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**WHAT
MATTERS
MOST**

A review of the
Parkinson's community's
campaign priorities for 2020-2024

What matters most?

A review of the Parkinson's community's campaign priorities for 2020-2024

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Introduction

The views and needs of people with Parkinson's, and their families and carers, are integral to both the work that Parkinson's UK does, and our ultimate ambition, which is to find a cure and improve life for everyone affected by the condition.

This report summarises the findings of the 'What matters most?' survey conducted by Parkinson's UK in 2020. It also includes the findings of the more recent coronavirus poll, which ran from 25 June to 31 July 2020, to understand if our communities' views had changed due to the coronavirus (COVID-19) pandemic.

These surveys aimed to identify the key issues facing people affected by Parkinson's, in order to ensure that our future campaigns effectively tackle the most important issues.

This report looks at the key issues by demographic, both geographically and by respondent type, in order to provide an insight into campaigns which will be of particular importance to our specific audiences.

The insight into each geographical group is particularly important because of the differing nature of health, social care and welfare systems across the UK. Since 1999, devolved governments in Scotland, Wales and Northern Ireland have used their powers separately from the UK government based at Westminster. That means that health and care systems are increasingly different in England, Scotland, Wales and Northern Ireland. Some aspects of the social security system are different in Scotland and Northern Ireland.

Examining the results of the 'What matters most?' survey and the coronavirus poll in this way aims to identify any health, social care or welfare issues which are particularly important to people affected by Parkinson's within each country, so we can effectively target future campaigns.

Acknowledgements

The Policy and Campaigns team would like to thank everyone who completed the survey; Alice Turner, Karen Smith, Gabs Abrahams and Philippa Bell in the design studio; Emma Halahan and Emma Hypher for copy editing; Parkinson's UK staff for promoting the survey; and also Sigita Stankeviciute and Benali Hamdache who analysed the data.

Executive summary

A total of 1,343 people completed the ‘What matters most?’ survey, which ran from 13 January to 17 May 2020. It was available both online and as a paper version, which was distributed to all Parkinson’s UK members with the March edition of *The Parkinson* magazine. Respondents were asked to state the three top areas they think Parkinson’s UK should campaign on.

To get the overall results, the three issues that people stated were categorised and then all the categories were analysed in order to find our priority issues.

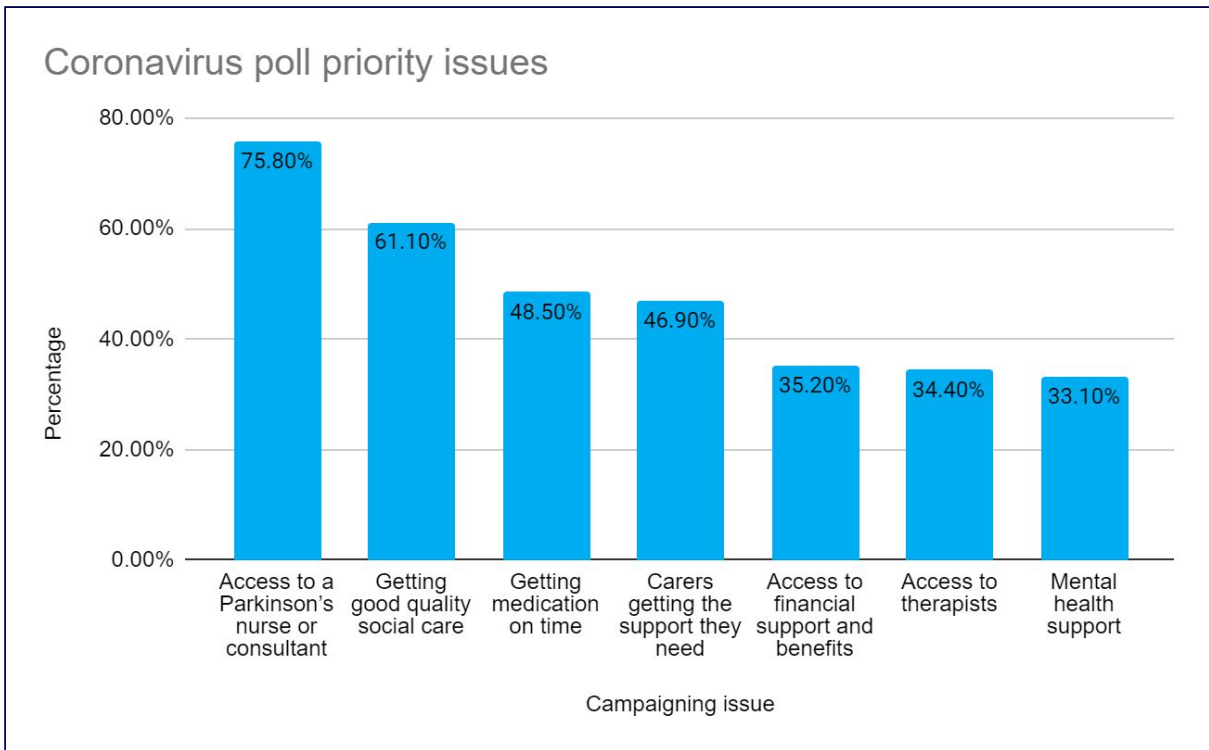
946 people completed our coronavirus poll, which was an online poll open from 25 June to 31 July 2020. As the pandemic had hit halfway through our survey, causing a great deal of uncertainty, we wanted to validate the views of our community with this additional poll.

