EPDA Survey of EU Policymakers 2020-2021

REPORT

Contents

Introduction

As part of the EPDA’s advocacy mission, we asked a select group of EU decision-makers to tell us more about how Parkinson’s disease and the EPDA are perceived in Brussels.

Over a one year period in 2021 and 2022, 33 policymakers and stakeholders responded to our anonymised survey – and the results underscore the importance of our continued work to advocate for the Parkinson’s community – but also, the need to address serious knowledge gaps.

> *“The EU needs to do more, and health needs to go up the political agenda big time“*
>
> - EU policymaker (anonymous)

Executive Summary

- While most respondents had some degree of awareness of Parkinson’s, **21% revealed they had little to no knowledge of the disease**, despite its prevalence in Europe.
- Over **half of the respondents personally know someone who has Parkinson’s**, of which half again has a relative with Parkinson’s.
- The vast majority (97%) of respondents felt they **were not sufficiently informed about Parkinson’s** – despite many knowing someone with the disease.
- Only 2 respondents had worked on Parkinson’s at the EU level – compared to 6 on Alzheimer's and 23 on cancer. **Nearly all respondents said that they felt that Parkinson’s was underrepresented at EU level.**
- Most respondents said they would go to a patient organisation – such as the EPDA – to get information on Parkinson’s, and their top 3 asks to receive would be: **policy recommendations, data, and case studies.**

> *“It's clear the EU doesn't focus at all on neurological diseases. It needs to!”*
>
> - EU policymaker (anonymous)

Recommendations

These results offer important insights into knowledge of and attitudes towards Parkinson's among EU policymakers.

The survey itself also serves as a useful communication tool, to reach out to both known and new stakeholders in the EU institutions and start a conversation – but it is clear that there is still work to be done.

Given that these decision-makers represent a critical group and are our key stakeholders, it is important that we draw lessons and ensure that the results feed into our advocacy work moving forward.

We therefore make the following recommendations for next steps to the survey:

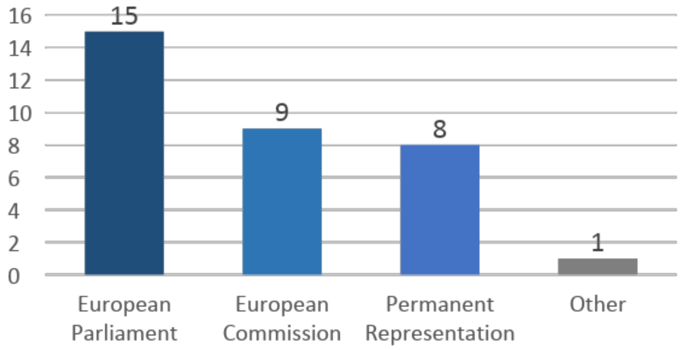
1. **Share the survey results** with policy-makers and stakeholders we surveyed as well as other key contacts that did not participate. This will not only provide them with a holistic picture of attitudes towards Parkinson's among their peers, but also serve as a useful hook to build up our relationship with these key people.
2. **Run the survey again in 2023** - while some policymakers were reluctant to talk about EU action on Parkinson's given the EU's limited competence in health policy, we already see attitudes beginning to shift post-COVID and greater appetite for EU action on health in general. A follow up survey would allow us to evaluate the extent to which this trend has permeated down to disease-specific issues.
3. Ensure that we always **include an education element in our advocacy work** – to fill the gaps in policymakers' knowledge and to challenge misconceptions (such as the prevalence of young people with Parkinson's).
4. Many policymakers know, or are even related to, someone who has Parkinson's – we should remember this in our advocacy messaging and ensure we are **using our personal stories as much as hard data.**
5. Since the survey was conducted, the EU has launched its first initiative on non-communicable diseases (NCDs) with a dedicated strand on neurological diseases – this is a golden opportunity to address a key finding of the survey, that Parkinson's is underrepresented at EU level (especially in comparison to other diseases including cancer) – therefore the EPDA must **make this NCDs initiative an advocacy priority** in the coming years.
6. **Provide policymakers with policy recommendations and data**, since these were the top two requests from policymakers in the survey. These should therefore always be part of the package we deliver to policymakers in our advocacy, for example on the three key workstreams of the Parkinson's Advocacy Group (PAG).
7. **Change the EPDA's name to "Parkinson's Europe"** – not many policymakers were aware of the EPDA before the survey. There are a huge number of patient organisations in Brussels – but by making the name simpler and more self-explanatory we will be able to better raise awareness of Parkinson's and of our organisation. This is especially important given that the survey shows that other diseases (such as Alzheimer's and dementia) are more familiar to policymakers.

