

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

TELL US

What questions would you like to see answered by Parkinson's research?

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research@parkinsons.org.uk

parkinsons.org.uk/researchquestions

In Partnership with



University College London Hospitals 
NHS Foundation Trust

The Cure Parkinson's Trust

King's College Hospital 
NHS Foundation Trust



Getting to the heart of your unanswered research questions

Background

In 2013 Parkinson's UK launched an exciting new project to find the top 10 research questions about Parkinson's that people living with the condition and health and social care professionals would like to see answered.

We want to use this information to guide future research and make sure researchers focus on the most urgent needs of people affected by Parkinson's.

The results so far

We created a simple survey asking about three key aspects of the condition:

- the symptoms of Parkinson's
- day-to-day life with Parkinson's
- the treatment of Parkinson's

More than 1,000 people took part in the survey. Our team of researchers looked through the responses, picking out questions which have not been answered by research already and removing repeats.

We now have 94 questions which our supporters would like to be answered by research that will go forward to the next stage.

We need your help

We now need to narrow down the list of 94 questions. To start with, we would like to ask volunteers to let us know their 'top 10'.

Please read through the enclosed list of 94 questions to choose the 10 you feel are most important and then rank them in order of importance.

What happens next?

In June we will be holding workshops to discuss and decide the final 10 questions. Your scores will be used during the workshop to identify those most important to our supporters.

We will announce the final list of 'Top 10' unanswered questions in Parkinson's research in July 2014.

More information

To find out more information about the whole project, please contact the research team on **0207 963 9398** or visit **parkinsons.org.uk/researchquestions**

“Our research aims to improve life for people living with Parkinson's now, and ultimately find a cure. But we need the input of people who have direct and personal experience of Parkinson's to make sure we're addressing the right questions to help us achieve this.”

Dr Katie Le Blond, Research Development Manager, Parkinson's UK



Movement symptoms

Question number		Notes
1	What treatments are helpful in reducing tremor in people with Parkinson's?	
2	What interventions are best for improving slowness of movement (bradykinesia) in people with Parkinson's?	
3	What is the best treatment for stiffness (rigidity) in people with Parkinson's?	
4	What best helps prevent or reduce freezing (of gait and in general) in people with Parkinson's?	
5	What treatments are helpful for reducing muscle cramps (dystonia) in people with Parkinson's?	
6	What treatments are helpful for reducing balance problems and falls in people with Parkinson's?	
7	What interventions are best for improving posture in people with Parkinson's?	
8	What treatments are helpful for restless legs (an overwhelming urge to move the legs) in people with Parkinson's?	

Non-motor symptoms

Question number		Notes
9	What treatments are helpful in reducing urinary problems (urgency, irritable bladder, incontinence) in people with Parkinson's?	

10	What treatments are helpful in reducing bowel problems (constipation, incontinence) in people with Parkinson's?	
11	What treatments are helpful for reducing drooling (and the associated dehydration) in people with Parkinson's?	
12	What treatments are helpful for low blood pressure (hypotension) in people with Parkinson's?	
13	What treatments can help people with Parkinson's regulate their temperature better?	
14	What treatments are effective for excessive sweating in people with Parkinson's?	
15	What is the best treatment for pain in people with Parkinson's?	
16	What is the best treatment for lack of ability to smell (anosmia) in people with Parkinson's?	
17	What is the best treatment for erectile dysfunction (sexual problems) in men with Parkinson's?	
18	What is helpful for improving the quality of sleep in people with Parkinson's?	
19	What interventions are effective for reducing or managing unexplained fatigue in people with Parkinson's?	
20	How best to manage symptoms for women with Parkinson's who still have a menstrual cycle?	

Our helpline

If you would like to talk to about any of the symptoms and problems highlighted in the questions, please contact our confidential helpline on **0808 800 0303**.

Psychiatric/psychological

Question number		Notes
21	What approaches are helpful for reducing stress and anxiety in people with Parkinson's ?	
22	What treatments are helpful for reducing depression in people with Parkinson's?	
23	What therapies are helpful for improving the confidence (self esteem) of people with Parkinson's?	
24	Is cognitive behavioural therapy, (a talking therapy that helps people to manage problems by changing the way they think about them) effective for anxiety, confidence or depression in people with Parkinson's?	
25	What therapies are helpful for reducing apathy, (feeling a lack of interest or concern) in people with Parkinson's?	
26	What interventions are helpful for impulsive and compulsive behaviours (e.g. addiction, gambling, impulse control disorders) in people with Parkinson's?	
27	What best treats mild cognitive problems such as memory loss, lack of concentration, indecision and slowed thinking in people with Parkinson's?	
28	What best treats dementia in people with Parkinson's?	
29	What treatments are most helpful for reducing challenging behaviours (agitation, wandering, anger, aggression) in people with Parkinson's?	
30	What treatments are effective in reducing hallucinations (including vivid dreams) in people with Parkinson's?	
31	What treatments are best for the prevention and management of delirium (psychosis) in people with Parkinson's?	