As some areas of social policy are devolved to parliaments and assemblies across the UK, different priorities and needs regarding campaigns were identified. This was an important factor in analysing the results.

Looking at the ‘What matters most?’ survey, below are the most frequently mentioned issues that respondents stated they want Parkinson’s UK to campaign on:

Campaigning issue	Percentage
High quality health and social care	25.1%
Having access to the right treatments at the right time	16.1%
Being able to access financial benefits	13.7%
Getting medication on time in hospital or a care home	11.4%
Greater public awareness of the condition	5.7%
More support for patients, carers and families	4.8%
Factoring Parkinson’s into standards and guidelines	3.4%
Free prescriptions (although this is only an issue in England)	3.1%
Funding research	3.1%
Finding a cure	3%
Supporting people to demand better services	2.5%
Training NHS staff	1.8%

Looking at the coronavirus poll, below are the priority issues identified by respondents:



Geographical location

Looking at the 'What matters most?' survey in each geographical location, the following five issues were consistently important:

- High quality health and social care.
- Having access to the right treatments at the right time.
- Being able to access financial benefits.
- Getting medication on time in hospital or a care home.
- Greater public awareness of the condition.

However, there were some interesting differences in priority order across the four nations:

England (1,025 responses): Proportionally, the findings for England were nearly identical to those overall. However, respondents from England made up 79% of respondents, so will have had the greatest influence on overall findings.

Northern Ireland (27 responses): For people in Northern Ireland, being able to access financial benefits (13.5%) was more important than having access to the right treatments at the right time (12.2%) and greater public awareness of the condition (12.2%). Respondents in Northern Ireland were also more concerned about funding research, with 6.8% of respondents sharing that we should prioritise campaigning on this issue (compared to 3.1% for the UK). However, with only 2.1% of responses from Northern Ireland, we are unable to draw significant conclusions.

Scotland (161 responses): For people in Scotland, getting medication on time in hospitals and care homes (15.3%) was slightly more important than being able to access financial benefits (14.6%). More support for patients, carers and families

(6.1%) was more important than greater public awareness of the condition (4.5%). Responses from Scotland made up 12.4% of the total responses.

Wales (65 responses): 5.0% of the responses came from Wales and their priority order matched the UK order.

Other (20 responses): 1.5% of the responses came from the United States of America, Spain, Belgium, Denmark, Egypt, France and Serbia. They broadly mentioned the same issues in a similar way, even though there are wildly different health, care and welfare systems in these countries.

Respondent type

We have only been able to split the responses to the 'What matters most?' survey and not the coronavirus poll by respondent type, as the poll only asked what issues the respondent would prioritise and not their relationship with Parkinson's.

Below is a summary of the respondent types:

People with Parkinson's (774 responses): This group had similar findings to those overall and was by far the largest group at 58.9% of respondents.

