> <p>Assessment process</p> <p>Assessment techniques</p> <p>Unit 5. Functional, social, cognitive and mobility assessment</p> <p>Functional assessment</p> <p>Concept of function</p> <p>Disability and its pathways</p> <p>Assessment of activities of daily living</p> <p>Socio-environmental assessment</p> <p>Psychological and cognitive assessment</p> <p>Cognitive assessment</p> <p>Assessment process</p> <p>Instruments or scales for mental assessment</p> <p>Assessment of emotional state</p> <p>Assessment of the patient's mobility</p> <p>Immobility syndrome in Parkinson's patients</p> <p>Didactic unit 6. Treatment of Parkinson's disease</p> <p>Treatment</p> <p>Pharmacological treatment</p> <p>Surgical treatment</p> <p>Physiotherapeutic treatment</p> <p>Psychotherapy</p> <p>Didactic unit 7. Necessary tools for coping with the changes caused by Parkinson's disease</p> <p>Coping with the disease</p> <p>Communication of the disease</p> <p>Environment: where, when, with whom, time</p> <p>Skills</p> <p>Buckman protocol: protocol for communicating bad news</p> <p>Social resources</p> <p>Home help services</p> <p>Telecare</p> <p>Technical aids</p> <p>Intermediate and family respite services</p>			
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								<p>(temporary stays and day centres) Day stays in gerontological centres Day centres for dependent elderly people Institutions, programmes and direct care professionals The importance of associations and institutions for dependent persons Spanish associations that collaborate with PD Geriatrics and gerontology associations Didactic unit 8. The importance of nutrition in Parkinson's disease Conceptual approaches: food and nutrition Nutrients and their requirements in the elderly Nutrition-related problems in the elderly Nutrition in PD Adapted basic nutrition Diet for dysphagia and oesophagitis Dietary advice for people with PD Didactic unit 9. Hygiene habits Importance of daily hygiene in older people Hygiene and personal care protocol General rules for personal hygiene and grooming Eye and ear hygiene Oral hygiene Use of dentures Foot hygiene Skin hygiene Dressing the elderly person Recommendations for dressing/undressing the elderly person Technical aids for dressing/undressing Tips for caring for people with PD didactic unit 10. the family and caregivers Family care of the geriatric patient Carers of dependent persons</p>				
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									<p>Impact on the carer's life</p> <p>Effects on the carer</p> <p>Role of the different social and health care professionals. The interdisciplinary team</p> <p>Tasks of the social and health care professional. Competence and responsibility in different areas</p> <p>Preparing for care</p> <p>Ethical principles of social intervention with people and groups with special needs. Attitudes and values</p> <p>Confidentiality and respect when handling personal information about the sick person.</p> <p>Dynamics of the helping relationship: adaptation, difficulties, limits and prevention of psychological risks</p> <p>Care for the carer</p>				
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SPAIN	Parkinson's specialist course: specialist in attention, care and treatment of Parkinson's disease in the elderly.	1) Aging and knowledge on PD The objectives of this Parkinson's Specialist Course are: - Describe the general notions of the ageing process. - To learn about Parkinson's disease, its symptoms, the problems associated with it and its treatment. - To determine the changes that occur in the lives of people with Parkinson's disease.	Euroinnova	Private	Under payment	General	Professionals from residential and day care centres with public places dependent on the Directorate General for Care for the Elderly and Dependency.	Face to face.	Module 1: Testimonial from a patient (person affected by PD) Module 2: Basic principles: PD. Symptoms and pharmacological treatment of PD. Importance of medication (neurologist) Module 3: Basic principles: Psychological aspects. Psychological, behavioural and cognitive aspects (psychologist) Module 4: Physical aspects: Nursing care. Need for nursing care in the patient: transfers, rhythm and mobilisations (nurse) Module 5: Physical aspects: activities of daily living. Technical aids (occupational therapist) Module 6: Psycial aspects: communication and dysphagia. Communication difficulties and the prevention of dysphagia (speech therapist) Module 7: Testimony of a carer. The illness also affects people around (carer) Module 8: Family relationships. Relation with family members, special situations (social worker) Module 9: Emotional care of professionals. Knowledge of emotions, strategies to prevent burnt out caregiver's syndrome	4 sessions. 20 hrs.	Each module includes presentations and videos	https://www.comunidad.madrid/actividades/2022/taller-formacion-atencion-enfermo-parkinson-profesionales-residencias-centros-dia	Students will be awarded a diploma provided they attend at least 80% of the classes.
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Italy	YOU ARE NOT ALONE - free online course for people with Parkinson's, family members and caregivers	The program offers a wide selection of current and important topics aimed at informing and improving the quality of life for people with Parkinson's and their family caregivers.	Fresco Parkinson Institute	Private	Free	General	Caregivers	Online	Juvenile Parkinson's Disease in the Working Age The Family Member in Parkinson's Disease ParkAdvisor for People with Parkinson's Disease Palliative Care in Parkinson's Disease What are Emergencies in Parkinson's Disease? Dance Well and Parkinson's Disease How to correctly perform postural transitions and transfers An example of integrated territorial management for Parkinson's disease Olfactory testing: what is it and what do you need to know in Parkinson's Disease? Art and Parkinson's Disease The importance of genetics in Parkinson's disease Occupational Therapy and Quality of Life in Parkinson's Disease Physical Activity and Parkinson's Disease: How and When? Respiratory Complications in Parkinson's Disease Fatigue and Parkinson's Disease: What Do We Know? What Model of Care in Parkinson's Disease? Neuromodulation in Parkinson's Disease? Theater and Parkinson's Disease Parkinson's Disease in Women Tourism and Parkinson's Disease	7 months, every Thursday	presentations and video	https://www.frescoparkinsoninstitute.com/eventer/corso-di-formazione-a-distanza-per-persone-con-malattia-di-parkinson-familiari-e-cargiver-al-tempo-del-covid-18/edate/2022-09-15/	
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Projects

