

PARKINSON'S<sup>UK</sup> CHANGE ATTITUDES. FIND A CURE. JOIN US.



# UNMET NEEDS

in Parkinson's research



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# Background

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## Our research strategy

Parkinson's UK has one overarching goal – to find a cure for Parkinson's. Our 2015–2019 strategy aims to deliver new and better treatments by:

- **unlocking scientific discoveries**
- **investing in drug development**
- **improving clinical trials**
- **repurposing approved treatments**

However, despite our best efforts, such a cure may be many years away. In the meantime, Parkinson's UK is committed to improving the lives of people with Parkinson's.

## Setting the research agenda

When the views of those affected by a condition are not considered, scientific research can fail to answer the most important questions. The James Lind Alliance was established to encourage collaboration between patients, clinicians and research scientists to ensure that questions that impact on the everyday management of health conditions are addressed by research agendas.

The Alliance encourages Priority Setting Partnerships to seek guidance from the lay public and clinical staff on the areas of research that are a priority for those affected.

## Our Priority Setting Partnership

In 2014, Parkinson's UK led a Priority Setting Partnership to identify the areas of research that would have the greatest impact on the management of Parkinson's from the perspective of people with Parkinson's, their family and friends, carers and relevant healthcare professionals.

The Parkinson's UK Priority Setting Partnership asked 1,000 participants which areas of research they considered a priority for the management of Parkinson's through both a paper and online survey. From these surveys we identified 94 unique questions.

Members of the Parkinson's UK Research Support Network and survey participants were invited to

evaluate these 94 unanswered research questions. 475 volunteers determined the 26 highest priority unanswered questions – or unmet needs – in the management of Parkinson's.

The top 26 unmet needs were ranked at a workshop by a panel of 27 participants including people with Parkinson's, carers, family members and healthcare professionals. The final list of the **top 10 research areas** for the management of Parkinson's was finalised in November 2014.

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Instead of hanging on to 'one day there will be a cure' – that day might never come...

I want my Parkinson's to be as best controlled as possible”

Volunteer in the Patient and Public Involvement (PPI) pilot

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# THE TOP 26 RESEARCH AREAS

to improve everyday life  
with Parkinson's



1. What treatments are helpful for reducing balance problems and falls in people with Parkinson's?
2. What approaches are helpful for reducing stress and anxiety in people with Parkinson's?
3. What treatments are helpful for reducing dyskinesias (involuntary movements, which are a side effect of some medications) in people with Parkinson's?
4. Is it possible to identify different types of Parkinson's, eg tremor dominant? And can we develop treatments to address these different types?
5. What best treats dementia in people with Parkinson's?
6. What best treats mild cognitive problems such as memory loss, lack of concentration, indecision and slowed thinking in people with Parkinson's?
7. What is the best method of monitoring a person with Parkinson's response to treatments?
8. What is helpful for improving the quality of sleep in people with Parkinson's?
9. What helps improve the dexterity (fine motor skills or co-ordination of small muscle movements) of people with Parkinson's so they can do up buttons, use computers, phones, remote controls etc?
10. What treatments are helpful in reducing urinary problems (urgency, irritable bladder, incontinence) in people with Parkinson's?
11. What treatments would ensure the medications were equally effective each day (prevented or managed wearing off, variability, on or off states) in people with Parkinson's?
12. What drug treatments are best for the different stages of Parkinson's?
13. What interventions are effective for reducing or managing unexplained fatigue in people with Parkinson's?

14. Would the monitoring of dopamine levels in the body (eg with blood tests) be helpful in determining medication timing and amount (dose)?
15. What is the best treatment for stiffness (rigidity) in people with Parkinson's?
16. What is the best type and dose of exercise (physiotherapy) for improving muscle strength flexibility, fitness, balance and function in people with Parkinson's?
17. What best helps prevent or reduce freezing (of gait and in general) in people with Parkinson's?
18. At which stage of Parkinson's is deep brain stimulation (a surgical treatment that involves implanting a 'brain pacemaker' that sends signals to specific parts of the brain) most helpful?
19. What treatments are helpful in reducing bowel problems (constipation or incontinence) in people with Parkinson's?
20. What treatments are effective in reducing hallucinations (including vivid dreams) in people with Parkinson's?
21. What training to improve knowledge and skills do informal carers (family and friends) need in order to best care for people with Parkinson's?
22. Can medications be developed to allow fewer doses per day for people with Parkinson's (for example combinations of medications in one pill, slow release pills)?
23. What is the best treatment for pain in people with Parkinson's?
24. What treatments are helpful for swallowing problems (dysphagia) in people with Parkinson's?
25. What training, techniques or aids are needed for hospital staff, to make sure patients with Parkinson's get their medications correctly and on time?
26. What treatments are helpful in reducing tremor in people with Parkinson's?