Carers of someone with Parkinson's (130 responses): This group prioritised issues in a similar way. However, more support for patients, carers and families (7.2%) was more important than greater public awareness of the condition (4.1%).

Family members of someone with Parkinson's (343 responses): For this group, getting medication on time in hospitals and care homes (14.3%) was more important than being able to access financial benefits (10.1%). More support for patients, carers and families (7.2%) was more important than greater public awareness of the condition (6.8%).

Health or social care professionals (28 responses): This group prioritised issues in a similar way to the overall findings. However, more support for patients, carers and families (10.8%) was more important than greater public awareness of the condition (3.6%). This group made up 2.1% of the overall total.

Researchers (5 responses): This group made up only 0.4% of the overall total. High quality health and social care (25%) and being able to access financial benefits (25%) were the most important issues, followed by having access to the right treatments (12.5%) and finding a cure (12.5%). This group mentioned tackling social care funding (12.5%) – an issue that other groups didn't flag up.

Key messages

It is crucial that Parkinson's UK campaigns on the issues that matter most to the Parkinson's community. This way, people with Parkinson's, families and carers, as well as new supporters, will engage with the campaigns, helping to create an impact and influence real change.

The findings of the ‘What matters most?’ survey have highlighted the issues where our community wants us to campaign and influence change. These findings have been confirmed by the coronavirus poll.

Therefore the following issues will be the focus for our 2020-2024 campaigning work:

- **High quality health and social care.**
- **Having access to the right treatments at the right time.**
- **Being able to access financial benefits.**
- **Getting medication on time in hospital or a care home.**

Our current campaigns already tackle some of these issues, such as ‘Get It On Time’, which aims to improve people getting their medication on time when in hospital, as well as our welfare campaigns to make the benefits system fairer.

Interestingly, greater public awareness of the condition was a bigger priority for respondents to our 2016 survey – 27% of respondents mentioned the issue then compared to just 5.6% this year. Similarly, 17% of respondents mentioned finding a cure and 17% mentioned funding research in 2016 compared to just 3% and 3% this year. While our policy and campaigning work does not focus on these areas, we will work with other teams across the organisation to try and deliver improvements in these areas.

Methodology

The ‘What matters most?’ survey was distributed to all Parkinson’s UK members as an insert in *The Parkinson* magazine in March 2020. Paper copies were also made available to Parkinson’s UK local groups.

The survey could also be completed online and this was promoted through Parkinson’s UK social media channels (Twitter and Facebook) and also on the Parkinson’s UK website.

The survey was also distributed to supporters through internal and external channels, including organisational and departmental email newsletters and *Network News* (a printed monthly publication sent to Parkinson’s UK local groups and branches).

The survey provided an opportunity for people with Parkinson’s, and their families, friends and carers, to give a qualitative account of which issues matter most to them, and what they think Parkinson’s UK should campaign on until 2024.

The first section asked whether the respondent was a:

- person with Parkinson’s
- carer of someone with Parkinson’s
- family member of someone with Parkinson’s
- researcher
- health or social care professional.

The second section asked 'What issues do you think Parkinson's UK should campaign on?', and provided space for up to three answers.

The third section asked whether the respondent lived in:

- England
- Wales
- Northern Ireland
- Scotland
- Other

This question was particularly important due to the differing nature of health and social care provision and the welfare system across the four countries in the UK.

The sample

In total 1,343 people completed the 'What matters most?' survey before the deadline of 17 May 2020. Of those, 1,131 completed it online and 212 completed the paper copy.

Of the 1,343 respondents:

- 774 were people with Parkinson's
- 130 were carers of someone with Parkinson's
- 343 were family members of someone with Parkinson's
- 5 were researchers
- 28 were health or social care professionals
- 35 were others.

The 'others' included: volunteers, a campaigner and past carers or family members of someone with Parkinson's – either they were widows or widowers or the person with Parkinson's was their father or mother.

Of the 1,343 respondents:

- 1,025 were from England
- 65 were from Wales
- 161 were from Scotland
- 27 were from Northern Ireland
- 20 were others.

