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# Consultation on genetic testing for Parkinson’s

The views of people affected by Parkinson’s on the idea of offering a genetic test to people newly diagnosed with the condition

August 2019

## Summary

- Parkinson’s UK is considering a programme which would give people newly diagnosed with Parkinson’s the opportunity to have a genetic test, in order to get information on potential eligibility for clinical trials for drugs targeting genetic forms of the condition.
- Feedback on this idea was sought from people with Parkinson’s, carers, partners and family members via a survey (n=723) and a half-day workshop (n=17).
- There was generally strong support for the idea - people felt it would have significant benefits for Parkinson’s research and the development of new treatments, as well as important individual benefits for the people affected by the condition.
- There were mixed feelings about the point at which genetic testing should be offered following diagnosis - people need time to get over the initial shock of diagnosis, but this will be different for everyone.
- There was concern about the information and support that would be available throughout the process for people with Parkinson’s, carers, partners and family members - it was felt that the current structures in place would not provide the quality of support needed.
- There needs to be careful consideration around how information about this programme is communicated to people affected by Parkinson’s and healthcare professionals who will be involved.

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# Acknowledgements

Thank you to the Parkinson's UK Research Support Network Development Team for providing feedback which helped shape the development of this consultation. Particular thanks to volunteers Alan Cameron, Carroll Siu and Tim King for their input in designing the survey questions and planning the workshop.

## Background

Most people with Parkinson’s have what is called ‘idiopathic Parkinson’s’, meaning that there is no known cause. For a small minority of people with Parkinson’s, there is a genetic link.

Parkinson’s UK is considering a programme which would give people newly diagnosed with Parkinson’s the opportunity to have a free genetic test. This test would tell people whether or not they have specific genes associated with Parkinson’s. Those who do may be eligible to take part in clinical trials that are aimed at targeting specific genetic forms of Parkinson’s.

While most people do not have a genetic link to Parkinson’s, these new trials will increase our understanding of Parkinson’s and have the potential to benefit all with the condition.

Parkinson's UK is keen to take a leading role in developing any such programme to be made available in the UK, in order to ensure the best possible outcomes for people affected by Parkinson’s.

## The consultation

We wanted to get feedback from people affected by Parkinson’s on the idea of offering a genetic test to people newly diagnosed with the condition. We wanted to know if this was something people would consider, and better understand people’s motivations for having such a test. We also wanted to find out what concerns people might have about this idea, and learn from people affected by Parkinson’s what practical things Parkinson’s UK need to consider if we were to take this programme forward.

We sought feedback from people affected by Parkinson’s via two routes: a survey and a face-to-face workshop.

### Survey

There were six questions to gather people’s feedback on the topic, as well as additional questions to capture people’s association with Parkinson’s and demographic information.

The survey was aimed at people affected by Parkinson’s - people with Parkinson’s, and carers, partners and family members of people with the condition.

The survey was shared via the following routes:

- Research Support Network
- Campaigns network

- Younger Parkinson’s Alliance
- Social media (Parkinson’s UK Twitter and Facebook)
- Via research volunteers
- Shared with Parkinson’s UK staff to distribute to their networks (shared with local advisors in the Monday Message, all staff via internal communications)

The following page gives an overview of survey respondents.

## Workshop

The workshop was held on 30 July in central London, from 10:30am - 2.30pm.

The opportunity to attend the workshop was shared with the following groups:

- Branches and groups (in locations accessible to London)
- Research Support Network and patient and public involvement volunteers (in locations accessible to London)
- Parkinson’s UK forum

17 people affected by Parkinson’s attended, including five partners/family members of people with the condition.

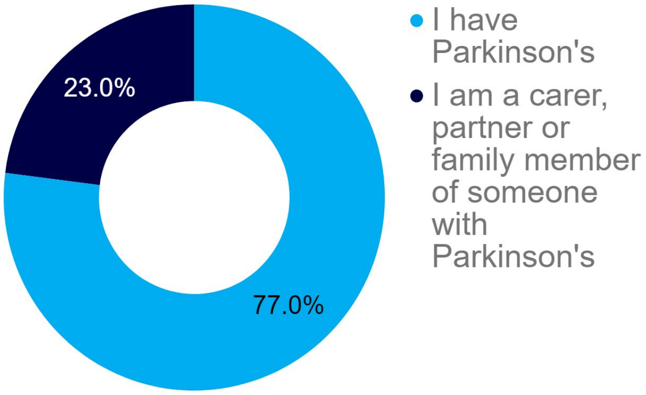
The workshop was hosted and facilitated by members of the Parkinson’s UK research team.