Medication – delivery

Question number		Notes
32	What treatments would ensure the medications were equally effective each day (prevented/ managed wearing off, variability, on/off states) in people with Parkinson's?	
33	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.)	
34	Can medications be delivered in non-pill form for people with Parkinson's? (For example, skin patches, liquid preparations, inhalers.)	

Medication – side effects

Question number		Notes
35	What treatments are helpful for reducing dyskinesias (involuntary movements, which are a side effect of some medications) in people with Parkinson's?	

Medication – patient adherence

Question number		Notes
36	What treatments are best at helping people with Parkinson's to keep taking their medications correctly?	
37	What information do people with Parkinson's need in order to use their medications to best effect?	
38	Are decision aids (information resources that help people make decisions) useful for clinicians and patients when deciding what medications to take?	

Medication – personalisation

Question number		Notes
39	Is it helpful for patients to be able to control how much medication they take – either proactive (ie before a particularly busy day) or reactive (ie for an 'off' day)?	
40	How can medication regimens be personalised for best effect?	
41	Is it possible to identify different types of Parkinson's eg tremor dominant? And can we tailor treatments best according to these different types?	
42	Can looking at an individual's genes inform decisions about medication or treatment choices in people with Parkinson's?	

Medication – stage

Question number		Notes
43	What drug treatments are best for the different stages of Parkinson's?	
44	Does delaying starting medications for a newly diagnosed person with Parkinson's help improve long term outcomes (eg reduce dyskinesia, side effects)?	
45	What medications are helpful in the later stages of Parkinson's?	

Medication – assessment

Question number		Notes
46	Would the monitoring of dopamine levels in the body (eg with blood tests) be helpful in determining medication timing and amount (dose)?	
47	What is the best method of monitoring a person with Parkinson's response to treatments?	

Non drug treatments – speech and language therapy

Question number		Notes
48	What treatments improve stiffness in the muscles of the face (masking) and could improve facial expression and communication in people with Parkinson's?	
49	What treatments are helpful for swallowing problems (dysphagia) in people with Parkinson's?	
50	What speech therapy techniques (including Lee Silverman Voice Therapy) are helpful for communication problems in people with Parkinson's?	
51	Is singing helpful for improving communication in people with Parkinson's?	

Non drug treatments – physical training and exercise

Question number		Notes
52	Does exercise have long term benefits (more than three months) for improving muscle strength, flexibility, fitness, balance and function for people with Parkinson's?	
53	What is the best type and dose of exercise (physiotherapy) for improving muscle strength, flexibility, fitness, balance and function in people with Parkinson's?	
54	What helps people with Parkinson's stick with (adhere) an exercise programme?	
55	What treatments and aids improve walking (indoors, outdoors, rough ground, crowds, stairs) in people with Parkinson's?	
56	Is yoga helpful for flexibility, tremor and quality of sleep in people with Parkinson's?	
57	Is the Alexander technique (a technique that teaches the better use of muscles) helpful for people with Parkinson's?	
58	Is T'ai Chi (a Chinese martial art that uses slow fluid movements) helpful for improving mobility and balance in people with Parkinson's?	
59	Is dance helpful for improving mobility and balance in people with Parkinson's?	
60	Is cycling helpful for improving the fitness of people with Parkinson's?	
61	Is cueing (prompts) helpful for people with Parkinson's? (Cueing includes rhythmic music, lines on the floor, 'ready, steady, go,' prompts.)	
62	Is conductive education (a specialised rehabilitation system) helpful for people with Parkinson's?	

Non drug treatment – occupational therapy

Question number		Notes
63	What helps improve writing in people with Parkinson's?	
64	What helps improve the dexterity (fine motor skills or coordination of small muscle movements) of people with Parkinson's so they can do up buttons, use computers, phones, remote controls etc?	
65	What best helps someone with Parkinson's get out and about socially (promoting social participation)?	
66	What aids, adaptations, and strategies are most helpful for improving people with Parkinson's ability to undertake activities of daily living eg dressing, eating and drinking, food preparation?	
67	What aids or strategies help people with Parkinson's move in bed, and get in and out of a bed or a chair (transfers)?	
68	Can occupational therapy help people with Parkinson's to remain in work?	