Beyond the search for a cure, this Priority Setting Partnership highlights the research areas that would have the greatest potential impact on quality of life with Parkinson's and management of the condition.

These priority areas will help direct research efforts in improving everyday life with Parkinson's.

This allows Parkinson's UK to focus funding and support – and scientists to focus their research – on the areas that will have the greatest impact on the everyday lives of people with Parkinson's.



# Summary of progress

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Since the completion of the Priority Setting Partnership, we have made progress in the top 26 areas by funding research, sharing opportunities to participate in research studies and supporting Patient and Public Involvement (PPI).

## Funding research

In 2015 and 2016, we provided funding worth more than £6.2million to eight research projects that directly address the top 26 areas of research to improve everyday life with Parkinson's.

## Participation

Research into the management of Parkinson's cannot be done without willing participants to take part in studies and clinical trials. By putting people affected by Parkinson's in contact with researchers we have helped recruit participants to 31 research projects that aim to tackle the top 26 unmet needs over the past two years.

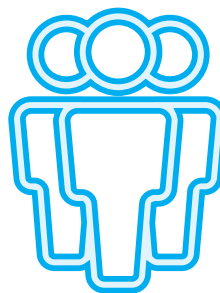
## Patient and Public Involvement

The perspective of people with Parkinson's, healthcare professionals and relevant members of the public can be valuable in guiding research. The Priority Setting Partnership itself was a major step forward in identifying the highest priority issues in the management of Parkinson's from the perspective of those most affected.

Since 2014, people affected by Parkinson's have been involved in 20 studies to ensure that research is of high quality, relevant and beneficial to people affected by the condition. With our help, volunteers affected by Parkinson's have steered research projects, aided in the design of clinical trials and offered advice on how to share research findings in plain English.



Between 2015-2016 we've funded **8 RESEARCH PROJECTS** worth more than **£6 MILLION**