The morning session included talks from Prof. David Dexter (Parkinson’s UK) and Prof. Arndt Rolfs (Centogene), as well as a Q&A. The afternoon consisted of table discussions to talk about some of the key themes arising from the morning.

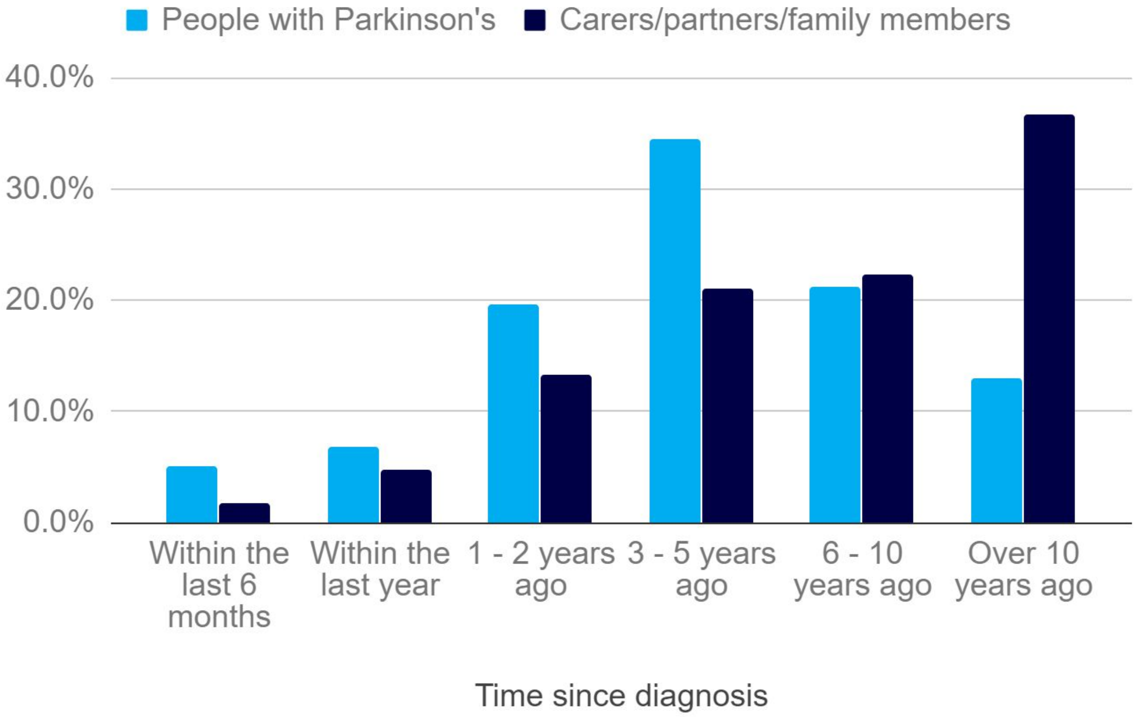
Survey respondents:

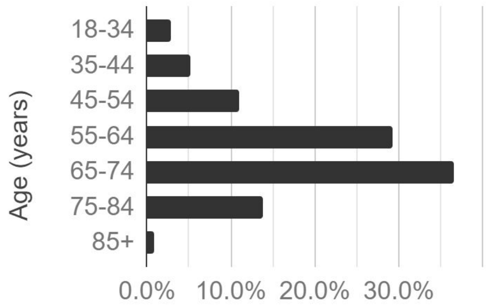
**723**

**survey responses**



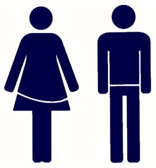
**62.7%** of respondents were members of the Parkinson’s UK Research Support Network





56.4% female

43.4% male



Ethnicity:

> 90% white

Education: > 50% university-educated

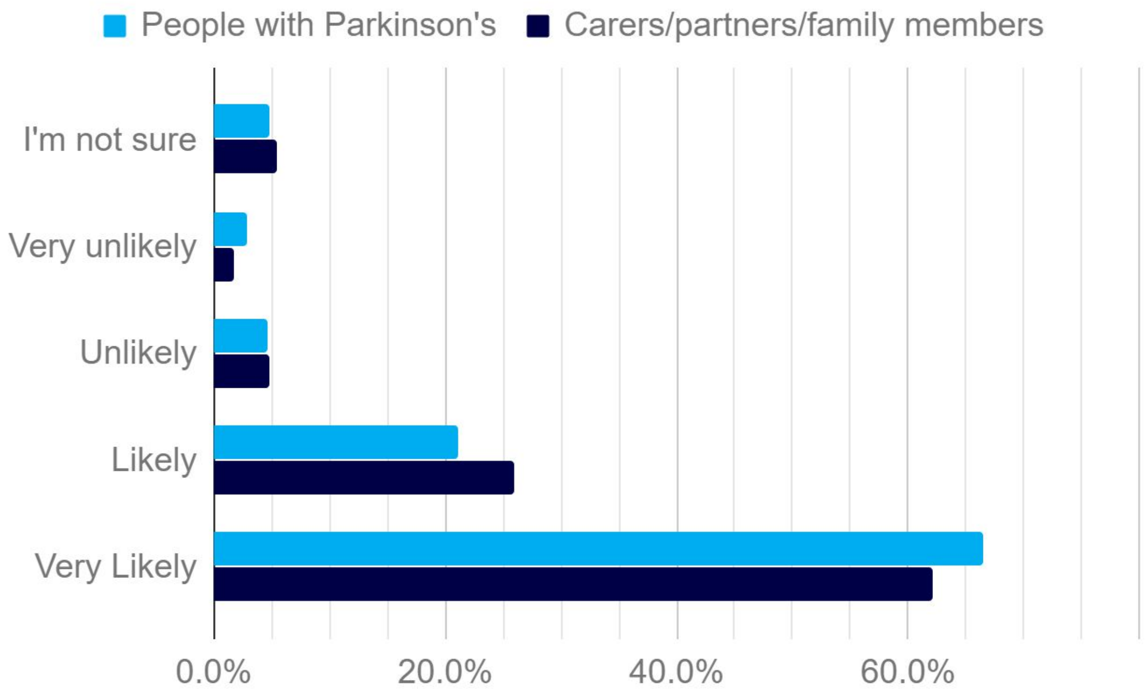
## Would people consider having a genetic test?

We asked survey respondents to think back to when they were diagnosed (or when their family member/partner/person they care for was diagnosed).

**Q. How likely would you have been to have chosen to have a genetic test?***

**[to find out if they had particular genes associated with Parkinson's which could enable them to take part in specific clinical trials]*

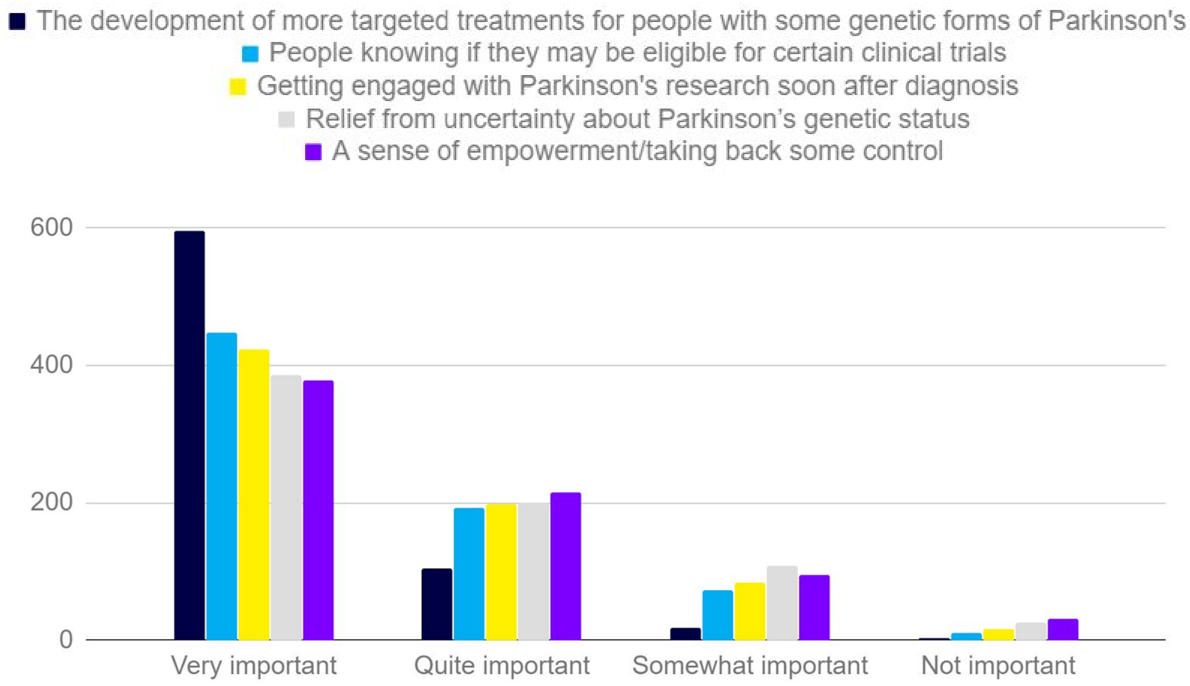
(Carers/partners/family members were asked how likely they would have been to want the person with Parkinson's to have the test).



