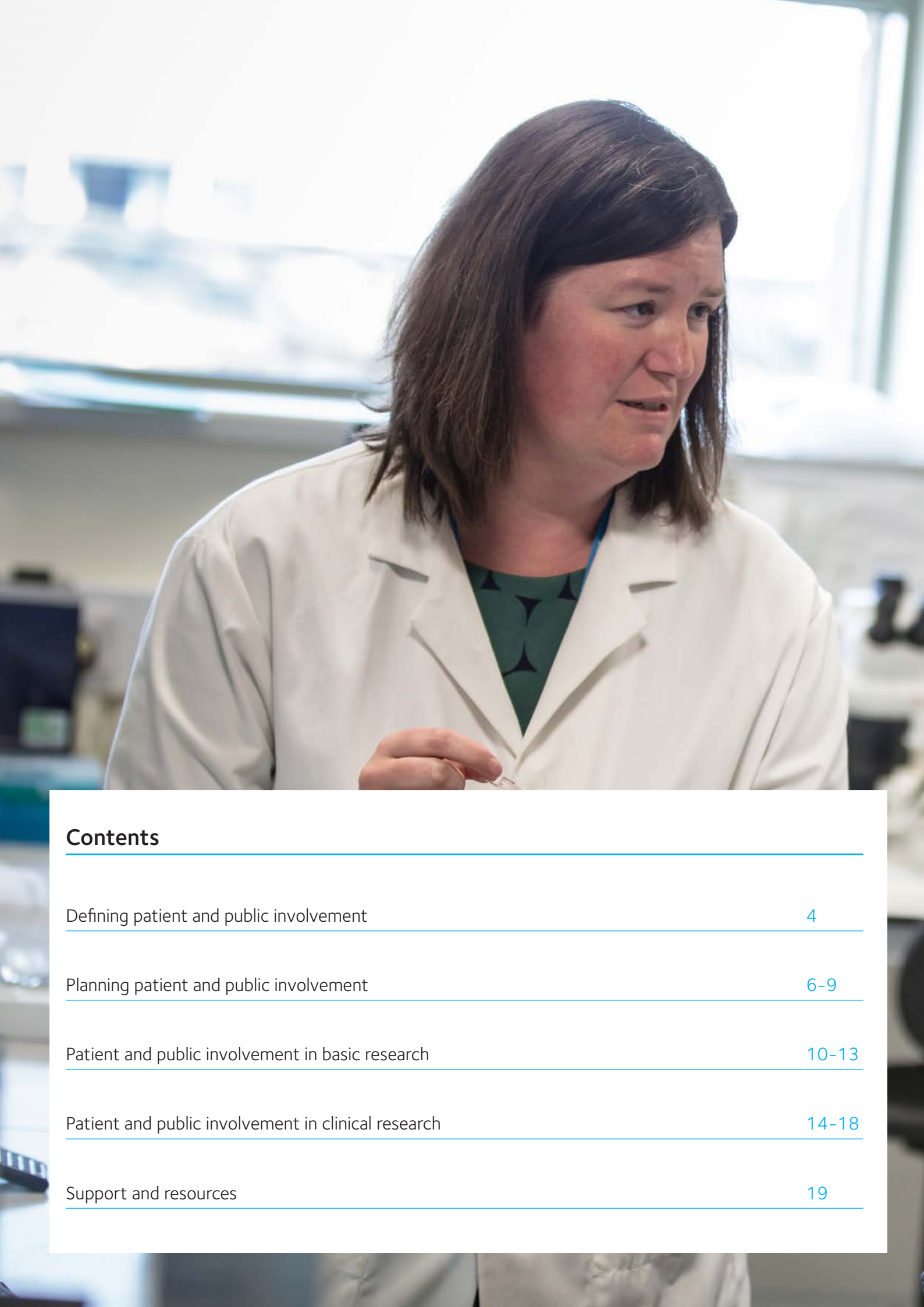




PATIENT AND PUBLIC INVOLVEMENT

Guidance for researchers

PARKINSON'S^{UK}
CHANGE ATTITUDES.
FIND A CURE.
JOIN US.