We've helped to recruit participants to **31 RESEARCH PROJECTS**

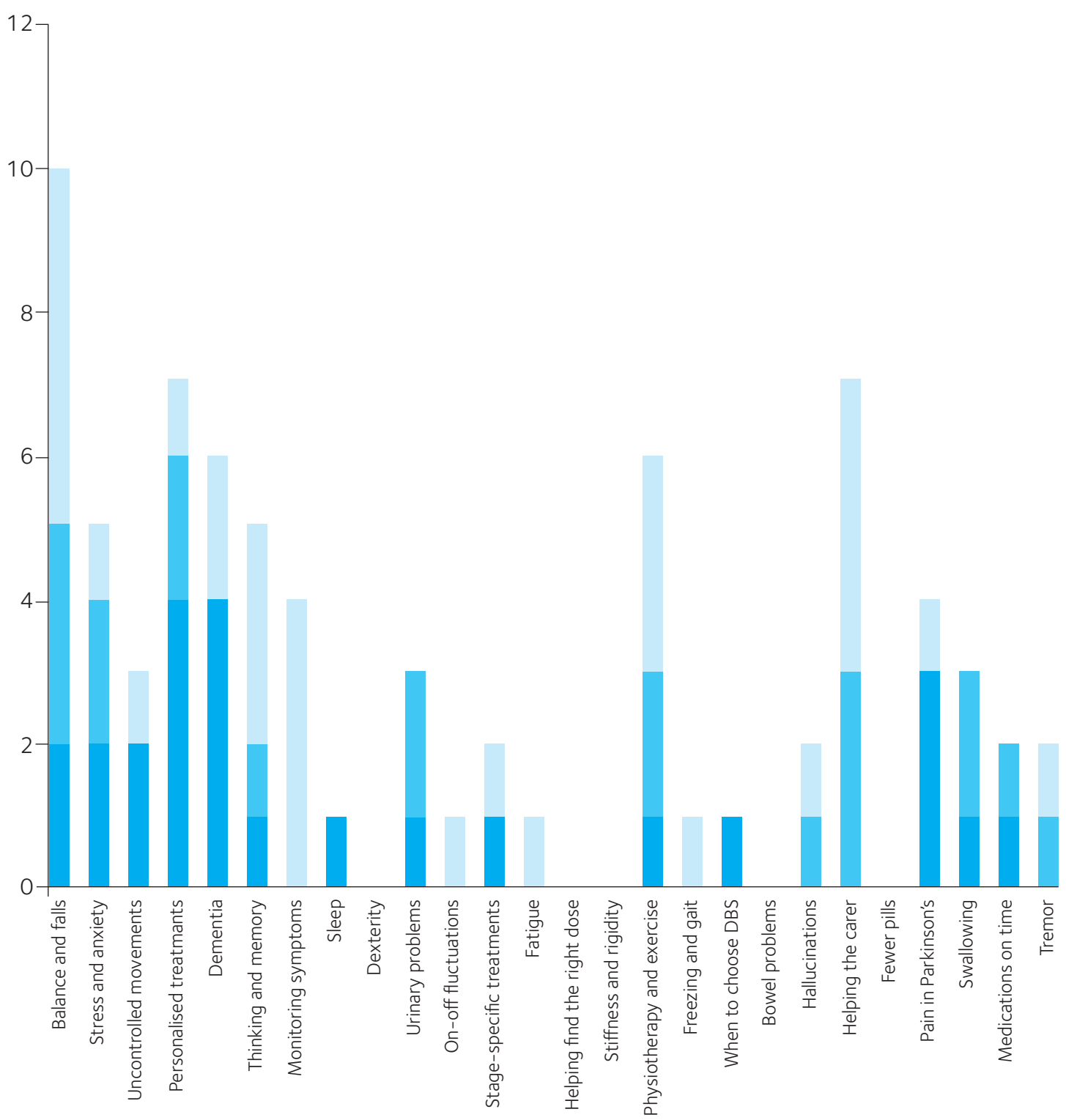


We've supported involvement in **20 RESEARCH STUDIES**

# Number of projects we've supported in TOP 26 PRIORITY RESEARCH AREAS

Funding ■  
 Participation ■  
 Involvement ■

Number of projects supported



# Funding

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We provide funding to scientists to carry out high quality research into the treatment and management of Parkinson's, as well as into the search for a cure.

Here at Parkinson's UK, everything we do is driven by people affected by Parkinson's. Identifying the top 26 unmet needs allow Parkinson's UK to prioritise funding of the research questions that people affected by Parkinson's feel are important. It is hoped this will help drive forward the progress of research in these priority areas and as a result improve everyday life for those with the condition.

## Progress from existing studies

We committed to funding 11 research projects within the top 26 unmet needs before the Priority Setting Partnership in 2014. Support for these projects, worth more than £5million, has continued with particular effort in sharing their findings.

### Balance and falls

Dr Emily Henderson (University of Bristol) was awarded £250,000 over three years to determine whether a drug traditionally used to help with memory problems, called rivastigmine, could also help improve balance and reduce falls in people with Parkinson's.

Problems with balance and falls seriously affect quality of life. Falls can lead to injuries that mean people need to go to hospital and can also make people feel anxious about falling again. This often makes people with Parkinson's less comfortable in busy areas and can cause people to give up hobbies and activities that they previously enjoyed.

Initial results show rivastigmine can reduce falls in people with Parkinson's by 45%, compared to a placebo or 'dummy' treatment. Due to the promising initial results and the identification of balance and falls as the top research area to improve everyday life, we extended this study by a further two years.

We hope this will maximise the potential benefits of this research, and could lead to a new treatment with the potential to reduce falls in people with Parkinson's.

## Progress from new studies

Since the Priority Setting Partnership, we've directly funded a further 12 projects that fall within the top 26 unmet needs.

### Dementia

At least one in three people with Parkinson's will develop some form of dementia. While each person experiences dementia in their own way, symptoms can include problems with memory and thinking, changes in behaviour and problems doing day-to-day things such as getting dressed. Those with mild memory and thinking problems or dementia tend to also experience depression and have more severe motor symptoms than those without.

Professor David Burn and his team at Newcastle University are leading a project to predict dementia in people with Parkinson's.