Non drug treatment – complementary

Question number		Notes
69	Is meditation (mindfulness) helpful for people with Parkinson's?	
70	Are relaxation techniques (including biofeedback, guided imagery) helpful for people with Parkinson's?	
71	Is massage helpful for stiffness, pain, tremor, and mobility in people with Parkinson's?	
72	Is acupuncture helpful for people with Parkinson's?	

Non-drug treatment – surgery

Question number		Notes
73	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?	
74	Is ultrasound lesioning of the brain (damaging certain cells within specific areas of the brain) helpful for people with Parkinson's?	

Non-drug treatment – other

Question number		Notes
75	What diets help improve appetite and prevent weight loss in people with Parkinson's?	
76	What diets are helpful for general improvement in people with Parkinson's?	
77	Do low protein diets help medications to work better (reducing motor fluctuations) in people with Parkinson's?	

Carers

Question number		Notes
78	What training to improve knowledge and skills do informal carers (family and friends) need in order to best care for people with Parkinson's?	
79	How should health and social care services be best organised to support the carers of people with Parkinson's?	

Information – tools and resources

Question number		Notes
80	What tools/resources can help people with Parkinson's manage their condition on their own?	
81	What tools (used from diagnosis onwards) can help healthcare professionals have conversations with and meet the information needs of people with Parkinson's?	
82	Do decision aids – information resources that help people make decisions – help people with Parkinson's make choices about care (including respite care, home care, sheltered accommodation, and care homes)?	

Information – hospital

Question number		Notes
83	What training, techniques or aids are needed for hospital staff, to make sure patients with Parkinson's get their medications correctly and on time?	
84	What training do hospital care staff need in order to best treat people with Parkinson's (other than getting medications on time)?	

Information – primary care

Question number		Notes
85	What training helps General Practitioners (GPs) have the knowledge to support people with Parkinson's?	
86	What training do care home staff and homecare staff need in order to best care for someone with Parkinson's?	

Service provision – Parkinson’s nurse specialists

Question number		Notes
87	Are Parkinson’s nurses needed to give people with Parkinson’s the best care possible?	
88	What is the optimum number of patients that a Parkinson’s nurse specialist should have on their care list?	

Service provision – multidisciplinary teams

Question number		Notes
89	How to best improve communication and co-ordination of care between consultants for people with Parkinson’s who also have another health problem (co-morbidity)?	
90	What helps improve communication and better coordinates services between and within health care teams and social care teams that deal with people with Parkinson’s?	
91	What frequency of appointments (level of provision) with hospital staff (consultants, Parkinson’s nurse specialists, physiotherapists, occupational therapists) is best for the care of people with Parkinson’s?	
92	Are multidisciplinary teams effective for people with Parkinson’s? (Including who should be in them and their expertise.)	
93	Is an inpatient rehabilitation program helpful to assess the effect of medications and/or improve daily activities for people with Parkinson’s?	
94	Are services specific for different ethnic minorities helpful for the management of Parkinson’s?	

More about the project

How were the areas symptoms, day-to-day life and treatments chosen?

The process is being guided by a steering group of people with direct experience of living with Parkinson's, health and social care professionals, a representative from the Cure Parkinson's Trust and Parkinson's UK staff.

Aren't you focused on finding a cure?

Yes. Our research aims to improve life for people living with Parkinson's now, and ultimately find a cure.

What do we mean by unanswered questions?

We worked with researchers at the University of East Anglia to establish whether or not these questions were adequately answered by existing research.

We know that some of the questions have been looked at in individual studies. However, instead of using single studies to give answers, we used systematic reviews that bring together all the existing evidence on a particular question. Systematic reviews show how reliable the evidence is and whether further research is required.

What will we do with the results?

The results of this survey will guide future research and inform our wider work as a charity. By sharing what we find with the international Parkinson's research community, we hope to shape research into the condition not just in the UK but all over the world.

When will the results be announced?

We will publish the results in July 2014.

Every hour, someone in the UK is told they have Parkinson's. Because we're here, no one has to face Parkinson's alone.

We bring people with Parkinson's, their carers and families together via our network of local groups, our website and free confidential helpline. Specialist nurses, our supporters and staff provide information and training on every aspect of Parkinson's.

As the UK's Parkinson's support and research charity we're leading the work to find a cure, and we're closer than ever. We also campaign to change attitudes and demand better services.

Our work is totally dependent on donations. Help us to find a cure and improve life for everyone affected by Parkinson's.

Parkinson's UK

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Free* confidential helpline **0808 800 0303**

Monday to Friday 9am–8pm,
Saturday 10am–2pm. Interpreting available.

Text Relay **18001 0808 800 0303**

(for textphone users only)

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*calls are free from UK landlines and most mobile networks.