

## **EPDA EU Policymaker survey**

### **Objective**

The objective of the survey is twofold:

1. Gather valuable data on how Parkinson's and the EPDA are perceived in Brussels and identify the level of knowledge (or lack thereof) amongst EU policymakers.
2. Use it as a communications tool to reach both old and new contacts in the EU institutions with our key messages and as a hook for engagement.

Therefore, each question of the survey is designed to also showcase a "Key Fact" after the respondent has answered to educate respondents about Parkinson's and the EPDA.

### **Process**

The short online survey would first be sent to our list of identified Brussels policymakers with an interest in health in general and Parkinson's in particular (based on the EPDA Advocacy and Engagement in Brussels report and stakeholder mapping). We will follow up with the launch of meeting requests on behalf of Russell Patten. For those policymakers who decline to meet, we will kindly ask them to spend five minutes to answer the 10-question survey.

### **Deliverables**

The results and key findings of the survey will mostly be used internally to the EPDA as it will inform our future approach with EU policymakers. Nevertheless, the key findings to some of the questions can be transformed into a factsheet for external use that can for example be used as a leave-behind after meetings. Example: *X% of EU policymakers know someone with Parkinson's and a majority (X%) think Y should be prioritised as a policy.*

## Questions

### 1. Do you know what Parkinson's disease is?

- Yes
- No

## What is Parkinson's?

Parkinson's is a neurodegenerative condition – an illness that affects nerve cells in the brain that control movement. Parkinson's is progressive, which means symptoms appear gradually and slowly get worse. It is named after James Parkinson, the London doctor who first reported the symptoms in 1817.

### 2. Are you aware of the European Parkinson's Disease Association ([EPDA](#))?

- Yes
- No

## About the EPDA

The EPDA is the only European Parkinson's umbrella association. It represents [national Parkinson's associations](#) in nearly 30 countries across Europe and advocates for the rights and needs of more than 1.2 million people with Parkinson's and their families. The EPDA's vision is to enable all people with Parkinson's to live a full life while supporting the search for a cure.

### 3. Do you personally know someone with Parkinson's?

- Yes
- No

## How many people have Parkinson's in Europe?

More than 10 million people have Parkinson's worldwide. In 2010, a study found that there are **more than 1.2 million people** living with Parkinson's in Europe and this number is forecast to double by 2030<sup>1</sup>. Worryingly the global [prevalence](#) of Parkinson's is increasing over time and it is expected to double within the next 20 years. To date, no global studies have been conducted to reliably ascertain the number of people who have Parkinson's. It is therefore possible only to estimate the worldwide prevalence of

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<sup>1</sup> Michela Tinelli, Panos Kanavos, Federico Grimaccia (LSE), The value of early diagnosis in treatment in Parkinson's disease - A literature review of the potential clinical and socioeconomic impact of targeting unmet needs in Parkinson's disease (2016)

*the condition, and the actual number of people living with Parkinson's in Europe is therefore likely to be much higher than current estimates show*

**4. (if yes) What is your relation to the person with Parkinson's?**

- A relative
- A friend
- A colleague
- Other (please specify)

**What impact does Parkinson's have on family and friends?**

Receiving a Parkinson's diagnosis is likely to affect the relationships a person has with their friends and family. Over time gradual adjustments will be needed on both sides of a relationship in order to adapt to a life with Parkinson's.

Many people become carers because they want to help a relative, friend or someone close to them, or perhaps there is no one else to do this so they have little choice. Being a Parkinson's carer (also known as a caregiver) can bring with it financial worries too, particularly if it means you have to give up or reduce working hours. For those who become carers later in life, their new role can be physically and mentally challenging.

Organisations such as EPDA play an important role in providing support, guidance and tips to carers, families and friends.