The others included people from: the United States of America, Spain, Belgium, Denmark, Egypt, France and Serbia.

Analysis

Respondents to the 'What matters most?' survey wrote in the free text boxes three issues they thought were most important for us to be campaigning on. These answers were then categorised.

To get the overall results, the three issues people identified were combined together to find our priority issues. Statistics (frequencies and percentages) were generated and are used as the basis for our prioritisation of the issues we will campaign on.

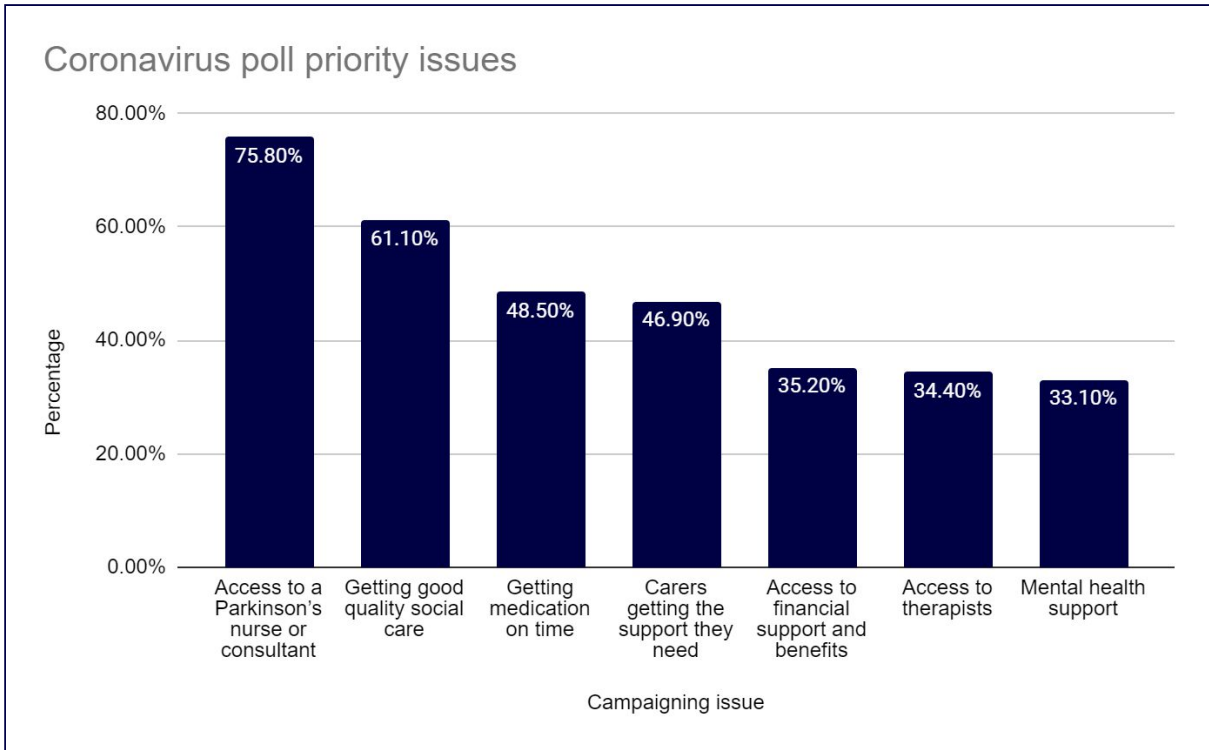
The data was broken down by country and type of respondent (with margins of error). As the numbers of respondents from countries other than England were low, confidence intervals were used to look for statistically significant differences.

Over 60 categories emerged. Below are the top 12 categories that were identified that had over 30 responses, and the percentages of respondents who mentioned them:

Campaigning issue	Percentage
High quality health and social care	25.1%
Having access to the right treatments at the right time	16.1%
Being able to access financial benefits	13.7%
Getting medication on time in hospital or a care home	11.4%
Greater public awareness of the condition	5.7%
More support for patients, carers and families	4.8%
Factoring Parkinson's into standards and guidelines	3.4%
Free prescriptions (although this is only an issue in England)	3.1%
Funding research	3.1%
Finding a cure	3%
Supporting people to demand better services	2.5%
Training NHS staff	1.8%

We thought it was important to identify the specific concerns by type of respondent, to highlight issues of particular importance for each group.