> *"Health per se is not an EU priority - but down the line something needs to change for Parkinson's disease"*
>
> - EU policymaker (anonymous)

Breakdown of Questions & Answers

Q1: Where do you work?

ANSWERS: There were a total of 33 responses to the survey. A majority (45%) came from the European Parliament, followed by the European Commission (27%) and EU Permanent Representations (24%). One respondent came from a pan-European patient organisation.

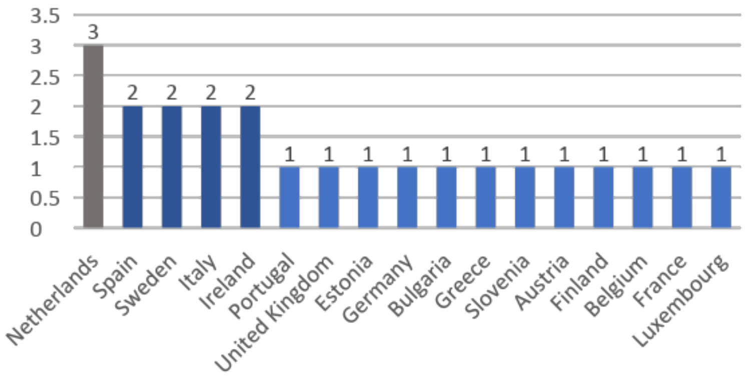


ANALYSIS & RECOMMENDATIONS: The vast majority of respondents to the survey came from the key EU institutions (European Commission and Parliament, as well as representatives of Member States from the Permanent Representations). We estimate that there are around 50 or 60 key relevant institutional policymakers, so we can conclude that these results provide a fairly accurate analysis of trends among policymakers.

At the time, several of the Commission officials were reluctant to respond as health was not within its remit. This might be different today as, coming out of the pandemic, the Commission has a newfound ambition on health policy, and has, for example, recently launched its first ever initiative on non-communicable diseases.

Q2: Which country do you represent?

ANSWERS: 23 of the respondents chose to identify the country they represent (this question was optional). Of these respondents, most came from the Netherlands, followed by Spain, Sweden, Italy and Ireland. Overall, at least 17 European countries are represented in this survey.

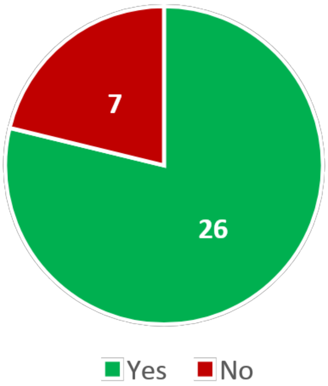


ANALYSIS & RECOMMENDATIONS: The survey results show a good geographical spread, with 17 countries represented of the 27 EU Member States. Not every respondent disclosed their nationality – this is understandable especially from Commission representatives who are supposed to represent the EU, not their home country.

Q3: Do you know what Parkinson’s disease is?

ANSWERS: Most of the respondents (79%) answered that they know what Parkinson’s disease is.

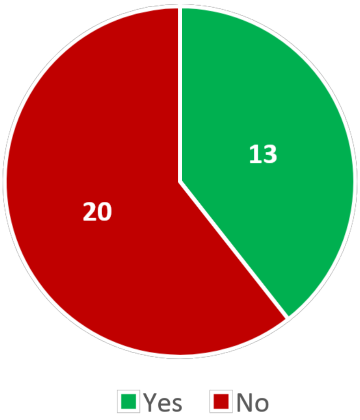
ANALYSIS & RECOMMENDATIONS: Over three quarters of the respondents reported that they had some degree of awareness of what Parkinson’s was. However, shockingly 21% of respondents revealed that they had little to no knowledge of the disease, which is especially concerning given we know that it is the fastest growing neurological disease in the world.



Q4: Are you aware of the European Parkinson’s Disease Association (EPDA)?

ANSWERS: By comparison, fewer respondents were aware of the EPDA, with only 39% aware of the EPDA prior to the survey.