Contents

Defining patient and public involvement	4
Planning patient and public involvement	6-9
Patient and public involvement in basic research	10-13
Patient and public involvement in clinical research	14-18
Support and resources	19



“People affected by Parkinson's provided such detailed and insightful feedback that hugely benefited the design of our study and the quality of our grant application.”

Defining patient and public involvement

Patient and public involvement (PPI) in research is when research is carried out **'with'** or **'by'** people affected by health conditions and members of the public, rather than **'to'**, **'about'** or **'for'** them¹.

We want all Parkinson's researchers to work in partnership with people affected by Parkinson's as much as possible. Involving people affected by Parkinson's in research leads to higher-quality, more efficient research focused on what matters most to those living with the condition.

Through our patient and public involvement programme, we support researchers to carry out meaningful involvement that will add value to their research. **We support all researchers**, regardless of who they are funded by or applying for funding from.

We help researchers:

- **understand** when and how they can involve people affected by Parkinson's in their work
- **plan** and carry out meaningful involvement activities
- **connect** with people affected by Parkinson's and develop working relationships with PPI volunteers

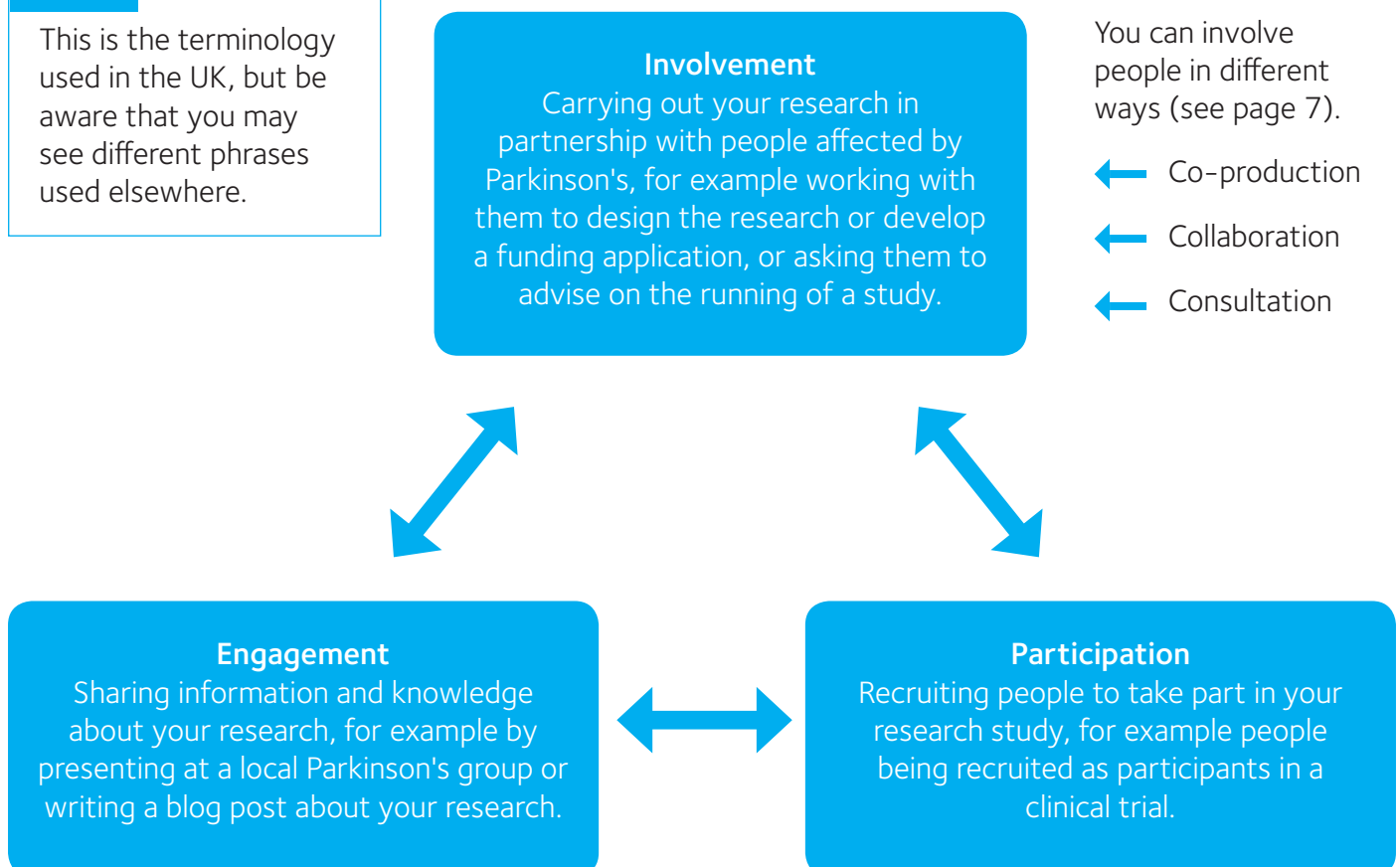
Defining involvement

It is important to understand how patient and public involvement differs from participation in research and public engagement.

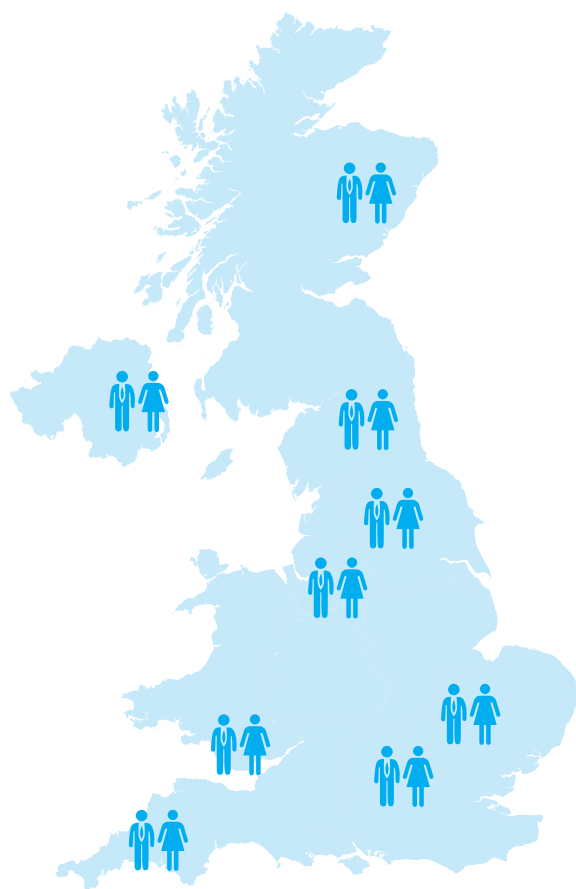
As the diagram below indicates, the three are linked and often one can lead to the other.

Top tip

This is the terminology used in the UK, but be aware that you may see different phrases used elsewhere.