Country	Title of training or program	Area/s covered	Training provider	Public/private	Open access/under payment	Type of care	Target group	Training modality	Training content (agenda, topics, units, modules)	Duration of training	Training material used	Useful links	Comments/additional information
Italy and others	PWR! Moves - Parkinson Wellness Recovery	Science of movement, control, and motor learning.	European Parkinson Training Centre; Fresco Academy; Regen Centre and European Parkinson Disease Association, Cure Parkinson's Trust, Oxford Brookes University, Parkinson's people e Becky Farley	Private	Under payment	Physical therapy	Physiotherapists, doctor, geriatrics	face to face; 4 days 13.00-16.00; 4 Modules: 1.	<ol style="list-style-type: none"> 1. To provide skills and methodology in rehabilitation treatment planning; 2. Accompany the skills learned with a new perspective: it is not just the application of techniques but the importance of empathy in treating them; 3. Explain the importance of movement as it is an essential pillar in maintaining the quality of life of a person with Parkinson's; 4. Learn about the rehabilitation approach founded by Becky Farley Chief Scientific Officer" of Parkinson Wellness Recovery PWR! - trasnational movement - axial mobility - weight shifting - antigravity extension 	30 hours		https://formazioneparkinson.com/calendario_corso/corso-post-laurea-intensivo-sul-trattamento-della-malattia-di-parkinson-per-fisioterapisti-power-moves/	



Italy	Training Course for Family Members and Caregivers Living with People with Parkinson.	Every area in global	www.frescoparkinsoninstitute.com	Private	Free	General	Caregivers	Face to face; 1 day different sessions	Parkinson's M.: how to recognize motor and non-motor symptoms 1. Behavioral and psychiatric disorders: how to recognize and manage them 2. Drug therapy: the importance of proper management 3. How to manage advanced therapies 4. The importance of a proper lifestyle (nutrition and physical activity) 5. Speech disorders: how to recognize and manage them 6. How to correctly perform postural transitions and transfers? 7. What motor activities are indicated at home?	7 hours			https://www.frescoparkinsoninstitute.com/exploratory-pilot-ars-pd-study/?lang=en
SPAIN	Parkinson's specialist course: specialist in attention, care and treatment of Parkinson's disease in the elderly.	1) Aging and knowledge on PD The objectives of this Parkinson's Specialist Course are: - Describe the general notions of the ageing process. - To learn about Parkinson's disease,	Euroinnova	Private	Under payment	General	Clinic assistant, geriatric staff or nurse.	Online	MODULE 1. GENERAL NOTIONS OF AGEING DIDACTIC UNIT 1. AGEING DIDACTIC UNIT 2. GERONTOLOGICAL CLASSIFICATION DIDACTIC UNIT 3. CHANGES IN AGEING: NORMAL AGEING, COGNITIVE IMPAIRMENT AND DEMENTIA MODULE 2. PARKINSON'S DISEASE DIDACTIC UNIT 4. CLINICAL ASPECTS OF PARKINSON'S DISEASE DIDACTIC UNIT 5. FUNCTIONAL, SOCIAL, COGNITIVE AND MOBILITY ASSESSMENT DIDACTIC UNIT 6. TREATMENT OF PARKINSON'S DISEASE DIDACTIC UNIT 7. TOOLS NECESSARY FOR COPING WITH THE CHANGES CAUSED BY PARKINSON'S DISEASE DIDACTIC UNIT 8. THE IMPORTANCE OF NUTRITION IN PARKINSON'S	200 hrs	Course in SCORM format	https://www.euroinnova.edu.es/cursos/tratamiento-parkinson?mathtype=&device=c&l=v1&promo=default&gclid=Cj0KCQjwzLCVBhD3ARIsAPKYTcQaxZmE TR_67o45Zu7TSXUj2gmLzd0hw9b68ICBFHDQ4CdVVEAW0aAkmueALw_wcB#seccion-titulacion	Double Degree awarded by EUROINNOVA BUSINESS SCHOOL and accredited by the Higher School of Professional Qualifications.