In my opinion, this is the biggest area of unmet therapeutic need.”

Professor David Burn, Director, Institute of Neuroscience, Newcastle University

The project was initially awarded £1.2million over five years. But, following promising results and the identification of dementia as a top five research priority in the Priority Setting Partnership, a further £175,000 was awarded to continue the work for a further 18 months. This extension has allowed the team to collect more useful data on the progression of dementia in people with Parkinson's.

From this study, dementia has been linked to the development of mild memory and thinking problems, particular genetic factors and abnormal levels of certain proteins. These findings could be used to predict which people with Parkinson's are at a greater risk of developing dementia in the future.

Identifying people with Parkinson's at a high risk of developing dementia will allow people with Parkinson's to be better informed in planning for their future. It would also allow for earlier use of future treatments that slow or stop the progression of dementia. By following a group of people with Parkinson's over five and a half years, this study has also contributed to our wider understanding of the early stages of Parkinson's.

The team has also developed two sub-studies on walking and sleep quality in people with Parkinson's. As such, the single group of participants taking part in this dementia study will help progress research in three of the top unmet needs.



Depression in Parkinson's is like a cloud over your head”

Volunteer, 100forParkinson's study.

## Stress and anxiety

Normal drugs for psychological difficulties are often not as effective in people with Parkinson's. Taking a new direction on the management of stress and anxiety, Parkinson's UK has given £32,800 in funding to Dr Angeliki Bogosian for a one year study looking at using mindfulness and meditation to improve stress and anxiety in people with Parkinson's.

This study aims to redesign and test an existing mindfulness course that was designed for people with multiple sclerosis (MS). A previous study by Dr Bogosian found that at the end of the course, participants with MS reported significantly less distress and some improvements in pain, fatigue and motor symptoms. If successful, this study would offer a cost-effective and accessible way to relieve stress and anxiety in people with Parkinson's. This could offer knock-on improvements in sleep quality, pain management and even some motor symptoms.

Parkinson's UK has recently also given £140,000 to Professor Richard Brown to complete a study to reduce sensitivity to 'danger signals' in the environment, which could help people with Parkinson's to reduce stress and anxiety in everyday life.

We hope exploring alternative treatments for stress and anxiety may improve the management of these non-motor symptoms and so improve quality of life.



# Participation

Recruiting participants to research studies can be a major hurdle, particularly when large numbers of participants are needed. Parkinson's UK helps recruit participants to relevant studies by putting researchers in contact with people with Parkinson's who are passionate supporters of research.

We do this through:

- **the Research Support Network**  
A network of over 2,000 people interested in Parkinson's research.
- **the Parkinson's UK website**
- **Parkinson's UK local groups**
- **Parkinson's UK magazines *The Parkinson and Progress***

Recruitment of participants is not only essential for researchers, but is also valuable to people with Parkinson's. A Parkinson's UK survey found that while 70% of people with Parkinson's are interested in taking part in research, only 24% have actually done so. Encouraging participation through initiatives such as the Research Support Network gives people with Parkinson's greater opportunities to be directly involved in research projects.

## Recruitment for Parkinson's UK-funded projects

The majority of projects funded by the charity also request our help in recruiting participants. For example, the Research Support Network recruited 60 volunteers for Dr Bogosian's study into the value of meditation and mindfulness for people with Parkinson's.

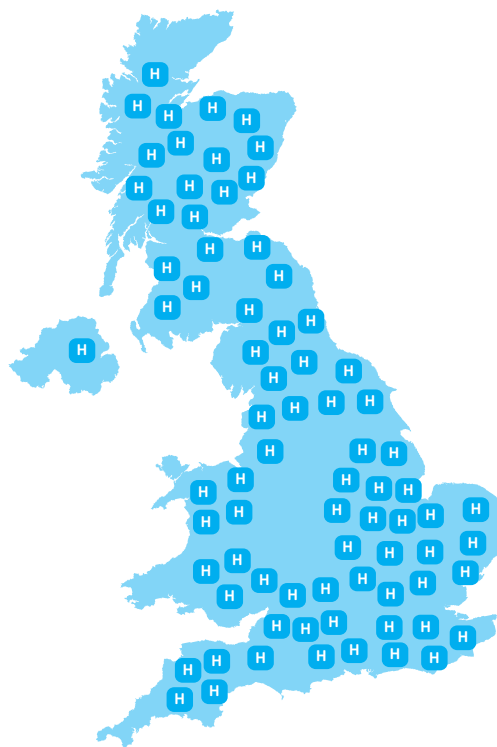


We also provided assistance in recruiting participants for Dr Henderson's study into balance and falls through sharing the opportunity with the Research Support Network and on the Parkinson's UK website. Crucially, their goal of recruiting 130 participants was reached in just six months, allowing the project to progress without delay.