¹ INVOLVE definition

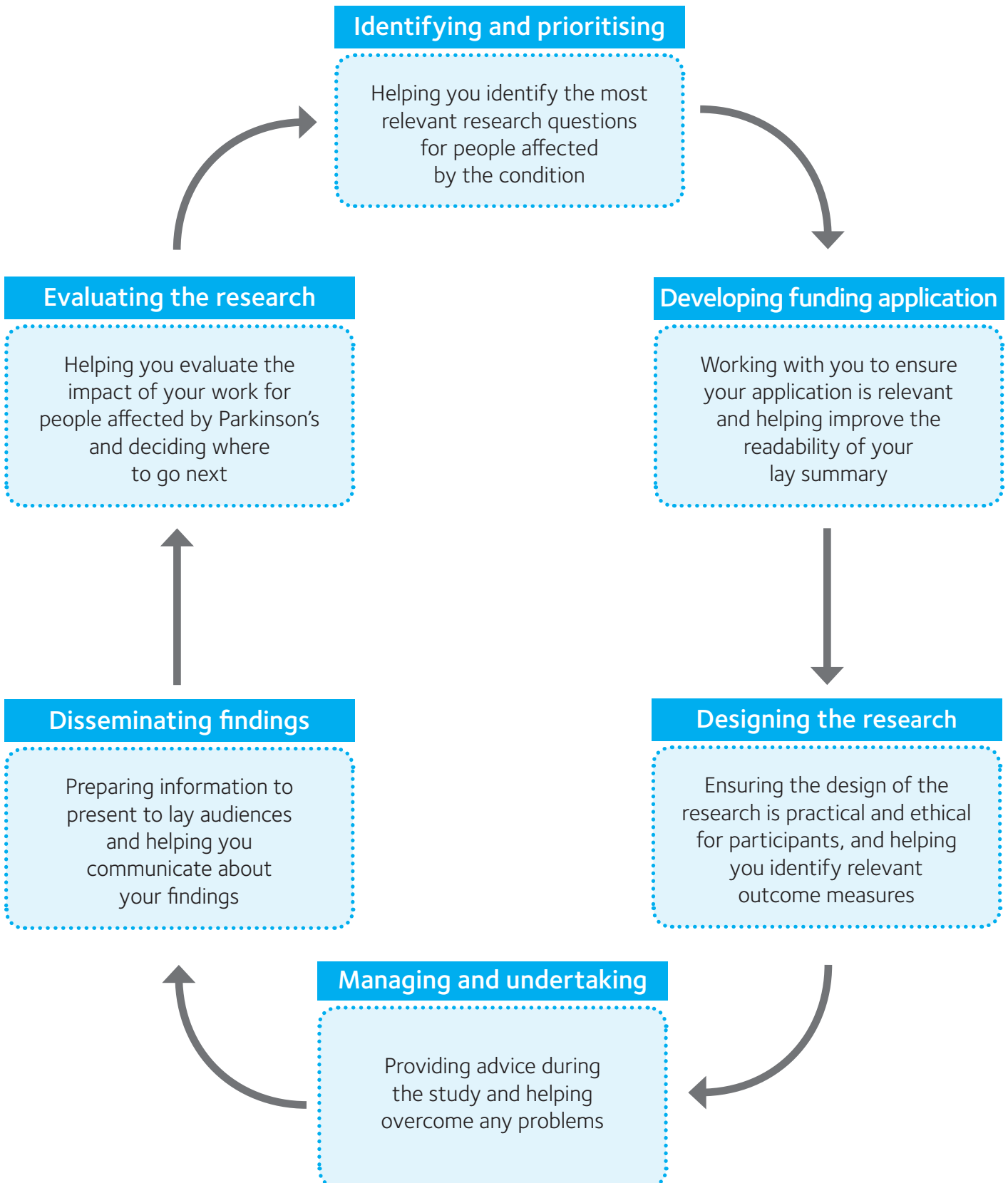


**Patient and public involvement
volunteers based around the UK**

Our patient and public involvement volunteers include people with Parkinson's as well as carers, family members and friends of those with the condition. Volunteers undergo PPI training to prepare them to work in partnership with researchers.

We can also connect researchers to our Research Support Network – a community of thousands of people interested in Parkinson's research across the UK.

People affected by Parkinson's can be involved throughout all stages of the research cycle:



Planning patient and public involvement

There is no one-size-fits-all approach. How you involve people will depend on many factors, including the level of input you want, the type of project and the stage of research.

Consultation

Gathering the opinions of people affected by Parkinson's is a useful way to shape your research. You may wish to ask people affected by Parkinson's to share their thoughts on topics such as:

- what it's like to live with Parkinson's
- broad areas of Parkinson's research, for example genetics or technology
- priorities and aims of a research project

You can then use this feedback to help shape your research.

Surveys are a great way to gather opinions from a broad group.

We regularly send surveys to our Research Support Network – a community of thousands of people interested in Parkinson's research.

Liaise with a group of people affected by Parkinson's over email.

Many researchers use email to get feedback on their plain English summaries for funding applications.

Hold a meeting to consult with a small group of people.

Meetings are a great opportunity to hear people's thoughts on areas of unmet need or to discuss the realities of living with Parkinson's.

Collaboration

This is about working in true partnership with people affected by Parkinson's to shape your work. Those involved will suggest ideas and help make decisions about how the research is carried out. You can work with people affected by Parkinson's to:

- design your research study
- manage the running of a project
- plan how you will disseminate the findings of your study

Hold a focus group meeting to plan the design of your research.

At a meeting you can talk through your ideas and give people the opportunity to contribute their thoughts and suggestions.

Continue discussions beyond the initial meeting.

Collaboration is an iterative process. After an initial face-to-face meeting, you can continue discussions over email or video conference.

Invite people affected by Parkinson's to sit on a project advisory or steering group.

