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JULY 2023

CHANGE THE FUTURE – PREVENTING A PARKINSON'S PANDEMIC.





Foreword

We commissioned this research because we wanted to understand how well the world's fastest growing neurological condition¹ is understood by the British public. The results shine a very bright spotlight on the misperceptions, low awareness and poor understanding of this devastating condition.

We called the report "Change the Future – preventing a Parkinson's pandemic" because, if we act now, we can change the future. When we find a cure, we will not only change the future for the 145,000 people currently living with Parkinson's in the UK², but we will also change the future for the millions of people around the world predicted to develop the condition in years to come.

In the 2018 paper, The Emerging Evidence of the Parkinson Pandemic², the authors noted that Parkinson's was exhibiting many of the characteristics of a pandemic. Parkinson's impacts every corner of the globe; its prevalence is increasing in every major region and the trajectory is rising sharply in response to changes in aging, industrialisation and other external factors. Like other pandemics, the authors reported, "the Parkinson's pandemic is experiencing exponential growth and no-one is immune to the condition".

Fast forward to today and the picture has only got worse. Globally, disability and death resulting from Parkinson's are increasing faster than for any other neurological disorder.

Whilst UK public figures like Jeremy Paxman and Billy Connolly, and in the US Michael J Fox, have done much to raise the profile of the condition in recent years, this report highlights that the majority of symptoms experienced by people living with the condition remain hidden, and public perception of what the condition means to those living with it is very different from the reality.

There needs to be a step change in attitudes and awareness around Parkinson's to speed up progress in the search for the cure so desperately needed for people living with Parkinson's and their families. The government can play a critical role in delivering this change; a catalyst is what we need. Our aim is to change the future for everyone affected by Parkinson's and consign Parkinson's to medical history.



Will Cook, CEO
Helen Matthews, Deputy CEO



I'm worse today than I was yesterday, and I'll be worse again tomorrow. We get worse every day. It feels like being in prison in your own body. You wonder where you're going to find the fight. Whether it's worth the fight. But then if you anchor back to everything that's good in life, it is worth the fight."

David, person living with Parkinson's

**Around
145,000**
people in the UK are
currently living with Parkinson's.



01

INTRODUCTION



Towards a Parkinson's pandemic

Parkinson's is the fastest growing neurological condition in the world¹. Globally, the number of people with Parkinson's has nearly trebled since 1990, to 8.6 million. Driven principally by aging, this number is projected to reach over 12 million by 2040. Additional factors, including increasing longevity, declining smoking rates, and increasing industrialization, could raise the impact to over 17 million².

The research paper titled, Emerging Evidence of the Parkinson Pandemic², highlighted the disease is increasing in every major region in the world. It emphasised how the prevalence of the condition is increasing at an alarming rate and that no-one is immune. Were it an infectious disease, it would be appropriate to label it a pandemic as it exhibits most of the characteristics.

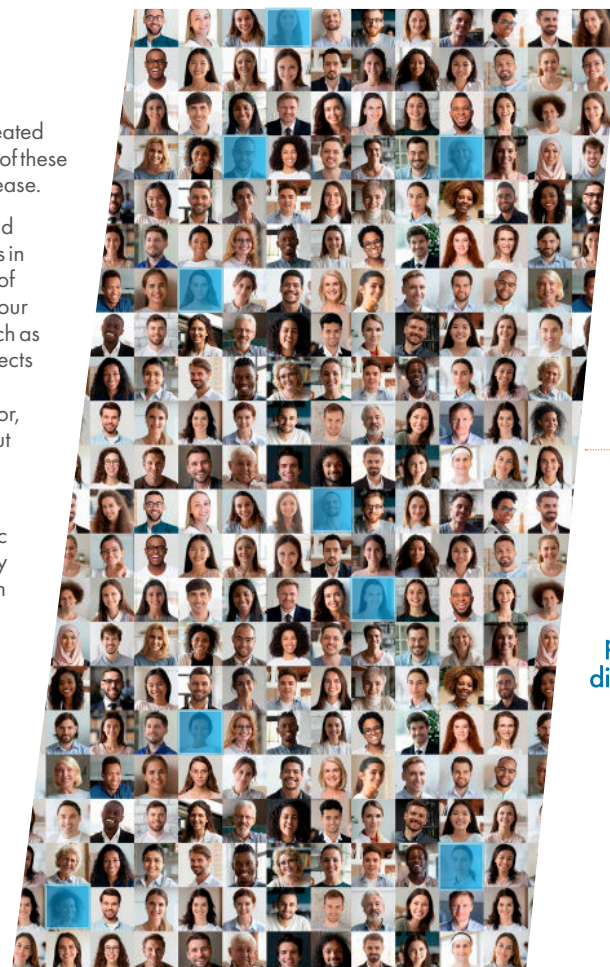
In the UK, every hour two people are told they have Parkinson's. It is predicted that 1 person in 37, in the UK, will receive a diagnosis of Parkinson's during their lifetime³. Currently, in this country, around 145,000 people are living with Parkinson's.