## Tracking Parkinson's

Tracking Parkinson's is the world's largest in-depth research project looking at how Parkinson's develops over time. The project was originally funded from 2011 to 2014, and has since received extra funding to extend the study.

The ultimate goal of this ambitious project is to speed up our search for a cure by finding biomarkers that could be used to reliably diagnose Parkinson's. We advertised the opportunity through the Research Support Network and the study has now recruited more than 2,240 participants.



More than 2,000 people across 70 hospitals in the UK are involved in the world's largest study of Parkinson's



Since most research studies recruit from only the largest research centres (eg London, Oxford, Cambridge etc), opportunities for people with Parkinson's to participate in research in more rural areas of the UK are limited. This study recruited participants from 70 centres across the UK and so made participation in research far more accessible for people with Parkinson's outside major research centres.

The study has been successful, publishing four research papers and identifying a potential genetic marker that appears to triple the risk of early-onset Parkinson's. The samples collected were also made available to other researchers and have led to a number of new Parkinson's UK-funded studies that are now running alongside this one. These include the largest ever study into pain in Parkinson's – led by Dr Monty Silverdale – and a separate project by Dr Simon Lovestone which is also hoping to discover biomarkers.

Sharing the samples collected has maximised the impact of volunteers' participation in the Tracking Parkinson's study. Although the main project is targeted at the discovery of biomarkers for Parkinson's, it is clear that by sharing data with other researchers this study will have a major impact on a much wider range of the unmet needs.

## Recruitment for non-funded projects

Unfortunately we cannot fund every study relating to Parkinson's, but we remain committed to helping drive forward progress however we can. We provide support to all Parkinson's researchers looking to recruit participants to their studies.

### 100forParkinson's

The 100forParkinson's project was launched in November 2015 and aimed to collect anonymous data from people with and without Parkinson's to help improve our understanding of Parkinson's and shape future research. It involved a smartphone app, designed by UK digital health start-up Umotif, that allows self-tracking of wellbeing and symptoms such as sleep, mood, exercise, diet and stress levels.



This app makes you think about what you're doing and how you can manage your illness ”

Michael, 100forParkinson's participant.

While not directly funded by Parkinson's UK, the project received strong support from the charity because monitoring symptoms had been identified as a top 10 priority. Furthermore, a study by The Cure Parkinson's Trust found that 90% of people with Parkinson's were interested in using technology to better understand their symptoms, making this study a clear priority for Parkinson's UK.

The 100forParkinson's study required a huge number of participants – their goal was to get almost 40,000 participants to use the app for 100 days. The opportunity to take part was advertised through the Research Support Network, social media, the Parkinson's UK website and in articles in both *Progress* and *The Parkinson*.

Unlike many participation opportunities, this study was open to both people with Parkinson's and healthy volunteers. This allowed members of the public passionate about Parkinson's to take an active role in research and raised the profile of Parkinson's in the general public. It was also an opportunity to participate in research from home, making it available to those unable to travel.

The total number of UK participants recruited to date is more than 3,100. 23% of these were recruited through Parkinson's UK, meaning the charity made the single largest contribution to recruitment of any organisation. Given the number of participants required, our continuing support for this project is critical to its success.

The project is still ongoing but hopes to demonstrate the value of digital health tracking for self-management of Parkinson's. Individuals have already reported how the app has enabled them to take back control of their health.

If successful, 100forParkinson's would be a cost effective and accessible system for people with Parkinson's to more closely monitor their own symptoms. This study will also collect a large amount of valuable data on people with Parkinson's and their symptoms, which will be made available to other researchers to help advance research into other areas of Parkinson's.