The coronavirus poll identified the following priority issues for our campaigning work to focus on:



Coronavirus poll results by country, number and percentage

	England (793 responses)	Northern Ireland (17 responses)	Scotland (90 responses)	Wales (46 responses)
Access to a Parkinson's nurse or consultant	(717) 90.4%	(14) 77.8%	(57) 63.3%	(32) 69.6%
Getting good quality social care	(578) 72.9%	(12) 66.7%	(57) 63.3%	(25) 54.4%
Getting medication on time	(459) 57.9%	(7) 38.9%	(46) 51.1%	(29) 63.0%
Carers getting the support they need	(444) 56.0%	(10) 55.6%	(39) 43.3%	(16) 34.8%
Access to financial support and benefits	(333) 42.0%	(7) 38.9%	(27) 30%	(18) 39.1%
Access to therapists	(325) 41.0%	(4) 22.2%	(17) 18.9%	(6) 13.4%
Mental health support	(313) 39.5%	(4) 22.2%	(35) 38.9%	(12) 26.1%

The coronavirus poll results were mainly a check and balance for us to make sure the pandemic hadn't changed our communities' views greatly.

Campaigning issues identified: Geographical location

UK

Below are the percentages of 'What matters most?' survey respondents overall who mentioned each of the 12 categories.

- High quality health and social care – 25.1%
- Having access to the right treatments at the right time – 16.1%
- Being able to access financial benefits – 13.7%
- Getting medication on time in hospital or a care home – 11.4%
- Greater public awareness of the condition – 5.7%
- More support for patients, carers and families – 4.8%
- Factoring Parkinson's into standards and guidelines – 3.4%
- Free prescriptions (although this is only an issue in England) – 3.1%
- Funding research – 3.1%
- Finding a cure – 3%
- Supporting people to demand better services – 2.5%
- Training NHS staff – 1.8%

England

Of the 1,343 respondents, 1,025 were from England, making up the majority (79%) of those taking part in the survey. Respondents in England had the same priorities as respondents as a whole. However the large response from England could skew the overall findings.

Northern Ireland

Respondents from Northern Ireland made up the smallest proportion of respondents overall, at 2.1%, with 27 people completing the survey. Due to this small sample size, we must take care when generalising these findings, and not apply them to all those in Northern Ireland affected by Parkinson's. However, the findings were still able to provide an insight into what is important to those affected by Parkinson's living in Northern Ireland.

As the table below shows, the most important issues for people in Northern Ireland were:

Campaigning issue	Percentage
High quality health and social care	25.7%
Being able to access financial benefits	13.5%
Having access to the right treatments at the right time	12.2%
Greater public awareness of the condition	12.2%
Getting medication on time in hospital or a care home	8.1%
Funding research	6.8%

Factoring Parkinson's into standards and guidelines	5.4%
More support for patients, carers and families	5.4%
Finding a cure	4.1%
Supporting people to demand better services	2.7%
Aids and adaptations	1.4%
More local support and improve access to local support	1.4%

Scotland

Of the 1,343 respondents, 161 were from Scotland, making up 12.4% of respondents overall. As the table below shows, the most important issues for people in Scotland were:

Campaigning issue	Percentage
High quality health and social care	24.7%
Having access to the right treatments at the right time	15.7%
Getting medication on time in hospital or a care home	15.3%
Being able to access financial benefits	14.6%
More support for patients, carers and families	6.1%
Greater public awareness of the condition	4.5%
Training NHS staff	2.9%
Factoring Parkinson's into standards and guidelines	2.7%
Finding a cure	2.7%
Funding research	2.7%
Supporting people to demand better services	1.8%

Wales

Of the 1,343 respondents, 65 were from Wales, making up 5.0% of respondents overall. As the table below shows, the most important issues for people in Wales were:

Campaigning issue	Percentage
High quality health and social care	24.2%
Having access to the right treatments at the right time	16.9%
Being able to access financial benefits	16.3%
Getting medication on time in hospital or a care home	14.6%
Greater public awareness of the condition	7.9%

Factoring Parkinson's into standards and guidelines	3.9%
More support for patients, carers and families	3.4%
Supporting people to demand better services	2.8%
Finding a cure	2.2%
Funding research	1.7%
Training NHS staff	1.7%
Access to exercise opportunities	1.1%
Information about the condition	1.1%

Other

20 respondents fell into the 'other' geographical category, living in the United States of America, Spain, Belgium, Denmark, Egypt, France and Serbia.