		its symptoms , the problems associated with it and its treatment. - To determine the changes that occur in the lives of people with Parkinson' s disease.							DISEASE DIDACTIC UNIT 9. HYGIENE HABITS DIDACTIC UNIT 10. THE FAMILY AND CARERS				
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SPAIN	Training in semiology of parkinson's disease	1) Knowledge on PD: Semiology of Parkinson's disease and parkinsonisms	Vivactis Lexic	Private	Info not available in web	Specialized	Neurologists	Online	<p>6 training modules. Each module includes presentations and videos of patients given by leading neurologists in this disease. All the presentations are accompanied by explanatory videos in order to provide highly visual material when dealing with movement disorders. At the end of the training the student will be able to:</p> <p>Conduct an appropriate clinical interview (anamnesis and physical examination) to define and identify relevant symptoms and signs that allow differentiating PD from other parkinsonisms.</p> <p>Interpret the data from the physical examination and the symptoms reported by the patient in order to formulate a syndromic diagnosis and determine the most appropriate therapeutic interventions.</p> <p>Establish efficient communication with the patient and caregiver.</p> <p>Module 1: Cardinal signs of Parkinson's disease .</p> <p>Module 2: Differential diagnosis of PD: atypical and secondary parkinsonisms.</p> <p>Module 3: Non-motor symptoms of parkinson's disease.</p> <p>Module 4: Phenomenology of motor fluctuations in PD.</p> <p>Module 5: Phenomenology of dyskinesias in PD.</p> <p>Module 6: Non-motor fluctuations in PD</p>	3 weeks (between 03/02/22 - 02/02/2023)	Each module includes patient presentations and videos made and taught by leading neurologists in this disease.	https://semiologyaep.es/	1,1 credits ; 7 Lective hours; With the scientific endorsement of the Spanish Society of Neurology
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SPAIN	Parkinson's disease	1) Knowledge on PD: Anatomical and functional review of PD disease PD disease	ASISPA	Private	50 Euros This training can be 100% subsidised through FUNDAE credit.	General	Socio-health care professionals and other professionals	Online	<p>Unit 1.- Anatomical and functional review of the nervous system. Function and structure of the nervous system. Brain organisation at motor level. Associated pathologies: extrapyramidal and pyramidal symptoms.</p> <p>Unit 2.- Parkinson's disease (PD). Incidence and aetiopathogenesis. Diagnosis: Parkinsonian syndrome, exclusion criteria and diagnostic aids. Main clinical signs and symptoms. Stages of the disease: Hoehn-Yahr scale, evolution and complications. Pharmacological treatment: preventive, symptomatic, surgical and restorative. Non-pharmacological treatment: physiotherapy. Living with Parkinson's disease.</p>	Open all year	Interactive content: videos, text, images, animated activities, downloadable files, practical exercises, etc.	https://asispa.org/formacion/curso/la-enfermedad-de-parkinson/	Compulsory assessment at the end of each module. The student will take a final assessment covering all the contents. It is necessary to pass all the evaluations, carry out the activities and visualise all the contents in order to obtain the accredited diploma.
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SPAIN	Course on Attention, Care and Treatment of Parkinson's Disease in the Elderly	1) Knowledge on aging and PD	IPFAP Formación	Private	170 euros	General	Different profiles	Online Virtual Platform OR book format for 40 euros more.	