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It gave me a focus that I found very positive and it has proved invaluable when it comes to talking through my symptoms with my consultant”

Sam, 100forParkinson's participant

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# Patient and Public Involvement

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Patient and Public Involvement (PPI) is when researchers work in partnership with people affected by health conditions – such as Parkinson’s – to improve the quality and impact of their work. This can be achieved through forming focus groups or through consultations and workshops with people affected by Parkinson’s. PPI contributes to research studies at every level through:

- helping decide on a research question and designing an appropriate study
- developing grant applications by improving plain-English summaries
- assisting participants, for example by helping fill in questionnaires
- managing ongoing studies
- publicising and evaluating the impact of results

The purpose of the Priority Setting Partnership itself was to allow people affected by Parkinson’s to be involved in deciding which research areas are a priority. Parkinson’s UK has since built on this foundation, encouraging PPI in research studies – particularly within the top 26 unmet needs.

## Involvement in Parkinson’s UK-funded projects

When funding projects, Parkinson’s UK encourages researchers to set up PPI programmes to inform their work.

### **Mindfulness study**

Involvement played a valuable role in the design of Dr Angeliki Bogosian’s Parkinson’s UK-funded mindfulness study to tackle stress and anxiety. The first stage of the study involved adapting an existing mindfulness course. At this stage the research team included two people with Parkinson’s to ensure that the course was specific to the needs and challenges associated with the condition.

The team also held two group meetings with people with Parkinson’s to receive feedback on the idea of using mindfulness to improve mood and wellbeing in Parkinson’s. The Research Support Network helped recruit 14 volunteers, who made

valuable changes to the design of the study, such as:

- Testing of a range of meditation techniques, since people with Parkinson’s may respond better to some than others.
- Delivering the course via Skype to allow access for people in rural areas or whose symptoms make travelling difficult.

## The Patient and Public Involvement pilot

In order to explore the benefits of PPI, the charity funded and organised a pilot programme in 2015. This programme recruited and trained 52 volunteers to advise on eight selected research projects. The pilot collected feedback from both volunteers and researchers, and Parkinson’s UK staff attached to the groups, to find the best way to help researchers set up useful involvement programmes.

The pilot programme received overwhelmingly positive feedback from both researchers and volunteers alike, and clearly indicated that PPI can be of great value to both.

One clear consensus from the pilot report was our importance in bringing together volunteers and researchers. Despite the value of involvement to research studies, most researchers felt that studies were much less likely to involve people affected by Parkinson’s without input and encouragement from Parkinson’s UK.



## Projects involved in the Patient and Public Involvement pilot

### Tracking Parkinson's

Dr Grossett's Tracking Parkinson's study, which provided huge opportunities for participation, was a trial project in the PPI pilot. The team realised when presenting the results from previous research that questions raised by people with Parkinson's could have been easily answered during the study if those people had been involved in the original study design. This led them to seek out opportunities to get people with Parkinson's involved in their research at an early stage.

During the pilot programme, a group of volunteers provided advice on the nature and layout of the study's questionnaires to make them easier to manage for people with Parkinson's. The team found this improved the quality of responses, particularly when asking more personal questions which could make participants uncomfortable.

The volunteers also added an explanation of why the questionnaire was important and how it contributed to the study. Researchers found this was useful, as participants who felt valued and understood the importance of the research were more likely to provide honest and detailed answers.

### Staying UpRight

A study testing the value of a new gadget to aid balance and prevent falls – led by Dr Alan Godfrey – was transformed by input from a focus group.

An interactive workshop allowed volunteers to handle and use the technology to determine if it was easy to use for people with Parkinson's. They gave advice on how to make participants feel more comfortable with using the technology and even changed the design of the gadget itself to make it more user-friendly to people with Parkinson's with reduced dexterity.

This focus group also helped with the recruitment campaign for the project, making major changes to the team's academic poster.

Volunteers felt that people would be more interested in participating in the study if the poster focused on the gadget and its potential impact on people with Parkinson's, as this would get them excited about the technology. The team agreed with these views and made changes that helped them recruit participants to their study.



# Future aims

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Beyond the search for a cure, Parkinson's UK is committed to answering research questions that address the top 26 unmet needs identified in the Priority Setting Partnership. We have provided funding, advice and support to research addressing questions in many of these priorities. Taking steps towards improving the lives of people with Parkinson's.

However, some areas remain poorly addressed. For example, in the last two years the charity has not supported any studies into these areas:

- **Dexterity**
- **Helping find the right dose**
- **Stiffness and rigidity**
- **Fewer pills**
- **Bowel problems**

Going forward we plan to encourage studies in priority areas which are currently under-researched.