People affected by Parkinson's can help guide the direction of the project and assist with the management of the study, including helping problem solve and evaluate progress.

Co-production

The essence of co-production is sharing power and responsibility throughout a project. Researchers and people affected by Parkinson's have an ongoing dialogue, as well as joint ownership over key decisions. Examples of co-production include:

- having someone affected by Parkinson's as a co-researcher on the project
- working with people affected by Parkinson's to design a new resource

Invite someone affected by Parkinson's to be part of the project research team.

As a member of the team, this person will be involved in the development of the project from the outset. They will contribute to key decision-making and will help shape all aspects of the research.

Top tip

If you are planning to use video conferencing or other online platforms, consider how you will support people to use this technology confidently – it's a good idea to provide guidance documents or instructions.

Planning patient and public involvement

Things you will need to consider when planning PPI:

Stage of the research process

In the early stages of the research process it can be useful to consult a wide range of people to get a broad perspective. You can then collaborate with PPI contributors to develop your ideas further.

Who you want to involve

Think carefully about who you want to involve and how you can ensure the group is representative. You may need people with specific experiences or characteristics – the prevalence of which may affect how many people you will need to involve.

Level of insight you would like

Getting a snapshot of information by consulting with PPI contributors can be extremely informative for your research. At other times, you may wish to get more detailed input over a longer period of time.

Practicalities

You need to consider the practicalities of how you will work with PPI contributors and ensure you minimise any barriers to involvement. It is important to ensure that PPI activities are as inclusive as possible.

Time and resource

When planning PPI activities, carefully consider how much time you have. Consultation can be easy and fairly simple to carry out, whereas true collaboration and co-production requires more time, including for planning and maintaining relationships.

Training and support

It's important that you support PPI contributors and provide them with the tools they need to make a meaningful contribution. This includes simple things, such as providing guidance documents for joining video conference meetings or some background information about the research topic, as well as more advanced support. This may include training on specific aspects of the research process.

Capturing impact

Funding bodies and journal editors are keen to hear about the impact of involvement. It's important to document the feedback and suggestions you receive during the PPI process. As well as capturing how PPI has influenced the research, think about the impact it has had on those involved too.

Top tip

Once you know who you are going to involve, and what you are going to do, it's important to:

- clearly communicate the questions you would like people to answer and what you would like them to contribute
- be clear on deadlines
- if a difficult situation arises, be prepared to be flexible on the method of involvement
- think of some of the barriers you may face in a meeting, such as keeping the conversation focused



What methods can I use to communicate with people?

Meeting in person

Face-to-face meetings are a great way to build relationships with PPI contributors, and they can also help people focus and think creatively.

Meeting remotely

Remote meetings are also an excellent way to communicate with PPI contributors. They offer more flexibility and can enable you to involve a wider range of people. Some people are more at ease when they can contribute from the comfort of their home. Video conference meetings are an ideal way to mimic the face-to-face experience. Teleconferences can also work well.

Communicating via email

When PPI contributors are commenting on study documents, or answering specific questions, it may be easiest to liaise with them over email. This enables people to contribute at a time that suits them. Note that it's best practice to give people deadlines for when you'd like them to provide feedback.

Using project management tools

If you're working with a steering or advisory group, you may want to think about using a project management tool so you can store all the documents and updates in one place. Useful tools include Trello, Slack, Microsoft Teams and Google Drive.

If you're planning a face-to-face meeting you will need to think about the practicalities including:

- room hire
- venue and accessibility
- travel arrangements
- time of day and length of meeting
- expenses for a carer or an additional person to support attendance
- refreshments, and lunch for longer meetings

Top tip

Remember to give regular feedback to PPI contributors, for example on the outcomes of funding applications or at the end of a project. Even if there is nothing happening it's good to keep people in the loop.

PATIENT AND PUBLIC INVOLVEMENT

in basic research

Involving people in laboratory-based basic research ensures research is focused on what matters most to people with Parkinson's from the start of the research and development process.

How can involvement add value in basic research?

Better communication

Communicating the benefit and potential impact of basic research to non-expert audiences can be difficult – this is one reason PPI in basic research is so valuable.

People affected by Parkinson's can help you to communicate the importance and impact of your work in a way that is understandable for non-expert audiences:

Improving the readability of your plain English summary

Most grant applications are reviewed by a lay panel as well as scientific experts. The lay review is an important part of the decision-making process.

