Genetic testing in Parkinson's disease: An online survey among ERN-RND centers

DG/WG
Atypical Parkinsonism

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Introduction

Major progress in the knowledge on the genetic architecture of Parkinson's disease (PD) was made in the past decades**. Genetic testing** in PD is becoming **increasingly available** in different countries. Recent therapeutic developments and ongoing clinical trials targeting genetic forms of PD **have raised interest for genetic testing in patients and health professionals**.

However, up-to-date guidelines for genetic testing in PD are currently not available. Therefore, we seek to **explore current practices** in genetic testing in PD patients across European countries. Ultimately, we aim to **improve and harmonize genetic testing** in people with PD (PwP).

Work Plan

An **online survey** was designed with input from the members of the Atypical Parkinsonism-Genetic PD disease group.

An invitation to complete an online survey was circulated by the ERN-RND coordination office among ERN-RND centers between September 2024 and July 2025.

Main objectives is to describe **current practices concerning genetic testing in PD** in ERN-RND centers..

Response data of these set of questions have been collected and will be analyzed and reported.

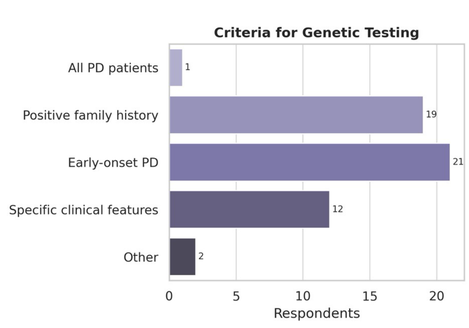
Results

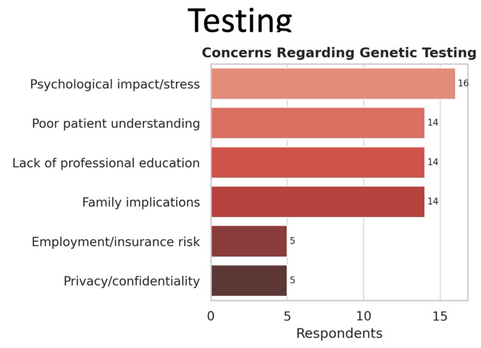
This dataset summarizes findings from 24 academic centers across **17 European countries** on genetic testing and counselling practices for Parkinson's disease (PD).

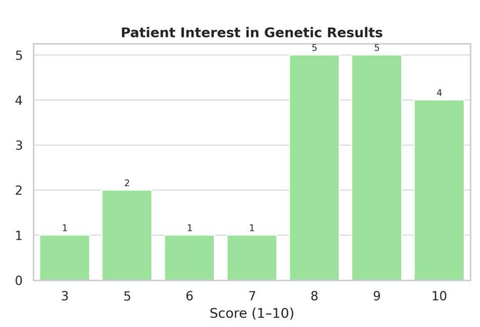
Respondents were predominantly **movement disorder specialists or neurologists**. Genetic testing is offered to a **subset of PD patients** at most centers, guided primarily by **early-onset PD** and **positive family history.** The most common age cut-off for early-onset testing is under 50 years. Approximately one third of the centers test around 10% of their PD patients, and only one center tests 90%.

Regarding **reimbursement of genetic testing**, almost half of the centers report public insurance coverage, while ca. 20% rely on research protocols. Almost half of the centers use **individualized approaches to testing, rather than uniform criteria.**

Genetic counselling is provided mainly by **clinical geneticists and neurologists**, most often both before and after testing. Reported testing strategies favor targeted panels or single-gene analysis, with limited use of whole exome or whole genome sequencing. **Concerns** include **psychological impact**, **insufficient patient understanding**, and **lack of clinician education** on genetics. Nevertheless, confidence in counselling is generally high, and patients show **strong interest in receiving genetic results**.







Outlook

Our findings highlight **growing engagement** with genetic testing in PD, with **variability in practices** across Europe, and indicate the **need for HCP/patient education** as well as for **further harmonization** of genetic testing and counseling practices in PwP across Europe.

European Reference Network
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