Poster Title:

iCARE-PD

Integrated Parkinson Care Networks: addressing complex care in Parkinson disease in contemporary society

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Healthcare for people with Parkinson's Disease - The need for change.

In Europe, around 1.2 million persons are living with Parkinson's disease (PD). PD is a progressive non-curable neurodegenerative disorder with complex motor and non-motor features. Persons with PD require personalized, easily accessible, and multidisciplinary care models. While integrated health care approaches show promising effects for patients and providers, there are currently no projects which aim to implement and compare an integrated care approach in several countries although this comparative perspective could provide many valuable insights. The aim of the iCARE-PD project is to develop a personalized, integrated care model and to pilot it in several European countries and Canada. The central hypothesis of the project is that an integrated care approach is not only feasible, but also cost-effective and beneficial for the quality of life of the included patients.

Co-Designing healthcare – the iCARE-PD approach

The development of the care model took place via participatory and consultative processes, in which the perspectives of patients, caregivers and care providers were integrated across sites representing different EU countries and Canada. The result of this co-design process is a care model in which specialized Nurses act as care navigators, helping patients navigate their local healthcare system. Navigating in local healthcare systems and across sectoral boundaries requires entirely new skills. Therefore, a central component of the project was the development of a formal training program of specialists who can implement the iCARE-PD care approach the iCARE-PD Nurses. The care model itself is currently being evaluated in a feasibility study.

What have we achieved so far?

So far, the following milestones and key results have been achieved in the project:

- Evaluation of patient needs for personalized Parkinson's care across EU and Canada
- Training of nurses for the iCARE-PD healthcare process
- Implementation of the iCARE-PD model in the participating countries and evaluation of its feasibility and impact.
- Development of a first competency profile for nurses specialized in integrated care for PD.

The activities of the iCARE-PD consortium have so far been published in several scientific publications. In addition, the consortium organized a hybrid symposium in the summer of 2022, where the project results were presented and discussed. You can find out more about iCARE-PD from the media via the homepage and on social media.

In the coming period, the iCARE-PD consortium will continue to expand its impact. The strengths of the project are: There have not been any projects that have dared to pilot a new approach to PD care across national jurisdictions. The project thus offers a valuable crossnational perspective that makes it possible to compare the strengths and weaknesses of individual healthcare systems for Parkinson's care. With its co-design approach, the project has also shown how the perspectives of various stakeholders can be specifically included in a design process. In addition, the project contributes significantly to the definition of a new profession role – the iCARE-PD Nurse.

Where we will go next

The next steps are the completion of the feasibility study in the individual countries and the evaluation of the results. In addition, the results of the evaluation and the findings from the co-design process are to be translated into a competence profile for Parkinson Nurses to strengthen a profession for sustainable Parkinson's integrated care. A future challenge is to continue to evaluate and implement a pragmatic integrated care model across EU.