<p>Module 1. General notions of ageing</p> <p>Didactic unit 1. Ageing</p> <p>Definition of ageing</p> <p>Active ageing</p> <p>Theories of ageing</p> <p>Stochastic Theories</p> <p>Non-stochastic theories</p> <p>Important disciplines in ageing</p> <p>Geriatrics and gerontology</p> <p>Psychogerontology</p> <p>Longevity</p> <p>Cellular and molecular ageing</p> <p>Modifications of ageing by organs and systems</p> <p>Higher mental functions and the ageing process</p> <p>Didactic unit 2. Gerontological classification</p> <p>Introduction to geriatrics and gerontology</p> <p>Classification of the elderly</p> <p>Healthy elderly person</p> <p>Sick or dependent elderly person</p> <p>Geriatric patient</p> <p>Frail or high-risk elderly</p> <p>Didactic unit 3. Changes in ageing: normal ageing, cognitive impairment and dementia</p> <p>Normal ageing and pathological ageing</p> <p>Impairment in old age</p> <p>Mild cognitive impairment</p> <p>Dementias</p> <p>Diagnostic criteria for dementia</p> <p>Module 2. Parkinson's disease</p> <p>Didactic unit 4. Clinical aspects of Parkinson's disease</p> <p>What is Parkinson's disease?</p> <p>Causes of Parkinson's disease</p> <p>Types of Parkinson's disease</p> <p>Characteristics for detection.</p> <p>Symptomatology</p> <p>Parkinson's in the elderly</p> <p>PD assessment tests</p>	380 hours	Downloadable files, practical exercises..	https://www.educaweb.com/curso/atencion-cuidados-tratamiento-enfermedad-parkinson-mayores-distancia-366898/	Diploma awarded by Clea University.
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								Diagnosis of the disease Aims of comprehensive assessment and main areas of assessment Assessment process Assessment techniques Unit 5. Functional, social, cognitive and mobility assessment Functional assessment Concept of function Disability and its pathways Assessment of activities of daily living Socio-environmental assessment Psychological and cognitive assessment Cognitive assessment Assessment process Instruments or scales for mental assessment Assessment of emotional state Assessment of the patient's mobility Immobility syndrome in Parkinson's patients Didactic unit 6. Treatment of Parkinson's disease Treatment Pharmacological treatment Surgical treatment Physiotherapeutic treatment Psychotherapy Didactic unit 7. Necessary tools for coping with the changes caused by Parkinson's disease Coping with the disease Communication of the disease Environment: where, when, with whom, time Skills Buckman protocol: protocol for communicating bad news Social resources Home help services Telecare Technical aids			
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								<p>Intermediate and family respite services (temporary stays and day centres)</p> <p>Day stays in gerontological centres</p> <p>Day centres for dependent elderly people</p> <p>Institutions, programmes and direct care professionals</p> <p>The importance of associations and institutions for dependent persons</p> <p>Spanish associations that collaborate with PD</p> <p>Geriatrics and gerontology associations</p> <p>Didactic unit 8. The importance of nutrition in Parkinson's disease</p> <p>Conceptual approaches: food and nutrition</p> <p>Nutrients and their requirements in the elderly</p> <p>Nutrition-related problems in the elderly</p> <p>Nutrition in PD</p> <p>Adapted basic nutrition</p> <p>Diet for dysphagia and oesophagitis</p> <p>Dietary advice for people with PD</p> <p>Didactic unit 9. Hygiene habits</p> <p>Importance of daily hygiene in older people</p> <p>Hygiene and personal care protocol</p> <p>General rules for personal hygiene and grooming</p> <p>Eye and ear hygiene</p> <p>Oral hygiene</p> <p>Use of dentures</p> <p>Foot hygiene</p> <p>Skin hygiene</p> <p>Dressing the elderly person</p> <p>Recommendations for dressing/undressing the elderly person</p> <p>Technical aids for dressing/undressing</p> <p>Tips for caring for people with PD</p> <p>didactic unit 10. the family and</p>			
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								<p>caregivers</p> <p>Family care of the geriatric patient</p> <p>Carers of dependent persons</p> <p>Impact on the carer's life</p> <p>Effects on the carer</p> <p>Role of the different social and health care professionals. The interdisciplinary team</p> <p>Tasks of the social and health care professional. Competence and responsibility in different areas</p> <p>Preparing for care</p> <p>Ethical principles of social intervention with people and groups with special needs. Attitudes and values</p> <p>Confidentiality and respect when handling personal information about the sick person.</p> <p>Dynamics of the helping relationship: adaptation, difficulties, limits and prevention of psychological risks</p> <p>Care for the carer</p>				