PPI contributors can help ensure your summary is clear for lay reviewers.

Helping you share your findings with lay audiences

Sharing your findings is an important part of the research process – research institutions want to see evidence of the impact of research and how you have communicated your findings with the wider community.

PPI contributors can help you to communicate to lay audiences, such as by helping you prepare presentations and write blogs.

Putting your research in context

Involving people affected by Parkinson's in basic research can put your research into context and help you prioritise your current and future research questions.

People affected by Parkinson's can help you ensure your research stays relevant and meaningful by:

Helping you prioritise future research questions

It's important to make sure your research is investigating the issues that are most relevant to people affected by Parkinson's.

PPI contributors can help you prioritise the direction of your research and decide what your next research questions should be.

Thinking about your research in a wider context

Basic research is crucial for the development of new treatments. But, sometimes, it can be easy to lose sight of how early work in the lab will impact people living with a condition.

PPI contributors can help you think about your research in a wider context and the longer-term impact it can have.

Can involvement happen in the design stage of basic research?

We recognise that involving people in the design of basic research may at first seem daunting, or even impossible. However, we believe it is possible to meaningfully involve people in the design of basic research. We're committed to supporting researchers to do this.

Examples of involvement in the design stage of basic research:

- Deciding which animal models to use – which models are most representative of the aspects of the condition you are looking at?
- Deciding which tissue samples to work with – is it better to use cells from animals or humans?
- Deciding what to test – how will your findings relate back to the clinic?

How can I move from engagement to involvement in basic research?

Great involvement in basic research often stems from good engagement. Sharing your findings with people affected by Parkinson's and talking about your research is a great way to develop meaningful connections with PPI contributors.

Case study: Chris Elliott, University of York

Chris uses fruit flies to study the fundamental causes of Parkinson's. Chris had been presenting his research to local groups for many years. His journey with patient and public involvement was initially driven by recognising he needed to communicate his research more clearly to lay members of funding panels.

Chris started working with people affected by Parkinson's to develop the plain English summary of his funding applications.

"The involvement made me realise that to try and find simple ways to explain the complexity of cellular life is quite a challenge and it's one I need to think about some more."

Improving communication

Chris has built up relationships with people affected by Parkinson's in his local area, and he regularly consults them on his research. He now routinely works with patient and public involvement contributors to develop his plain English summaries. He says this has allowed him to gain new perspectives on his research and has increased his knowledge of Parkinson's.

Prioritising research

People affected by Parkinson's have also helped determine the direction of Chris's work. For one of his funding applications, Chris had three research questions he could potentially explore. He asked PPI contributors to prioritise the questions to help him decide what he should focus on. To his surprise, people affected by Parkinson's listed the questions in the opposite order to what he had anticipated, which led him to change the focus of his application.



Case study: Emma Lane, Cardiff University

One area of Emma's research is investigating stem cell therapy for Parkinson's. Emma wanted to understand what concerns people affected by Parkinson's had about stem cell therapy, and see if there was anything she could do in her work in the lab to address these. She applied for a Research Involvement Award for more hands-on support from the Parkinson's UK team in planning and carrying out involvement activities.

Consulting with the wider community

Emma worked with the Parkinson's UK Research Involvement team to put together a survey to send to members of the Research Support Network.

The survey asked for people's thoughts on stem cell therapy, including what benefits they would expect from it, what they'd like to know before having it, and what issues would concern them most.

Collaborating to understand perspectives in more depth

Emma held a focus group meeting with people affected by Parkinson's to talk through the survey results and gain more in-depth insight into people's perceptions of stem cell therapy.

People highlighted the contrast between simplified animal models and the complexity of Parkinson's in humans, and emphasised the need for work in the lab to reflect the diversity of the condition.

We know that achieving meaningful involvement in the design of basic research means developing innovative ways of translating basic science concepts into clear and accessible forms. Through our Research Involvement Award, we can work with basic scientists to give hands-on support with planning and facilitating involvement activities to ensure they're relevant and useful (see page 19 for more information).



PATIENT AND PUBLIC INVOLVEMENT

in clinical research

Involving people in clinical research is key to ensuring studies are of a high quality and relevant, increasing the chance of successful outcomes.