The underlying symptoms of Parkinson's are treated with a range of medication, but currently none of these slow, stop or reverse the progression of the disease.

The symptoms of Parkinson's are mainly caused by the loss of dopamine-producing nerve cells in the brain which control movement. Low levels of dopamine affect many things including how your body moves, making day-to-day activities such as eating, getting dressed or using everyday objects like a phone or computer difficult. The most well-known symptoms of Parkinson's are tremor, muscle stiffness and slowness of movement, but not everyone will experience all of these.

Parkinson's can cause a wide range of non-movement related symptoms including chronic pain, sleep disturbance, constipation, memory concerns, anxiety and depression; all of which can significantly impact an individual's day-to-day life.

Each person diagnosed with Parkinson's has a different experience, with their own combination of symptoms and side-effects; this makes treating Parkinson's difficult.



Every hour



two people in the UK are told they have Parkinson's.

1 in 37

within the UK, are predicted to receive a diagnosis of Parkinson's during their lifetime³.

¹ <https://www.who.int/news-room/fact-sheets/detail/parkinson-disease>

² The Emerging Evidence of the Parkinson Pandemic – <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6311367/>

³ The Incidence and Prevalence of Parkinson's in the UK. Results from the Clinical Practice Research Datalink Reference Report (published Dec 2017) – Parkinson's UK



02

ABOUT CURE PARKINSON'S





About Cure Parkinson's

Everything we do is to move us closer to our goal, of finding new treatments to slow, stop or reverse the progression of Parkinson's.

Cure Parkinson's was set up by four people living with Parkinson's who refused to accept the lack of progress in research and specifically curative treatments. Driven by their desire to change the research agenda, they set up Cure Parkinson's – a charity dedicated to driving forward research projects with the potential to slow, stop or reverse the progression of Parkinson's.

Since then, the charity has made significant progress in the quest for a cure. Cure Parkinson's has funded millions of pounds of research, made scientific discoveries and opened new avenues of research. We have made enormous strides in involving people with Parkinson's in research and given hope to many who are living with the disease. Our innovative approach – which has led to collaborations with the world's leading researchers and their inspirational work, combined with the active support of thousands of people living with Parkinson's – is bringing the world closer to a cure for Parkinson's.

How we are funded

Cure Parkinson's work is made possible only by our donors and fundraisers each year. Our influence does not arise solely from the funding we raise and provide to research. Since our beginning, Cure Parkinson's has directly funded, or helped facilitate funding for over £100 million of research projects. We collaborate with institutional funders, governmental funding bodies and other charities, in search of a cure for Parkinson's.

Cure Parkinson's has funded millions of pounds of research, made scientific discoveries and opened new avenues of research.





03

KEY FINDINGS



1. Brits are blind to the danger

Our research reveals 1 in 3 adults in the UK know someone with a diagnosis of Parkinson's and we estimate over 100 will be touched, in some way, by every diagnosis. Whether it's friends, family, connections via social media or colleagues for example, the disease recognises no boundaries. According to the World Health Organisation (WHO)⁴, globally, disability and death due to Parkinson's are increasing faster than for any other neurological disorder. But the UK public is largely unaware. Most adults (51%) believe the world's fastest growing neurological condition is Alzheimer's with a further 23% saying they don't know. Fewer than a fifth (17%) are aware of the impending Parkinson's pandemic.



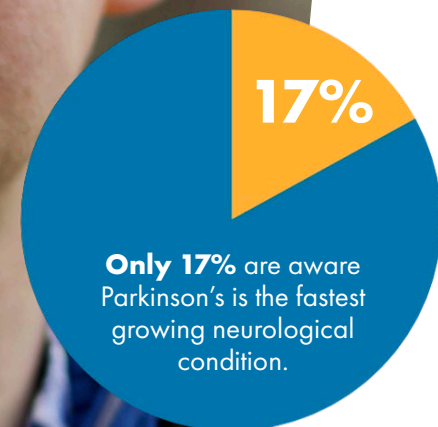
1 in 3

UK adults know someone living with Parkinson's.