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SPAIN	Parkinson's specialist course: specialist in attention, care and treatment of Parkinson's disease in the elderly.	1) Aging and knowledge on PD The objectives of this Parkinson's Specialist Course are: - Describe the general notions of the ageing process. - To learn about Parkinson's disease, its symptoms, the problems associated with it and its treatment. - To determine the changes that occur in the lives of people with Parkinson's disease.	Euroinnova	Private	Under payment	General	Professionals from residential and day care centres with public places dependent on the Directorate General for Care for the Elderly and Dependency.	Face to face.	Module 1: Testimonial from a patient (person affected by PD) Module 2: Basic principles: PD. Symptoms and pharmacological treatment of PD. Importance of medication (neurologist) Module 3: Basic principles: Psychological aspects. Psychological, behavioural and cognitive aspects (psychologist) Module 4: Physical aspects: Nursing care. Need for nursing care in the patient: transfers, rhythm and mobilisations (nurse) Module 5: Physical aspects: activities of daily living. Technical aids (occupational therapist) Module 6: Physical aspects: communication and dysphagia. Communication difficulties and the prevention of dysphagia (speech therapist) Module 7: Testimony of a carer. The illness also affects people around (carer) Module 8: Family relationships. Relation with family members, special situations (social worker) Module 9: Emotional care of professionals. Knowledge of emotions, strategies to prevent burnt out caregiver's syndrome	4 sessions. 20 hrs.	Each module includes presentations and videos	https://www.comunidad.madrid/actividades/2022/taller-formacion-atencion-enfermos-parkinson-profesionales-residencias-centros-dia	Students will be awarded a diploma provided they attend at least 80% of the classes.
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Italy	YOU ARE NOT ALONE - free online course for people with Parkinson's, family members and caregivers	The program offers a wide selection of current and important topics aimed at informing and improving the quality of life for people with Parkinson's and their family caregivers.	Fresco Parkinson Institute	Private	Free	General	Caregivers	Online	Juvenile Parkinson's Disease in the Working Age The Family Member in Parkinson's Disease ParkAdvisor for People with Parkinson's Disease Palliative Care in Parkinson's Disease What are Emergencies in Parkinson's Disease? Dance Well and Parkinson's Disease How to correctly perform postural transitions and transfers An example of integrated territorial management for Parkinson's disease Olfactory testing: what is it and what do you need to know in Parkinson's Disease? Art and Parkinson's Disease The importance of genetics in Parkinson's disease Occupational Therapy and Quality of Life in Parkinson's Disease Physical Activity and Parkinson's Disease: How and When? Respiratory Complications in Parkinson's Disease Fatigue and Parkinson's Disease: What Do We Know? What Model of Care in Parkinson's Disease? Neuromodulation in Parkinson's Disease ? Theater and Parkinson's Disease Parkinson's Disease in Women Tourism and Parkinson's Disease	7 months, every Thursday	presentations and video	https://www.escoparkinsoninstitute.com/venter/corso-di-formazione-a-distanza-per-persone-con-malattia-di-parkinson-familiari-e-cargiver-al-tempo-del-covid-18/edate/2022-09-15/	
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7.2. Annex II: Sociodemographic template