**5. Do you feel that you know enough about Parkinson's?**

- Yes
- No

**Did you know? Parkinson's does not only affect older people.**

*Most people who get Parkinson's are over 60, but one in ten are under 50. Slightly more men than women are affected. Early onset Parkinson's, also known as [young onset Parkinson's \(YOPD\)](#), is defined as occurring in someone below the age of 40.*

**6. Where would you go to get information about Parkinson's?**

*(please check all that apply)*

- Patient organisation
- Medical organisation or professional bodies (e.g. Neurological association)
- News media (Online, TV, Radio, Newspaper)
- Government websites (e.g. Ministry of Health)
- International organizations (e.g. WHO)
- Medical journals
- Community forums
- Colleagues
- Friends
- Other (please specify)

**Did you know? There is no cure for Parkinson's.**

*There is currently no cure for Parkinson's. [Treatment options](#) vary and include medications and surgery. There is no one-size-fits-all treatment approach when it comes to Parkinson's. While medication is the most common treatment, [surgical therapy](#) and lifestyle modifications, like rest and [exercise](#), help manage the disease.*

**7. Have you worked on policy issues related to any of the following health areas?**

- Cancer
- Stroke
- Cardiovascular disease
- Respiratory disease
- Diabetes
- Alzheimer's disease
- Parkinson's disease
- Kidney disease
- Liver disease
- Dementia
- Digestive tract disease
- Allergy
- Hypertension
- Depression

- Mental health problems
- Nutrition, metabolic and lifestyle-related conditions
- Narcotic drugs addiction
- Rare diseases
- Other (please specify)

**Did you know? Non-motor symptoms of Parkinson's can also impact quality of life.**

*Parkinson's is predominantly characterised by problems with body movements, known as motor symptoms, including tremor, rigidity, and postural instability. However, it is also associated with [non-motor symptoms](#), including sleep disturbances, anxiety, depression, hallucinations and psychosis, and dementia. Parkinson's is also a highly individual condition that differs from person to person, which requires a personalised approach to treatment and care.*

**8. How much of a priority do you think Parkinson's currently has at EU-level?**

- Too much attention
- About the right amount
- Too little
- Don't know

**Please explain your answer:**

*(optional)*

- TEXTBOX

**The cost of Parkinson's in Europe**

*The cost per Parkinson's patient amounts to approximately €11,000 on average across Europe, and a cost to Europe of **€13.9bn annually**<sup>2</sup>. The cost per person each year also increases as the condition becomes more severe, while non-motor symptoms are a major source of hospitalisation and institutionalisation – both key cost-drivers in Parkinson's care.*

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<sup>2</sup> European Brain Council, Costs of Disorders of the Brain in Europe (2010)

**9. Which areas of action do you think should be prioritised for Parkinson's at EU level?**

*(please select up to 3)*

- Access to care
- Data collection (prevalence, cost of care, surveys, etc)
- Sharing good practices among countries
- Innovation incentives for new treatments
- Employment conditions
- Regional funding to reduce inequalities between Europe's regions
- Training for healthcare professionals
- Support for informal carers/caregivers (family and friends)
- Improved and timely diagnosis
- Research into the causes of Parkinson's
- Research for a cure
- Non-pharmacological treatments
- Other (please specify)

**Five points on how the EU can concretely help people with Parkinson's**

**1. Address the challenges posed by Parkinson's in EU workstreams** related to access to medicines, health, long-term and integrated care, as well as in the research and innovation activities to provide the Parkinson's community with new treatments and models for adequate care across Europe.

**2. Improve employment conditions, reduce stigma and ensure accessibility to essential services** for people with Parkinson's in the context of the European Social Pillar.

**3. Improve systematic data collection** by including up-to-date information on Parkinson's in the 'State of Health in Europe' cycle, jointly organised by the European Commission and the **Organisation for Economic Co-operation and Development, OECD**, which would help to demonstrate the impact of the disease on healthcare systems.

**4. Consider developing a model for disease registries for Parkinson's**, based on existing good practices at national and regional level, and explore the possibility for the creation of European Reference Networks (ERN), with specific regards to rare forms and advanced stages of Parkinson's.

**5. Provide funding through existing programmes for projects that improve the lives of people with Parkinson's and their families**, for training on Parkinson's for healthcare professionals, as well as the scaling up of projects that aim to reduce waiting times for diagnosis and improve integrated care with the help of innovative technologies.

**10. As a policymaker, what do you primarily want from a patient organisation at EU level?**

- European data (data on prevalence, economic impact, etc.)
- Case studies and testimonials from patients
- Information about new research in a specific field of disease
- EU policy recommendations
- National policy recommendations
- Other (please specify)

**Finally, tell us about yourself!**

**11. Name** (optional)

- TEXT

**12. Which country do you represent?** (optional)

- Dropdown list of countries

**13. Where do you work?**

- European Parliament
- European Commission
- Permanent Representation
- Other (please specify)

**14. Would you allow us to contact you for more information?**

- Yes (please fill in your email)
- No