The response was very positive - the vast majority of people said they would have been likely or very likely to have chosen to have a genetic test or to have wanted the person with Parkinson's to have the test. This was echoed during discussions at the workshop.

## Understanding motivations for having a genetic test

In the survey, we gave people a list of possible outcomes of having the test and asked them to rate how important they thought they were. People with Parkinson's and carers/partners/family members rated each of the possible outcomes as similar importance. The graph below shows the combined responses from all respondents:



Another important outcome that was identified in survey free text responses, and at the workshop, was being able to pass on information about genetic status to children, grandchildren and other family members.

> *“I feel it is important that my children know about my genetic status.”*
>
> *“Ability to advise close family relations of their likelihood of being affected by Parkinson's.”*
>
> *“As a family member I would be interested to find out whether myself or my children would be likely to carry it if it turned out to be a genetic form.”*

Some people commented that having the test could give reassurance to family members:

> *“Being able to tell your children "not to worry" !!”*
>
> *“If negative about genetic link, being able to reassure close blood relatives.”*
>
> *“Peace of mind for myself and future generations ”*
> *[carer/partner/family member]*

It is important to remember that the genetic test under consideration would only tell people about a small number of specific genes currently associated with Parkinson’s. The potential outcomes referred to here emphasise the need to provide accurate information to people about what the genetic test can and cannot reveal.

At the workshop, another important motivation for having a genetic test via the proposed programme that was repeatedly mentioned was **hope**. The proposed programme offers people a “chance to see a way forward to possible new therapies” and a cure, which would motivate people to be involved.

Even though it wouldn’t help those taking part immediately, it might do in the future. For some, the motivation for taking part in any research is mostly altruistic anyway. People care about Parkinson’s - they want to help.

Other motivations identified at the workshop:

Making a difference

Helping towards finding a cure/treatment/better management of Parkinson’s

Peace of mind

It’s worth a try

Increase own knowledge - knowledge is power

Possibility to benefit from future research that is based on this information

Good for mental health

Better understanding of Parkinson’s

Being involved [in research] gives you more engagement with healthcare professionals

Making the UK a more appealing place for drug companies to conduct trials

## Understanding people’s concerns about having a genetic test

In the survey, the most significant concern both people with Parkinson’s and carers/partners/family members had was regarding **the implication of test results for family**. This was also identified as a key concern at the workshop.

- Some people with Parkinson’s were concerned about how they would discuss the outcomes of the test with their family. One person pointed out that different attitudes within families could cause issues. For people with young-onset Parkinson’s, the outcome of the test could impact family planning.

  *“How you communicate any ‘bad’ news, if that is a possibility.”*

  *“If there is no advantage to family members knowing early in terms of intervention or prevention, the information is only anxiety inducing.”*

- People also felt that testing should be available for family members (if genetic link found).

**The support/genetic counselling that would be available after receiving results** was also rated as a significant concern for all survey respondents - although carers/partners/family members rated this as slightly more of a concern compared to people with Parkinson's.

- It is important that emotional support is available alongside factual information.
- People commented that it was vital to include family members in support/counselling.

  *"Support should be available for the whole family."*

  *"Unsure re counselling- seems unavailable these days."*

- At the workshop, people highlighted that support needs to be available throughout the process - including before people have the test, to help them make an informed decision.
- There was significant concern about how readily available support and information would be.
- Many people also felt strongly that information sharing should happen in person or over the phone/Skype - reading information leaflets or online feels impersonal.

**Understanding how the results may affect insurance** was also a concern.

- At the workshop, people highlighted that there could also be other financial implications, as well as implications on people's lifestyles more generally.