Participant No.	
Method	Focus Group/Interviews
Interview Partner	<input type="checkbox"/> PD patient <input type="checkbox"/> Relative/Caregiver <input type="checkbox"/> Professional
Date/Time	___/___/ 2022 __:__

PD Patient or Relative/Caregiver

Age – Year of birth	
Gender	
Status (married, single ...)	
Country	
How long have you been living with the disease/How long have you been caring	

Professional

Age – Year of birth	
Gender	
Profession/qualification/position	
Country	
How long have you been working with Parkinson's patients	

7.3. Annex III: Informed consent template



Informed consent for co-design sessions (Focus groups/Interviews)

The main objective of SUPER project is to build knowledge, competences and skills of multidisciplinary care team members on the IC approach for PD through a co-designed training course and e-learning platform. The project aims to provide digital multidisciplinary training to effectively face:

- 1) The expected increase of People with PD (estimated high prevalence).
- 2) The progress of PD (due to ageing population) which has an economic impact on the health and care systems, society, professionals, caregivers, people with PD themselves.
- 3) The lack of knowledge on IC models adapted to the real needs of People with PD and their relatives/caregivers, through providing training for members of multidisciplinary teams.
- 4) The People with PD's poor digital skills related to health and care management which has a direct link with their autonomy.

Please, mark with an X all the points you agree:

<input type="checkbox"/>	I understand that I will participate in consultation and creative session on a voluntary basis, providing my experience and my point of view about cerebral palsy and its treatment.
<input type="checkbox"/>	The reason for this session has been explained to me and I had the opportunity to ask questions about it.
<input type="checkbox"/>	I understand that my answers are confidential and anonymous. No information that identifies me or any family member will be used.
<input type="checkbox"/>	I can request the results of this session when they are available.
<input type="checkbox"/>	I authorize the recording of the discussion that will be generated in the group for further study. The information provided can be used in new research.
<input type="checkbox"/>	I authorize photos and video of the session.
<input type="checkbox"/>	I understand that I have the right to withdraw from the session at any time without giving justifications.
<input type="checkbox"/>	I can request that my personal data is deleted or/and not transferred if I withdraw from the session.

Name: _____

Signature: _____

Date: __/__/__

7.4. Annex IV: Example of a Persona

John



Age
65
years

Personal history

I was diagnosed with Parkinson's at the age of 50. At first, the doctors I went to thought I had a brain tumour, but after the various specialist visits I was told in a very cold and detached manner that I had Parkinson's and that all the symptoms I reported were very normal for someone with Parkinson's. I remember that day the neurologist only looked at my wife when he spoke as if I were invisible or yet another case to be prescribed. I remember that day the neurologist only looked at my wife when he spoke as if I were invisible or yet another case to be prescribed medication. I was humiliated. I have to say that during the first few years of the disease, no one gave us the necessary guidance to understand it in all its developmental stages, and as a result we did not really know what to do. Mainly because of this, my wife and I felt very lonely, without an adequate support network even to share our experience with people in the same situation.

Health status

I am still autonomous, but I find it hard to accept that my wife has to take care of me, especially I am worried about how the disease will evolve in the future, I feel helpless and I experience the need for care badly. My wife recently decided to go to therapy to be able to support me better. In my opinion she is right to be supported by a psychologist and often this is not recommended by doctors, she has to learn not to feel guilty when she decides to take some space for herself which I think is fundamental otherwise she cannot help me as she would like.

Assistance received

We received little assistance from the social and health services with regard to how to behave, for example, when there are seizures at night, hallucinations. In addition, we did not receive technical information about the disease that would have been very useful to us.

Treatment

Levodopa and assisted physiotherapy

Daily routine

At the moment I am quite independent, but I am afraid for when they tell me that I can no longer use the car.

7.5. Annex V: Survey on the co-created training curriculum under the Erasmus+ super project

This brief survey is intended to know the health professionals' opinion about a training curriculum on Integrated Care applied to Parkinson Disease which was co-created with the help of end users. The main objective of the survey is to evaluate the curriculum adequacy and to assess if it covers the needs expressed by the end users.

After checking the training curriculum, please we kindly ask you to answer the questions honestly. We really appreciate your help.

Questions about TRAINING MODULE 1:

1. Do you think the content of this module will be useful for your daily practice? Yes/No
2. Would you include, modify or remove any topic from this module? Yes/No. If your answer is yes, please let us know which one.

Questions about TRAINING MODULE 2:

3. Do you think the content of this module will be useful for your daily practice? Yes/No
4. Would you include, modify or remove any topic from this module? Yes/No. If your answer is yes, please let us know which one.

Questions about TRAINING MODULE 3:

5. Do you think the content of this module will be useful for your daily practice? Yes/No
6. Would you include, modify or remove any topic from this module? Yes/No. If your answer is yes, please let us know which one.

Questions about the TRAINING COURSE:

7. Do you think the content of this training course covers your training needs? Yes/No
8. Do you think this training course could improve your provision of care? Yes/No
9. Do you think this training course could improve the quality of care offered to people with PD? Yes/No
10. Do you think the training course's content is innovative? Yes/No
11. Would you like to take this course? Yes/No. If your answer is No, please, let us know why.
12. Is there anything else you want to add? (*open question*)