⁴ <https://www.who.int/news-room/fact-sheets/detail/parkinson-disease>



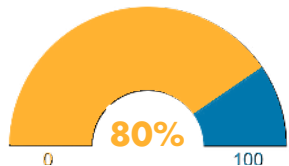
John, person living with Parkinson's





2. Majority still wrongly see Parkinson's as an old person's disease

According to the NHS⁵ "Most people with Parkinson's start to develop symptoms when they're over 50, although some people with the condition first experience symptoms when they're under 40." It's a fact unknown by 80% of the population who mostly see it as a disease for the over 60s. Interestingly, over a fifth (22%) of 18-24 year olds think the people most likely to get Parkinson's are aged 40 years and under. Older age groups, those 45 years and older, are also more likely to say they don't know.

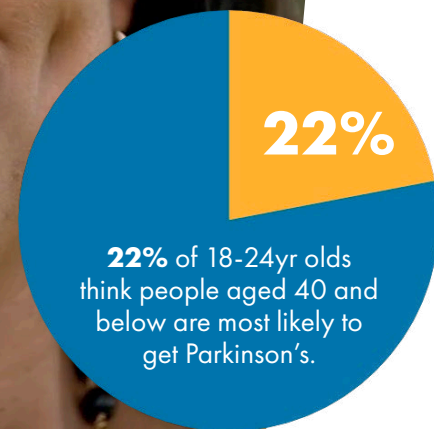


80%
of the population see
Parkinson's as a disease
for the over 60s.

⁵ <https://www.nhs.uk/conditions/parkinsons-disease/>



Omotola, person living with Parkinson's



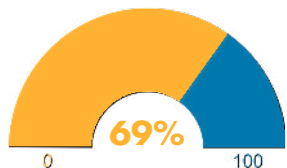
22%
of 18-24yr olds
think people aged 40
and below are most likely
to get Parkinson's.



3. Silent symptoms go unnoticed by the majority

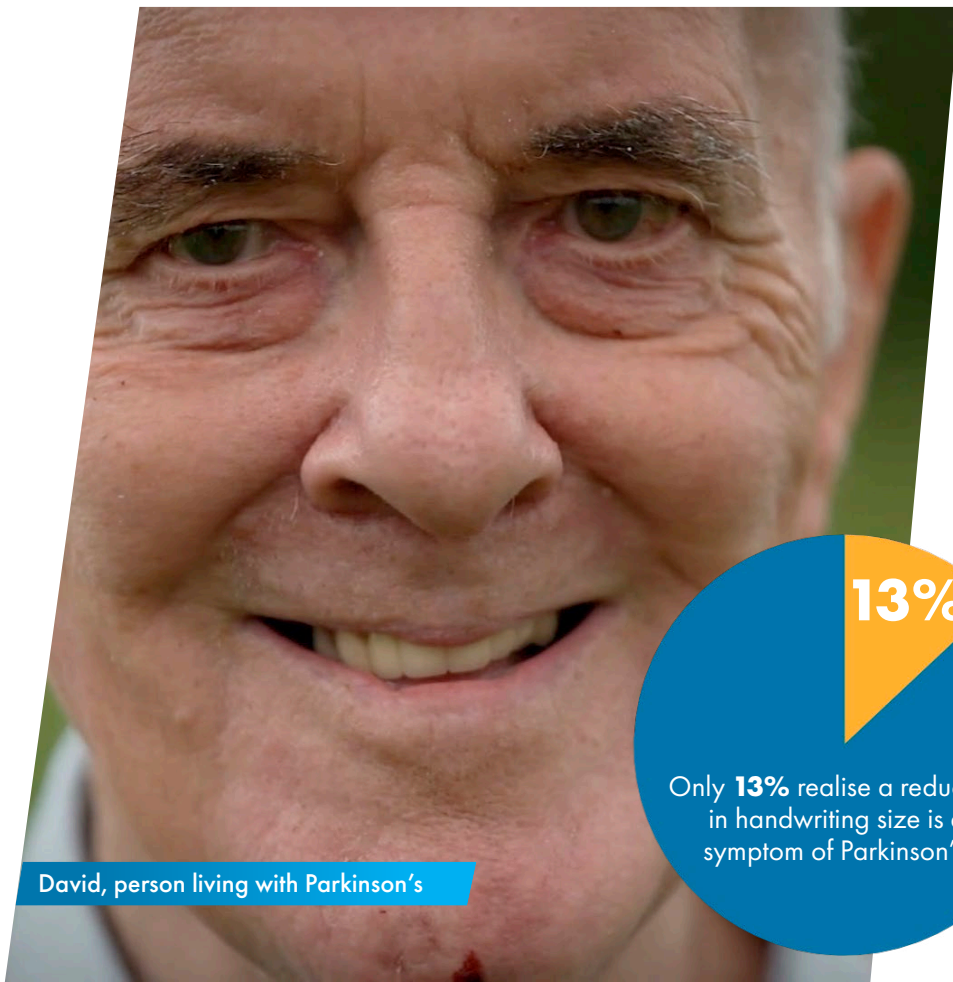
Only two symptoms of Parkinson's are recognised by over half the population – "shaking" (69%) and "problems with balance" (52%). Two other symptoms, "slowness of movement" (49%) and "difficulty moving" also scored highly (49% and 46% respectively).