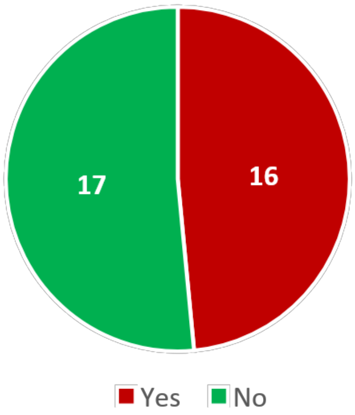
ANALYSIS & RECOMMENDATIONS: The results of the survey show that the majority of stakeholders have little to no awareness of the EPDA. During the interviews, it appeared that using the name “EPDA” was less effective, especially given how many associations with acronyms exist in Brussels but using a name such as “Parkinson’s Europe” immediately signals the organization’s purpose to the audience and therefore helps to raise awareness of both the organization and the disease.



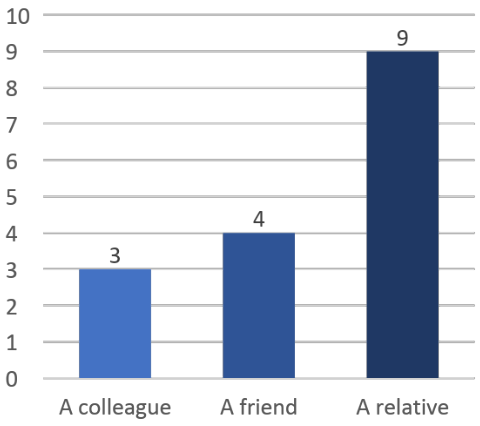
Q5: Do you personally know someone with Parkinson’s?

ANSWERS: About half (51%) of all respondents know someone with Parkinson’s.

ANALYSIS & RECOMMENDATIONS: Over half the respondents know someone who was directly affected by Parkinson’s. This is important as it draws the issue closer to home, meaning that if we frame our messages well, policymakers will be receptive to future discussions and engagement with EPDA.



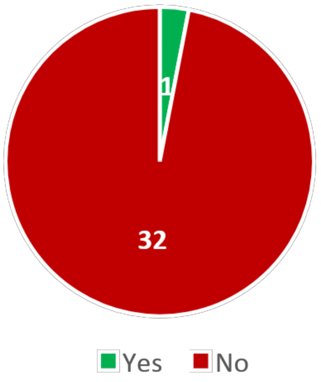
Q6: What is your relation to the person with Parkinson's?



ANSWERS: Of those who answered that they know someone with Parkinson's most (56%) answered that it's a relative.

ANALYSIS & RECOMMENDATIONS: The results of the survey showed that for most of the respondents who know someone with Parkinson's, that person is a relative. This means that a quarter of the respondents surveyed have a relative who has Parkinson's – illustrating that the impact of Parkinson's is perhaps greater than they realise. This emotional connection should make them more open to engaging with the EPDA.

Q7: Do you feel that you know enough about Parkinson's?

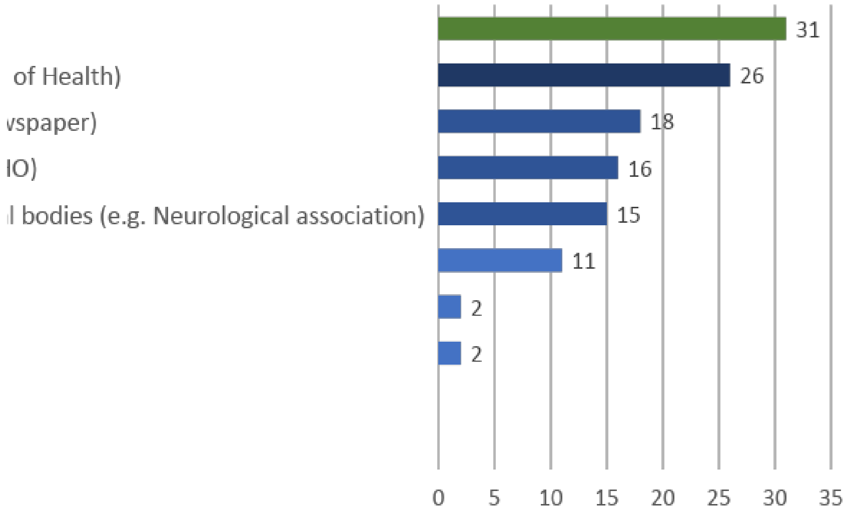


ANSWERS: An overwhelming majority answered that they feel they don't know enough about Parkinson's. Only one respondent answered that they feel that they know enough (this respondent was actually a representative from a patient organisation).