## Shaping new research

One reason for a lack of progress in certain unmet needs is a lack of research proposals in those areas. Greater awareness of the results of the Priority Setting Partnership could encourage researchers to pursue these areas and to tailor their research questions to address these unmet needs.

This would increase the opportunities for Parkinson's UK to fund and support studies to improve the quality of life of people with Parkinson's. One role of this report is to highlight to researchers the highest priority areas in Parkinson's research – and in which areas progress is lacking – in the hope of stimulating more research in these areas.

## Collaborations

Research in priority areas may not receive funding or support from us or other funding bodies if their research question is poorly constructed or their study is poorly designed. Parkinson's UK aims to help researchers produce high quality research proposals – particularly in areas where research is currently lacking.

Shortly after the completion of the Priority Setting Partnership, Parkinson's UK set up a shared learning group with other medical charities who had also completed Priority Setting Partnerships. The aim of this group was to collaborate in areas of research that were a priority for all the charities. The group decided to first address incontinence and urinary problems, which is a priority across a number of different health conditions and is currently an under-funded and under-researched area.

The group plans to hold an incontinence research workshop – designed to encourage networking and provide advice in planning studies, obtaining funding and involving those affected – for late 2016. The workshop has attracted a lot of attention, with more than 200 academics and healthcare professionals interested in attending.

If this workshop is successful in stimulating more high quality research proposals into incontinence, Parkinson's UK plans to apply the workshop model – either alone or again in partnership with other medical charities – to address other under-represented unmet needs.

## Tailoring existing research

Since 2014, Parkinson's UK has successfully tailored existing research programmes to maximise their impact on the top 26 unmet needs. Examples



of this can be seen in the development of ongoing studies, such as new sub-studies linked with Prof Burn's research into predicting dementia (targeted at improving gait and sleep quality). The charity has also extended successful studies in priority areas, such as Dr Henderson's two year extension to her work in reducing falls in people with Parkinson's.

## The Cohort Studies Council

Cohort studies are projects that monitor a group of people (the cohort) over many years. They help to develop our understanding of Parkinson's and how to treat it.

The Cohort Studies Council brings together expertise from people affected by Parkinson's, clinicians and academics from related fields to provide guidance for long-term studies into Parkinson's.

Following the results of the Priority Setting Partnership, Parkinson's UK involved the Cohort Studies Council in an initiative to collect data on the top 26 unmet needs through existing cohort studies.

Also as part of their new research strategy, the council aims to determine which of the unmet needs are suitable to be addressed by cohort studies with the hope of modifying existing studies to target them towards addressing the top 26 priority areas.

The Council has identified four priorities that could be addressed by cohort studies.

- [Personalised treatments](#)
- [When to choose BDS](#)
- [Monitoring symptoms](#)
- [Stage-specific treatments](#)

The Cohort Studies Research Strategy, incorporating those unmet needs that can be suitably addressed by cohort studies, is expected to be put in place by early 2017.

## Encouraging involvement and participation

Encouraging and funding more research into unmet needs is a clear priority for Parkinson's UK in the coming years, but we also aim to improve studies through Patient and Public Involvement (PPI) and to maximise participation opportunities for people with Parkinson's.

### Involvement

The results of the PPI pilot highlight our importance in bringing together volunteers and researchers. They also suggest that our training of volunteers in how to effectively contribute to research studies increases the value of involvement, and that covering expenses would encourage more researchers to set up involvement programmes.

As a result of this feedback, we are planning to set up a Research Partnership Award. This award will encourage PPI in research studies by:

- recruiting and introducing volunteers to relevant projects
- providing training to volunteers and researchers
- organising, chairing and covering expenses for the first meeting between volunteers and researchers.

### Participation

Parkinson's UK is also improving links with researchers and with other organisations to maximise the number of research opportunities offered to people affected by Parkinson's. Most notably, the charity is in the process of creating a system to help connect people who want to take part in research with researchers.

Here at Parkinson's UK, everything we do is driven by people affected by Parkinson's and we are committed to supporting research into these priority areas.

If you're interested in helping us address the top 26 unmet needs, we'd love to hear from you. Please email us at [research@parkinsons.org.uk](mailto:research@parkinsons.org.uk) or call **020 7963 9313**