While the three most common symptoms are indeed a tremor (shaking), slowness of movement and rigidity (muscle stiffness) there are over 40 other symptoms which the majority of the public are unaware of. Reduced sense of smell, constipation, depression, fatigue and a reduction in size of handwriting are just a few of the indicators people should be aware of, indicators that could be early warning signals. For many people, by the time the symptoms manifest, Parkinson's has already been progressing for a while.



69%
of the population identify 'shaking' as a symptom of Parkinson's.

David, person living with Parkinson's

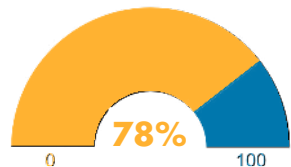


Only **13%** realise a reduction in handwriting size is a symptom of Parkinson's.



4. Education lacking for fastest growing neurological disease

One of the most consistent narrative threads throughout the research is how little people know about the disease. Nearly 4 out of 10 people (39%) don't know if Parkinson's is fatal or not (while Parkinson's itself is not treated as a fatal disease by the medical profession, it makes people more vulnerable to other conditions). Nearly a quarter (24%) don't know if it's curable. Another 25% wrongly believe it is. 78% of adults are unaware that there are ways of managing the symptoms of Parkinson's beyond drugs (there are lots of proven ways of managing symptoms) and 70% have no idea whether genetics are the main cause of Parkinson's (genes can play a role in whether someone develops Parkinson's, however only a small percentage of people are affected in this way).



78%
of adults are unaware that there are ways of managing the symptoms of Parkinson's.



Alison, person living with Parkinson's

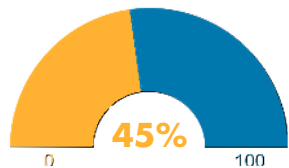


25% believe Parkinson's is curable.
(it currently is not).

5. Majority believes government should be doing more

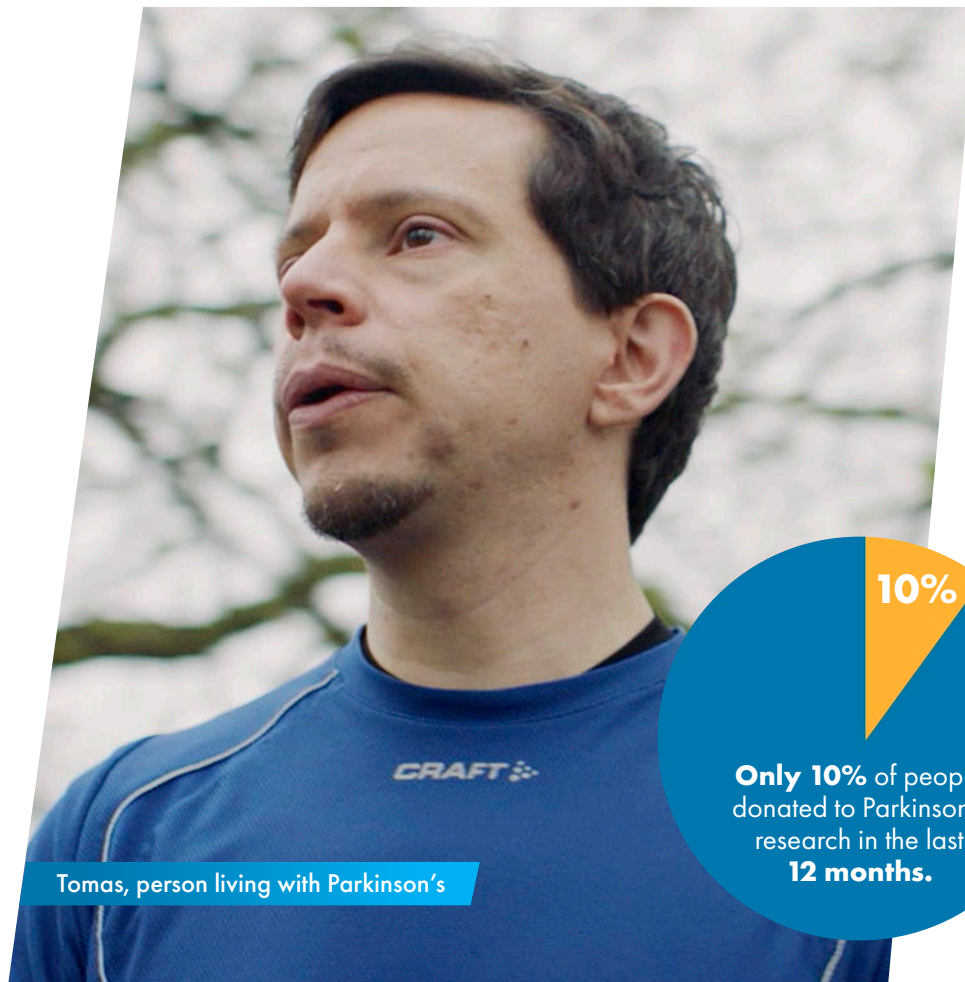
The cost of healthcare for the estimated 145,000 people living with Parkinson's in the UK is over £728m⁶ per year. But considering the wider cost of out-of-pocket expenditures by patients, caregiving costs or social costs, for example, the total economic impact rises to over £3.6bn per year. Over time the costs will increase, highlighting the importance of finding treatments which will slow the disease's progress and ultimately, cure it.