**Other concerns raised at the workshop included:**

- Benefits of the programme could be undermined by the current political climate - the UK less appealing for research
- Being 'dropped' by drug companies - companies losing interest in clinical trials that are targeting genetic forms of the condition
- The time that it might take to see any benefits from this programme
- The cost to Parkinson's UK - could the money spent on this programme be better spent elsewhere?
- Finding out about something you can't do anything about

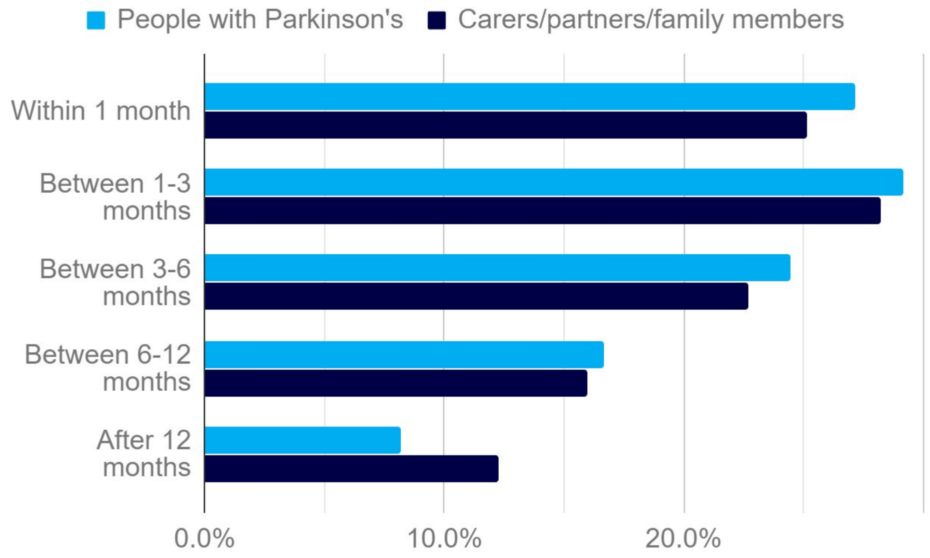
Relatively few people rated 'the accuracy of sequencing technology' or 'how the data might be shared' as significant or moderate concerns.

- In free-text comments, and at the workshop, people did emphasise the importance of data protection and ensuring that data was secure and would not be sold to other companies.

## When should people be offered the test?

**Q: At what point after diagnosis should people be offered the opportunity to have a genetic test?**

The survey revealed mixed opinions on when the testing should be offered:



Over 50% of people thought that testing should be offered within 3 months of diagnosis, and over 75% within 6 months.

Many people felt like there needed to be a period of time for people to consider this after diagnosis:

> *"I think the shock of diagnosis would need to settle before the tests were offered."*
>
> *"I don't think that offering this at point of diagnosis or soon after is appropriate for everyone. In our case the diagnosis itself was very difficult, and being presented with information that you could have passed a Parkinson's gene on to children or grandchildren would have only added to the stress."*
>
> *"A sensitive approach is necessary with good information.."*

At the workshop, some people said they thought that the information should be introduced as soon as possible.

- Often people's first thoughts after diagnosis are about their children - genetics is often on people's minds from the start.

- Giving people information about genetics sooner rather than later could help prevent misinformation.
- It could bring relief to people, and help them have a better idea of ‘why’.

The timing of the offer could also have implications for the research.

- Most people start medication for their Parkinson’s straight away, but many trials are looking for people who haven’t started taking dopamine agonists. Therefore, people need to be informed about this programme as soon as possible, before they begin medication.

## Information and communication

### What information would people need?

The survey asked:

**Q: What information do you think people would need to be able to decide whether to have a test to find out their Parkinson’s genetic status?**

(Carers/partners/family members were asked what information they would need to support someone with Parkinson’s to decide whether to have a test).

In the survey, people were given a list of eight different types of information and were asked to rate the importance of each.

For both people with Parkinson’s and carers, family members and partners, **information about what the test results could reveal** was rated as the most important piece of information to have.

Other information that was considered important:

- Information about relevant research opportunities *(2nd most important for people with Parkinson’s)*
- Information about genetic counselling services
- Information about how genetic testing works
- Details about who will be able to access the data
- Details about the possible implications for insurance

An introduction to genetics and information on how the consent process works were mostly rated as ‘somewhat’ or ‘quite’ important.