At what stages can I involve people in my research?

Patient and public involvement can happen at all stages of the clinical research cycle. Involving people affected by Parkinson's in the design and development of your study can have a significant impact on the quality and success of your research.

Helping you design your study protocol to maximise recruitment and retention

It is vital that clinical studies are designed in a way that is accessible and feasible for prospective participants. Doing so increases the success of recruitment and retention.

PPI contributors can provide key insights into the practicalities of study design.

Identifying relevant and meaningful study outcomes

Study outcome measures need to not only be robust, but also meaningful to people affected by Parkinson's. Including relevant outcome measures increases your chance of finding statistically significant outcomes.

PPI contributors can help identify relevant outcome measures.

Addressing important considerations for the ethics application

Involving people affected by Parkinson's in your ethics application can significantly benefit the ethics process.

PPI contributors can help identify and address ethical issues, leading to more straightforward and faster approval.

Advising on the design of participant-facing documents

All participant-facing documents need to be written in plain English and contain all the necessary information for people to make an informed decision about participating.

PPI contributors can help design information sheets and consent forms to ensure they are suitable for participants.



Can I still involve people once I've started data collection?

Involvement doesn't have to be limited to be before or after data collection – people affected by Parkinson's can be involved throughout the entire research cycle.

Involving people in the management of your study

Forming an advisory group or project steering group means you can consult with people affected by Parkinson's throughout the study.

Advisory group

These are often small groups of four to six PPI contributors who advise on all stages of the research, from study design to dissemination¹.

Steering group

This tends to be two to three PPI contributors, plus several members of the research team, who oversee the project, provide advice and troubleshoot. The group usually meets at key stages during the project and influences strategic decisions¹.

Working in partnership with people throughout your research can help to improve the quality of your research and ensure it stays focused from beginning to end.

Collecting data, interpreting findings and drawing conclusions

In some projects, it may be appropriate to involve people affected by Parkinson's in data collection. For example, PPI contributors could carry out interviews with participants or be involved in delivering testing sessions.

Involving PPI contributors when interpreting findings can give you unique insight into the results. This can be particularly valuable when findings are unexpected or against the trend. People affected by Parkinson's can also bring another perspective when drawing conclusions from the data. PPI contributors can help you think about results in a wider context and relate findings to other aspects of the condition.

Case study: University of Hertfordshire

One area of focus for the Dance Psychology lab is exploring the benefits of dance and exercise for people affected by Parkinson's.

Following an initial research study into dance and Parkinson's, the university started community dance classes for people affected by the condition. The researchers thought it would be good to involve people from the dance class in an advisory group, with the aim of getting feedback on further research studies and as a way of updating people about the lab's ongoing work. Feedback soon turned into 'feed forward', with people affected by Parkinson's advising the researchers on various aspects of their work. The advisory group has been key in influencing the direction of the research group's work.

Examples of how the advisory group has helped shape the research:

- People affected by Parkinson's commented that the music element of dance is one reason why they found it so beneficial. This sparked a new line of investigation for the research team, and they now have a postdoctoral research fellow working on a project investigating this.
- The group advises on small but significant details relating to the practicalities of the research, such as ensuring there is parking nearby for participants, or making sure to provide refreshments during visits.
- Two members of the advisory group are now working with the research team as co-applicants for a funding application. If successful, they will work in partnership with the research team throughout the whole project.

¹ INVOLVE definition

How do I move from consultation and collaboration to co-production?

In a co-produced research project, all those involved are equal partners, sharing responsibility, ownership and decision-making from the start of the project to its end. Co-production is driven by principles, an understanding of which is key if you're considering taking this approach to your research project.

Having a clear understanding of PPI

A solid understanding and experience of patient and public involvement is key for successful partnerships. All those involved need to recognise the value of working together, and respect the experience and knowledge each individual brings.

Commitment to building relationships

Good relationships are an essential foundation for co-production. It is important to recognise that relationships need to be cultivated, and this takes time. Before embarking on co-production, you should have developed a good relationship with the PPI contributors you will be involving.

Providing development opportunities

Empowering those involved, by supporting them to develop their skills and knowledge, will help ensure everyone feels able to contribute and reach their potential. This includes opportunities for training, learning and networking.