The surest and quickest way to achieving this is by making more funding available for research, and that should be the responsibility of government and of the NHS according to the data collected. Charities and private organisations should also bear the funding brunt but, without greater support and focus from government, the journey to a cure will be a lot slower. The public is largely supportive of helping to fund a cure with only 12% saying they wouldn't donate to that cause. Although when asked "which of the following areas of human medical research have you donated to in the past 12 months", only 10% said Parkinson's. 40% supported cancer, 24% heart disease and 16% dementia.



45%
believe the government
should be doing more to
fund the search for a cure.

⁶ <https://www.ucl.ac.uk/ion/news/2018/may/medical-costs-parkinsons-ps3000year-higher-others-same-age>



Tomas, person living with Parkinson's



Only 10% of people
donated to Parkinson's
research in the last
12 months.



04

UNDERSTANDING & AWARENESS





A disease that touches many

Our research reveals that just over a third of the adult population of the UK (34%) knows someone living with Parkinson's. That represents over 16m people who are not just aware of the disease, but who have a personal connection with it. The figure could also be much higher. There are many examples of people hiding their diagnosis during the early stages of Parkinson's for fear of the impact on their working life and family. In some instances, people have also been advised not to share the news because of the impact it might have on others.

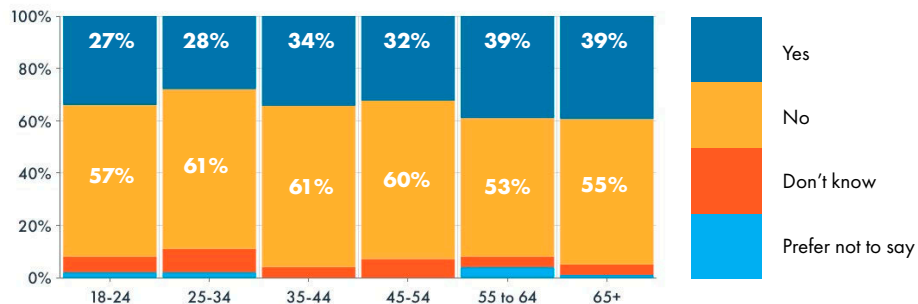
Estimates from Parkinson's UK⁷ show that around 145,000 people are currently living with Parkinson's. It could mean on average, for every person diagnosed, over 100 people are in some way touched by it. Whether it be family, friends or work colleagues, for example, it brings to life the impact of the disease – not just on those diagnosed. The research also shows the disease touches all age groups but there are some variances. For example, you are 7% less likely to know someone with Parkinson's if you're aged 18 to 34 and 5% more likely if you are aged 55+. Both variances are statistically significant.

1 in 3
adults know someone
living with Parkinson's.

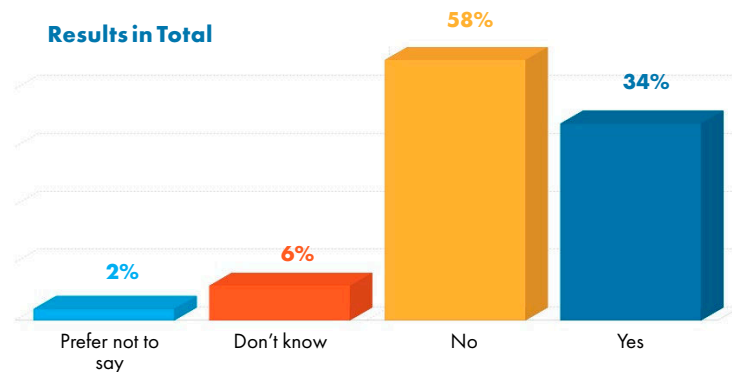
⁷ <https://www.parkinsons.org.uk/about-us/reporting-parkinsons-information-journalists>

Q. Do you know anyone, or have you known anyone, who has been diagnosed with Parkinson's e.g., friend, family, family friend, colleague etc.?