The findings from the survey were supported by discussions in the workshop:

- People highlighted the importance of delivering a clear message about the programme - only a small percentage of people will have genes that could make them eligible for genetic clinical trials.
- People should be presented with all relevant information to be able to make an informed decision. It was felt important to be clear about the involvement of pharmaceutical companies in this initiative.

Discussions at the workshop also went beyond the ‘what’ to also discuss the ‘how’ and ‘who’.

## How should the information be communicated?

Using appropriate **language** to describe the programme is crucial.

- It was felt that describing this offer as ‘genetic testing’ is not really representative, given that the main aim is giving people information that could inform them about possible eligibility for clinical trials. The word ‘genetic’ may also scare some people.
- The information also needs to be communicated very clearly, in Plain English - but without ‘talking down’ to people. People affected by Parkinson’s should be involved in designing and reviewing information.

The **format** of information also needs to be carefully considered.

- It was suggested that there should be an information ‘pack’ available to all - this would offer consistency in the information delivered.
- However, there should be different options for what this ‘pack’ looks like and the format of the information. For example, some people may prefer videos, whereas others might prefer accessing information online, or others having a leaflet to read through.
- Ultimately, the information needs to be available in a range of formats to make it understandable and engaging for everyone, and to ensure that the information is reaching all demographics.  The availability of information in different languages is important.
- It can’t be assumed that everyone is online/has access to a computer for further information - many people don’t.

People felt strongly that an information pack should not be a substitute for a conversation - **the opportunity to speak to someone is vital**.

- People also suggested that it would be good to hear from people with Parkinson’s who’d had a test done. It would also be good to be connected with other people recently diagnosed and in the same situation.

## Who should give people the information?

At the workshop, there was much discussion around who should be giving people information about the programme.

Healthcare professionals were considered vital for sharing information. If information was only offered by Parkinson's UK, there was concern this would miss people who are not motivated/don't want to find out more about their condition. It was felt that **Parkinson's nurses** would be a good group to communicate the information.

- People often see their Parkinson's nurse more often and for longer compared to a consultant, and so they have a better relationship with them.
- GPs' knowledge of Parkinson's is very variable.

> *"Consultants or Parkinson's nurses will probably be best placed to decide when is appropriate to raise it with patients."*

The programme needs to be introduced when there is sufficient time to explain it properly.

> *"The tests should be useful to doctors and researchers, but may not mean much to many patients without careful, basic explanation which would need time, not a brief consultation with a busy doctor or nurse."*

- It would be good to have someone available following the initial appointment to answer questions and talk through the programme in more detail.
- Someone suggested writing a script for healthcare professionals, again to ensure consistency in the information given.

Parkinson's UK local advisors would also be important for answering questions, as well as the Helpline.

Some people commented that their consultant had recommended against genetic testing, indicating that there could be reluctance from some healthcare professionals to be involved in the programme. It was felt that there needs to be education for healthcare professionals on the programme to ensure they are prepared to support people affected by Parkinson's.

The quality of the information and support provided as part of this programme was considered to be crucial. However, **people felt that at the moment, the support structure that would be required is not there**.

- People had very varied experiences of diagnosis and support. There was concern about a 'postcode lottery' for information and support, making the programme effectively unavailable for some communities due to the lack of support.

## Practicalities of the testing

At the workshop, the practicalities of having a genetic test were discussed, including the pros and cons of different types of test and where tests should be done.

| | **Test done by healthcare professional** | **Self-administered test done at home** |
|---|---|---|
| ⊕ | ○ Gives opportunity for people to ask further questions<br>○ Interaction with healthcare professional shows that it's important, that someone cares<br>○ Less risk of contamination<br>○ Confidence that it has been done properly | ○ Easy if saliva test<br>○ Would need clear instructions, including pictures, step-by-step video<br>○ Would need to safe and simple e.g., kits for bowel cancer |
| ⊖ | ○ Travel/transport could be an issue for people who need to attend an appointment<br>○ Could disadvantage rural communities<br>○ Hard to get appointments anyway - could lead to time delay | ○ Motor symptoms could make it difficult to do by yourself - fiddly to operate a pin-prick device<br>○ Worry about the validity of the test - have you done it correctly?<br>○ Questions about how to dispose of any sharps<br>○ Could be stressful |

Generally, people felt that having the test done by a healthcare professional would be preferable for most people.

- Some people said they would feel comfortable doing the test themselves, so long as clear information and guidance was provided. One person suggested the option of doing the test at home and then having it checked by a GP.