Awareness of practical considerations

Co-producing research with patients and the public is a shift from the typical way of doing research. Facilitating meaningful co-production may require changes to practices, processes and procedures. It is important to be flexible and be ready to take a different approach to the way you typically work.

Top tip

There is no set way of co-producing research – focus on championing the key principles of the approach. See INVOLVE's *Guidance on co-producing a research project* for more information.



Be prepared for change

Case study: Jade Pickering, University of Manchester

Jade involved people affected by Parkinson's in her PhD project exploring impulse control disorders in Parkinson's. She held a focus group meeting with PPI contributors to get input from people affected by Parkinson's on the design of one of her studies. In this study, she planned to test a behavioural task in a large group of people with Parkinson's experiencing impulsive behaviours.

A key discussion point that arose during the meeting was the personal nature of impulse control disorders. PPI contributors said it was vital this was considered in the design of tasks and suggested a one-size-fits-all approach may not be appropriate for impulse control disorders. The group also highlighted that there are many people who don't meet the clinical criteria for impulse control disorders, despite still struggling with impulsive behaviours.

"So much came out of the discussions that I might never have thought of, and will make a real impact on the way we plan, design and carry out this research."

As a result, Jade and the research team decided to change their approach to the research. Rather than conducting a study with lots of participants, they decided to focus on gathering more in-depth information from a smaller number of participants. They did this using a mix of behavioural tasks and interviews to capture people's experiences. The team is also revising how they define a person with an impulse control disorder to ensure the study sample is representative.



Support and resources

Support from Parkinson's UK

There are lots of people affected by Parkinson's who are ready to be involved in your research. We can connect you with people affected by Parkinson's by:

- putting you in contact with our PPI volunteers across the UK – our volunteers have completed training and are experienced in working with researchers
- emailing our Research Support Network – a community of thousands of people interested in Parkinson's research across the UK

We can also provide advice on carrying out involvement activities, and have a number of resources you can use including:

- template role descriptions, meeting agendas and facilitator briefings
- practical tips for working with people affected by Parkinson's
- guidance for providing feedback to those involved

If you want to involve people affected by Parkinson's, but need more help, you can apply for our Research Involvement Award. Successful applicants will receive hands-on support from staff in developing appropriate PPI activities to meet the specific needs of the research, including help with:

- identifying and recruiting people to involve
- planning the appropriate method for involvement
- facilitating and funding the first meeting with PPI contributors
- feeding back and maintaining relationships

For more information about our patient and public involvement programme, visit parkinsons.org.uk/ppiresearch

Or email the Research Involvement team at Parkinson's UK at researchinvolvement@parkinsons.org.uk

Further resources

Funded by the National Institute for Health Research (NIHR), INVOLVE aims to support active public involvement in research. INVOLVE has lots of resources on a range of topics, such as advice on writing lay summaries, budgeting for involvement and co-production guidance. Visit their website at www.invo.org.uk

INVOLVE also has a charity involvement page highlighting organisations that actively support involvement in research. If you're looking for PPI support for other conditions, get in touch with the relevant organisation via www.invo.org.uk/charity-involvement-directory/

The NIHR also has a Research Design Service that provides PPI support to researchers across England on developing a grant application. Find out more at www.nihr.ac.uk/about-us/how-we-are-managed/our-structure/research/research-design-service/



Every hour, two people in the UK are told they have Parkinson's – a brain condition that turns lives upside down, leaving a future full of uncertainty.

Parkinson's UK is here to make sure people have whatever they need to take back control – from information to inspiration.

We want everyone to get the best health and social care. So we bring professionals together to drive improvements that enable people to live life to the full.

Ultimately, we want to end Parkinson's. That's why we inspire and support the international research community to develop life-changing treatments, faster. And we won't stop until we find a cure.

**Together we can bring forward the day
when no one fears Parkinson's.**

Parkinson's UK
215 Vauxhall Bridge Road
London SW1V 1EJ

Free confidential helpline **0808 800 0303**
(Monday to Friday 9am–7pm,
Saturday 10am–2pm). Interpreting available.
Text Relay **18001 0808 800 0303**
(for textphone users only)

hello@parkinsons.org.uk
parkinsons.org.uk