Results by Age Range



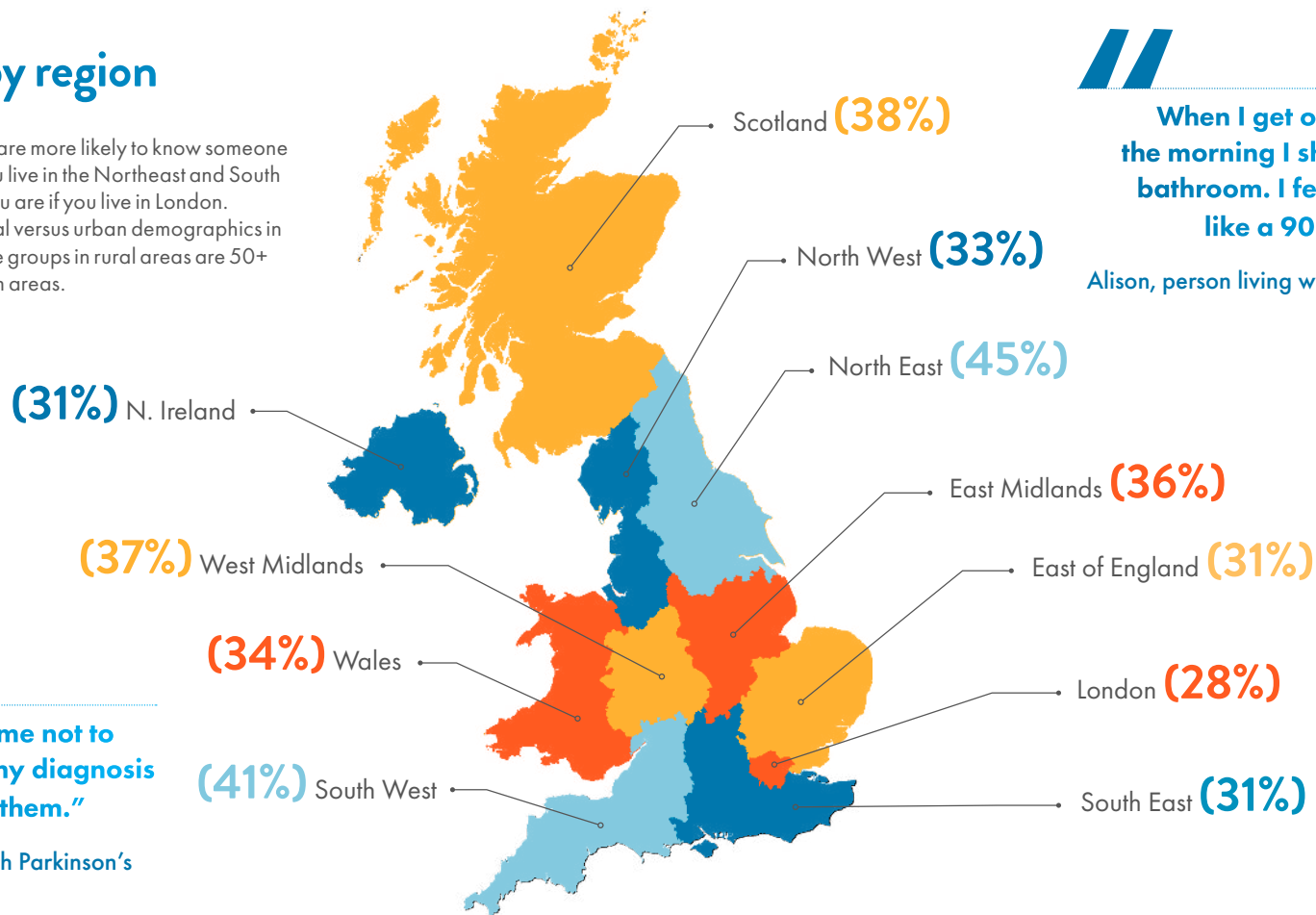
Results in Total





Awareness by region

In terms of regionality, you are more likely to know someone living with Parkinson's if you live in the Northeast and South West of the country than you are if you live in London. This could be related to rural versus urban demographics in that the most prominent age groups in rural areas are 50+ whereas it's 25-34 in urban areas.