## Additional feedback

At the end of the survey, people were invited to note down any other comments they wanted to share.

### Support for the idea

Many people were generally supportive of the proposed programme and wanted Parkinson's UK to take a lead in increasing the availability of genetic information.

> *"Fantastic idea, would be a relief for many with Parkinson's."*

Several people highlighted that genetics is often something that comes to mind upon receiving a diagnosis, so being offered the opportunity to have a test would be helpful.

> *"When I was first diagnosed after the shock subsided my next worry was for my sons. Would they get it?"*

However, some of the comments emphasised the importance of providing clear and accurate information about what the test results would and would not tell people.

### Testing should be offered to all

A number of people felt that genetic testing should be offered to anyone with Parkinson's, regardless of time since diagnosis. Not only would this information be important for people with Parkinson's and their families, but it was felt that this would be valuable for Parkinson's research in general.

> *"So if I'm 5 years post-diagnosis am I not worth studying in a gene-related trial?"*

> *"If this is a simple thing to do, then this should be offered to everyone, surely?"*

### Knowing genetic status doesn't affect treatment

A handful of people felt that having the test wouldn't provide any useful information for people with Parkinson's. Even when people know they have a genetic form of Parkinson's, currently this doesn't affect their treatment, so knowing might only cause more stress.

> *"Until we have better treatments, or a cure, knowing your chance of getting PD is interesting and may help research, but will not affect the outcome."*

## Key takeaways from the consultation

- There was a positive response towards the idea, with the majority of people with Parkinson's reporting that they would have been very likely to have had a genetic test if it had been offered to them when they were diagnosed. Carers, partners and family members reported that they would have been very likely to have wanted the person with Parkinson's to have a genetic test.
- The development of more targeted treatments for people with some genetic forms of Parkinson's was considered a very important outcome, as were other benefits for Parkinson's research.
- Knowledge of genetic status would bring additional important benefits for people affected by Parkinson's, including being able to pass on information about genetic status to family members and potentially reduce worry about developing the condition.
- There were mixed feelings about the point at which genetic testing should be offered following diagnosis. Many people highlighted the importance of giving people time to consider it, without feeling rushed. Others highlighted the benefits of being offered the test sooner rather than later.
- It is vital that adequate support and information is available throughout the process, to help people decide whether to have the test and to support them in understanding the results. Support needs to be available for family members as well as the person with the condition.
- There needs to be careful consideration about how this programme is delivered to people affected by Parkinson's, particularly around the information provided to people and the practicalities of preparing for and carrying out the test.
- People felt that there was not currently a sufficient support structure in place to support adequate delivery of this programme to all people affected by Parkinson's across the UK.
- A number of people felt that this is something that should be offered to everyone affected by Parkinson's, regardless of time since diagnosis. Others felt that the information is mostly useful for research and would have little benefit for the individual.

## What’s next?

The consultation has provided lots of important insights for Parkinson’s UK to consider in the continued development of this project.

The research team are in continued discussions with pharmaceutical companies and other industry partners who are interested in being involved to further scope out what this programme will look like and how it will be delivered. The consultation highlighted the importance of ensuring that the data collected through this programme is used as broadly as possible to increase our understanding of Parkinson's and help develop new treatments. The programme, therefore, needs to have the flexibility to incorporate this, whilst ensuring that the sharing of data is secure and in line with data protection policies. The feedback from people affected by Parkinson’s on the practicalities of the testing will also be crucial for deciding what approach to adopt.

The feedback from the consultation will also be vital in shaping Parkinson’s UK’s work to improve the support and information available for people newly diagnosed with Parkinson’s and their families. The charity is currently undertaking a large project to explore how to provide more personalised information to people affected by Parkinson’s right from the point of diagnosis. The consultation highlighted a number of challenges with respect to the provision of information and support for people affected by Parkinson’s. The insights gathered will be vital for informing the development of this wider project and ensuring that sufficient information and resources are available to support the introduction of the proposed genetic testing programme.

Parkinson’s UK will be continuing to develop the ideas for the programme both internally and with external partners over the coming months. A programme of this nature will require lots of pilot testing before it is made available more broadly. The aim is to be ready to start piloting this by April 2020. We will be continuing to work with people affected by Parkinson’s throughout the development to address the key topics raised in the consultation, to ensure the programme delivers maximum benefit for people affected by Parkinson’s.