They broadly prioritised the issues in a similar way, even though there are wildly different health, care and welfare systems in each of these countries.

Campaigning issues identified: Respondent type

People with Parkinson's

Of the 1,343 respondents to the survey, 774 were people with Parkinson's. They made up the majority (58.8%) of the sample. The most important issues for people with Parkinson's were:

Campaigning issue	Percentage
High quality health and social care	24.6%
Having access to the right treatments at the right time	17.0%
Being able to access financial benefits	15.8%
Getting medication on time in hospital or a care home	9.9%
Greater public awareness of the condition	5.3%
Free prescriptions (although this is only an issue in England)	4.1%
Finding a cure	3.9%
Funding research	3.3%
More support for patients, carers and families	3.2%
Factoring Parkinson's into standards and guidelines	2.7%
Supporting people to demand better services	2.4%
Training NHS staff	1.2%
Access to exercise opportunities	1.1%

These findings are broadly similar to those of the overall responses.

Carers of people with Parkinson's

Of the 1,343 respondents, 130 were carers of someone with Parkinson's, making up 9.9% of respondents overall. The most important issues for carers were:

Campaigning issue	Percentage
High quality health and social care	28.7%
Having access to the right treatments at the right time	14.1%
Being able to access financial benefits	11.6%
Getting medication on time in hospital or a care home	11.6%
More support for patients, carers and families	7.2%
Factoring Parkinson's into standards and guidelines	4.7%
Greater public awareness of the condition	4.1%
Supporting people to demand better services	3.6%
Funding research	2.8%
Training NHS staff	2.2%
Finding a cure	1.9%
Free prescriptions (although this is only an issue in England)	1.7%
Improved accessibility	1.4%

Family members of someone with Parkinson's

Of the 1,343 respondents, 343 were family members of someone with Parkinson's, making up 26.0% of respondents overall. The most important issues for family members were:

Campaigning issue	Percentage
High quality health and social care	25.4%
Having access to the right treatments at the right time	15.2%
Getting medication on time in hospital or a care home	14.3%
Being able to access financial benefits	10.1%
More support for patients, carers and families	7.2%
Greater public awareness of the condition	6.8%
Factoring Parkinson's into standards and guidelines	4.1%
Training NHS staff	2.8%
Supporting people to demand better services	2.7%

Funding research	2.7%
Free prescriptions (although this is only an issue in England)	1.9%
Finding a cure	1.5%