When I get out of bed in the morning I shuffle to the bathroom. I feel and look like a 90-year-old."

Alison, person living with Parkinson's



My consultant told me not to tell anyone about my diagnosis as it might depress them."

Gillian, person living with Parkinson's



Prevalence

It is predicted that 1 in 37 people alive today, in the UK, will be diagnosed with Parkinson's in their lifetime.

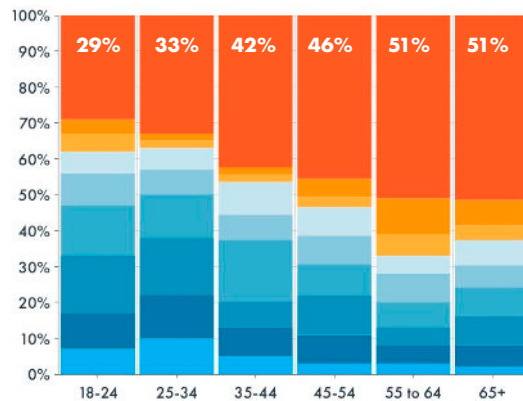
It's a startling statistic, and one which is unknown to 92% of the population. For those who answered, 44% of people think Parkinson's is far less common than it is.

The same percentage of people admitted they simply do not know. Interestingly, younger age groups are significantly more likely to think of Parkinson's as being more prevalent in older age groups; the latter also being more likely to answer "don't know" which is a concern as they have a higher risk of diagnosis.

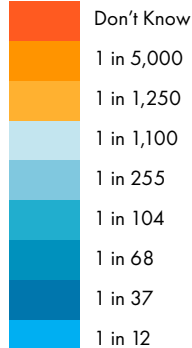
44%
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Q. One in how many people in the UK do you think will get Parkinson's in their lifetime?

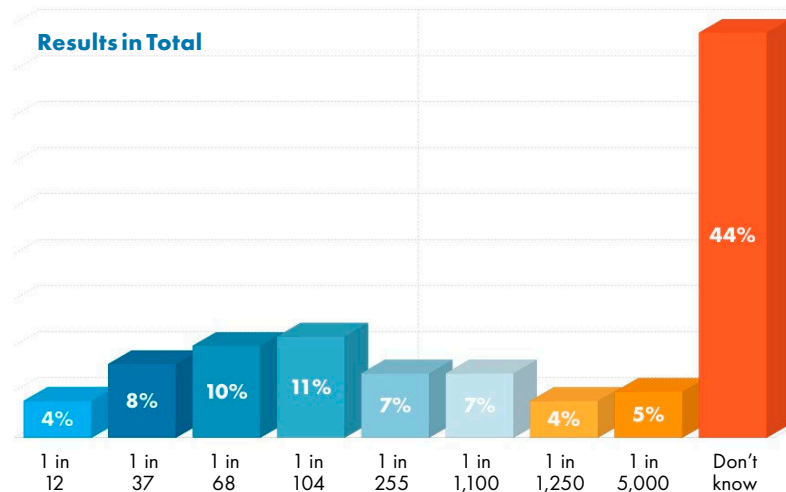
Results by Age Range



KEY



Results in Total





Fastest growing neurological condition

Every hour in the UK, two people are diagnosed with Parkinson's. The World Health Organisation (WHO) has identified Parkinson's as the fastest growing neurological condition in the world¹. However, awareness of this is alarmingly low, with 83% of adults in the dark about just how prevalent Parkinson's is becoming. More than half of the UK public (51%) believe that Alzheimer's is the fastest growing neurological condition and a further 23% answered "don't know".