ANALYSIS & RECOMMENDATIONS: The results of the survey showed that all respondents, bar one (who was representing a patient organization, not an EU institution) felt that they were not sufficiently informed about Parkinson's – despite many knowing someone who has Parkinson's. Many of the respondents interviewed were particularly surprised to learn that Young Onset Parkinson's is so present in Europe, affecting 5-10% of all Parkinson's patients.

This clearly demonstrates the vital role of EPDA in informing legislators of their role, and the fact that the EPDA must work to close the knowledge gap as a first step in our advocacy.

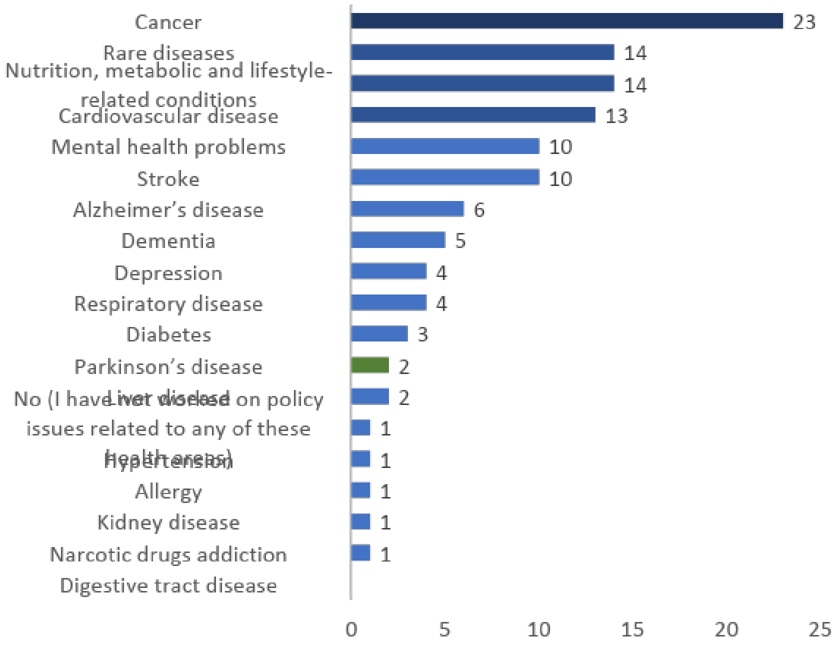
Q8: Where would you go to get information about Parkinson's?



ANSWERS: Almost all respondents (94%) answered that they would go to a patient organisation for information about Parkinson's. It is interesting to note that more respondents answered this compared to medical organization or professional bodies (15). Both of the respondents who answered "other" specified that they would go to the internet for information.

ANALYSIS & RECOMMENDATIONS: The survey showed that nearly all the respondents (94%) would go to a patient organisation for information about Parkinson's. This is promising for EPDA, as the survey confirms that respondents would resort to a patient organisation as their first port of call, rather than an official government website, news source, or medical organization. It also demonstrates the significant potential reach of the EPDA has when it comes to engaging with and influencing decision makers – something that must be exploited in our advocacy work.

Q9: Have you worked on policy issues related to any of the following health areas?



ANSWERS: Cancer is by far the area of health most respondents have experience with. 70% of all respondents answered this. Rare diseases and nutrition, and metabolic and lifestyle-related conditions both come in second place with 42% of respondents picking this option. Only 2 respondents answered that they have worked on policy issues related to Parkinson's; these two respondents are from the Commission and a patient organisation. By comparison, three times as many (6) have experience with Alzheimer's disease.