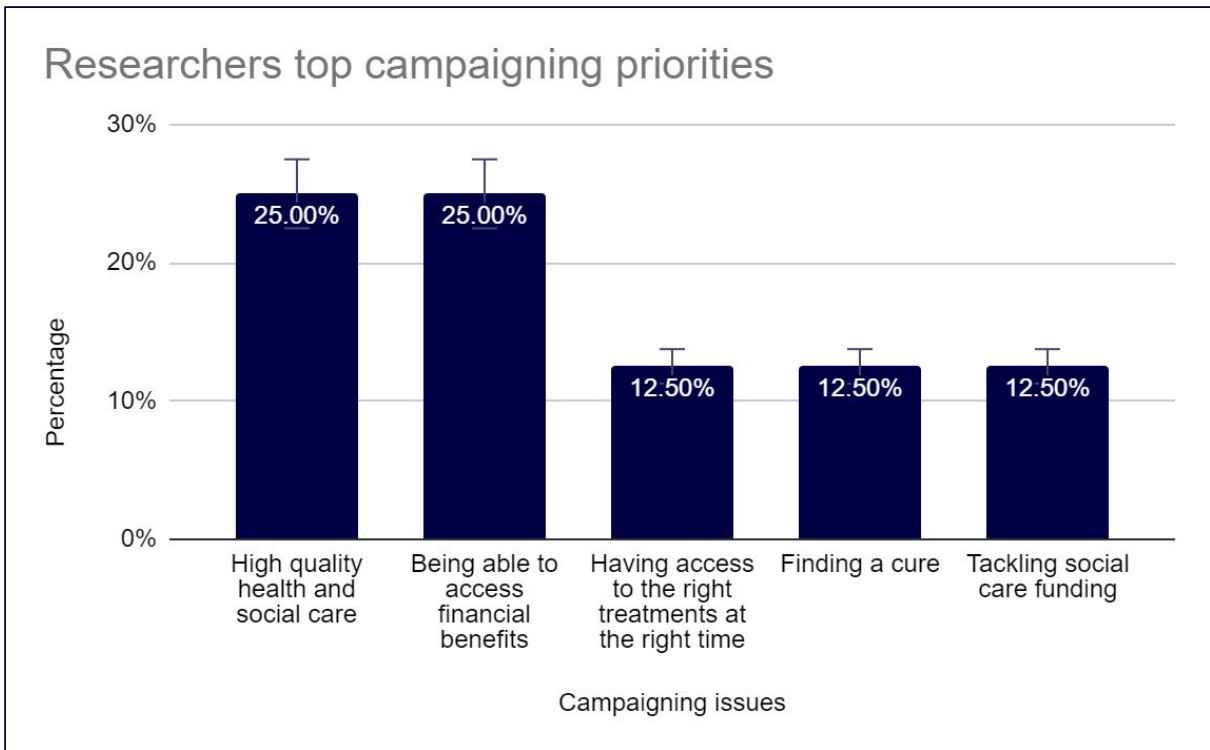
Health and social care professionals

28 of the respondents were health or social care professionals, making up 2.1% of respondents overall. The most important issues for health and social care professionals were:

- High quality health and social care – 19.3%
- Having access to the right treatments at the right time – 19.3%
- Being able to access financial benefits – 10.8%
- Getting medication on time in hospital or a care home – 10.8%
- More support for patients, carers and families – 10.8%
- Factoring Parkinson’s into standards and guidelines – 7.2%
- Funding research – 6.0%
- Greater public awareness of the condition – 3.6%
- Training NHS staff – 2.4%
- More assistance with aids and adaptations – 1.2%
- Local support – 1.2%
- Co-ordination of care – 1.2%
- Early diagnosis – 1.2%
- Finding a cure – 1.2%
- Free prescriptions (although this is only an issue in England) – 1.2%

Researchers

Of the 1,343 respondents, 5 were researchers, making up the smallest percentage of respondents at 0.4%. The most important issues for researchers were:



Other

A total of 35 people came under the 'other' category. Of these, many included volunteers, a campaigner, Parkinson's UK staff and past carers or family members of someone with Parkinson's – either they were widows or widowers or the person with Parkinson's was their father or mother.

The top issues identified by this category of respondents were broadly similar to the other respondent types:

- High quality health and social care – 25.3%
- Being able to access financial benefits – 14.1%
- Getting medication on time – 14.1%
- Having access to the right treatments at the right time – 12.1%

However, greater public awareness of the condition (9.1%) was higher than for the other respondent types.

Our future campaigns for change

It is crucial that Parkinson's UK campaigns on the issues that matter most to the Parkinson's community. This way, people with Parkinson's, families and carers, as well as new supporters, will engage with the campaigns, helping to create an impact and influence real change.

The findings of the 'What matters most?' survey have highlighted the issues our community want us to campaign and influence change on. These findings have also been confirmed by the coronavirus poll.

Therefore the following issues will be the focus for our 2020-2024 campaigning work:

- **High quality health and social care.**
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- **Getting medication on time in hospital or a care home.**

Our current campaigns already tackle some of these issues, such as 'Get It On Time', which aims to improve people getting their medication on time when in hospital, as well as our welfare campaigns to make the benefits system fairer.