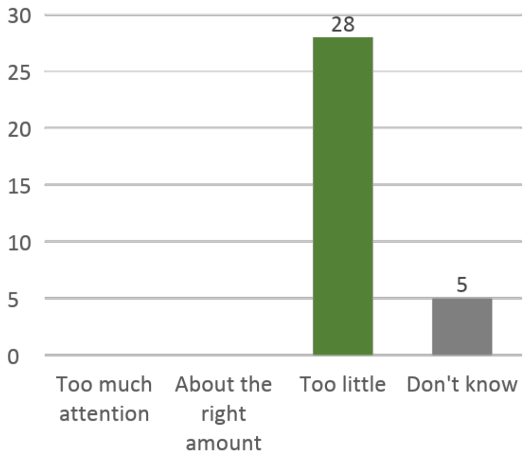
ANALYSIS & RECOMMENDATIONS: The survey shows that work on Parkinson's is considerably underrepresented at EU level, in comparison to other life limiting diseases such as cancer. This confirms that the attention given to Parkinson's at EU level is not in line with the burden it represents for patients and caregivers. Parkinson's is also underrepresented in comparison to other neurological diseases - three times as many (6) respondents have experience with Alzheimer's disease.

It would be interesting to ask the question again later this year, now that the European Commission has launched its "Healthier Together" initiative on non-communicable diseases, with a strand dedicated to neurological disease.

Q10: How much of a priority do you think Parkinson's currently has at EU-level?

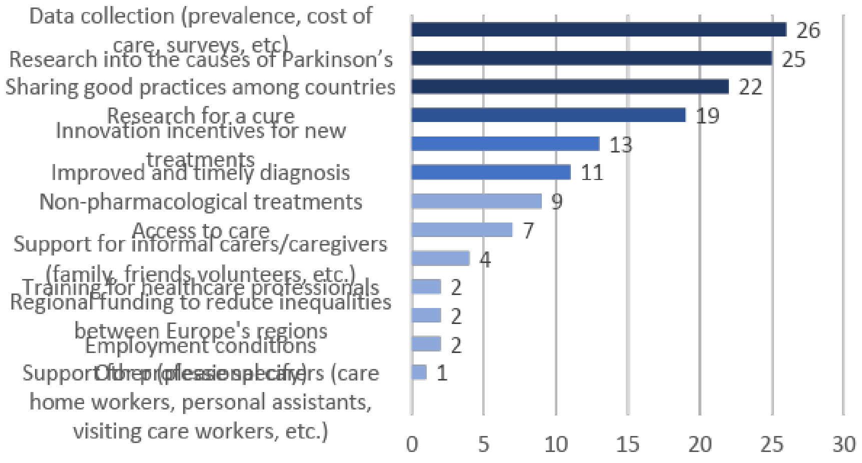
ANSWERS: It's clear that Parkinson's does not have much of a priority at EU-level. Nearly all respondents (85%) answered that it's "Too little" of a priority. The remaining respondents answered that they didn't know.

ANALYSIS & RECOMMENDATIONS: The results of the survey show that nearly all respondents feel that Parkinson's is underrepresented at EU level. As most (85%) feel that it is not a priority, it clearly demonstrates that there is a good basis for supporting further activities in EPDA's remit – particularly riding the wave of increased EU interest in health policy post COVID.



Q11: Which areas of action do you think should be prioritised for Parkinson's at EU level?

ANSWERS: The top three EU-level actions according to respondents were: data collection (prevalence, cost of care, surveys, etc) (79%), research into the causes of Parkinson's (76%), and sharing good practices among countries (67%). None of the respondents answered, "support for professional carers".



ANALYSIS & RECOMMENDATIONS: It makes sense that the top 3 areas of action chosen by the respondents are areas in which the EU traditionally has “added value”: data collection, supporting research and sharing good practices. While it is disheartening to see that none of the respondents answered “support for professional carers” – especially given the impact of Parkinson’s on care givers across Europe – but this is also understandable given the limited competence of the EU in this area. That said, this does indicate that the EPDA could make better use of its comprehensive Parkinson’s Carers Survey Report in its advocacy efforts.

Q12: As a policymaker, what do you primarily want from a patient organisation at EU level?

ANSWERS: EU policy recommendations (94%) and European data (91%) is what policymakers most want from an EU patient organization. Only very few respondents are interested in information about new research.

ANALYSIS & RECOMMENDATIONS: It is useful, though not surprising, to see that the respondents want policy recommendations, data and case studies from patient organisations such as EPDA. We will continue to ensure that this is something we provide as part of our advocacy outreach – as well as educating stakeholders about Parkinson’s itself.