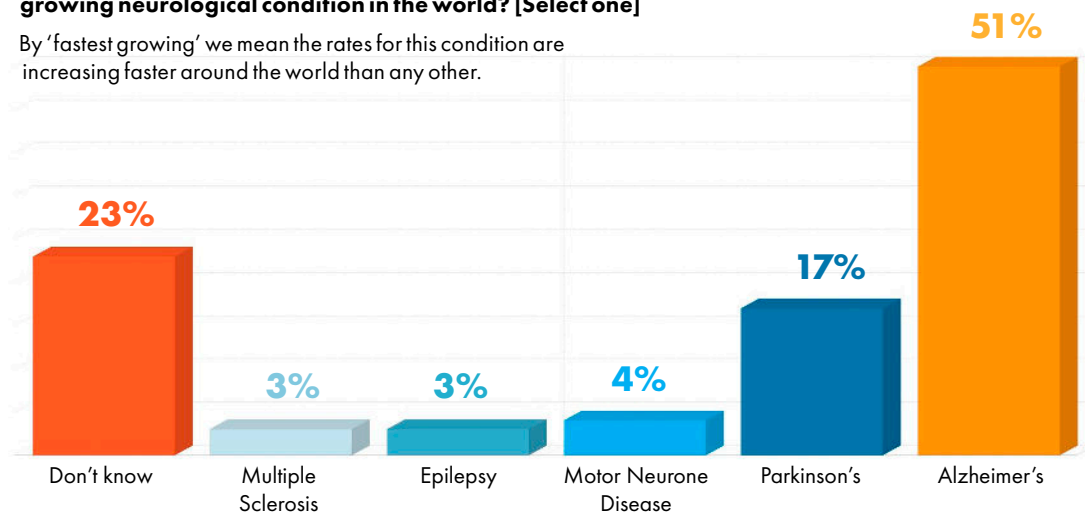
While dementia and, in particular, Alzheimer's, have seen greater exposure in the media than Parkinson's⁸, the low awareness is still somewhat surprising given more than 1 in 3 adults (34%) said they know someone with a diagnosis. As the WHO reports, "globally, the population and also non-specialist health-care professionals are generally poorly informed about Parkinson's⁹".

Until there is a better grasp of just how quickly the rates of Parkinson's are increasing, the catastrophic lack of urgency around the need for better treatments and care will not materialise.

83%
of adults are unaware of the prevalence of Parkinson's.

Q. Which of the following do you think is the fastest growing neurological condition in the world? [Select one]

By 'fastest growing' we mean the rates for this condition are increasing faster around the world than any other.



⁸ Analysis of news coverage and mentions of "Dementia", "Alzheimer's Disease", "Alzheimer's" and "Parkinson's" using Google News and Google Trends 01/06/22 – 01/06/23

⁹ Parkinson's Disease, A Public Health Approach, World Health Organization



50 isn't old

Public awareness of the age people are most likely to be diagnosed with Parkinson's is low. 13% think it's when people are in their 40s or younger; 16% think over 70s are most likely to be diagnosed and a quarter (25%) stated they didn't know; the latter statistic driven largely by the over 45s.

According to the NHS¹⁰, most people with Parkinson's start to develop symptoms when they're over 50, although some people with the condition first experience symptoms when they're under 40. Only a fifth (20%) considered the 50s to be the most likely decade to get the disease.

We should also not forget that 1 in 20 people with Parkinson's develop symptoms before the age of 50¹¹. This is known as young-onset Parkinson's.

1 in 20
develop symptoms
before the age of 50.

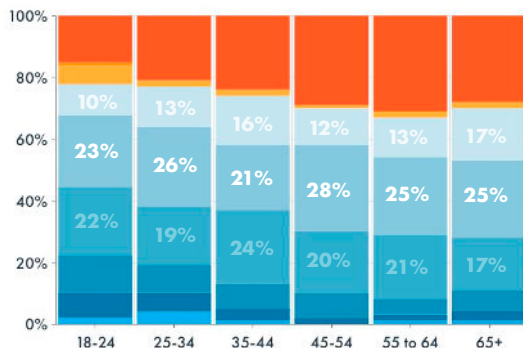


I want to hopefully be able to do the things most normal dads do."

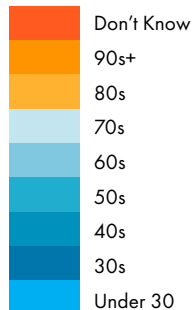
Tomas, person living with Parkinson's

Q. At what age do you think someone is most likely to get Parkinson's? [Select one] ?

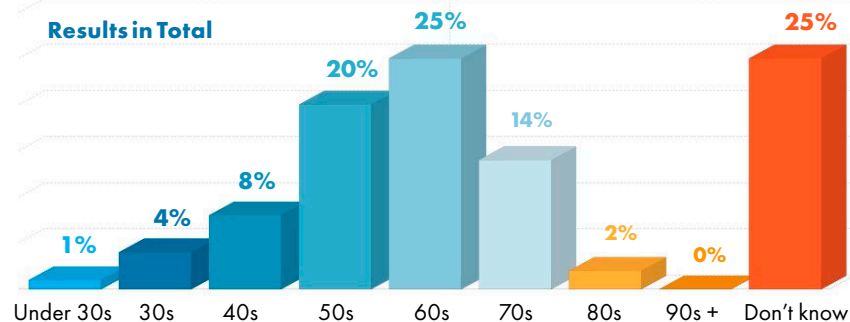
Results by Age Range



KEY



Results in Total



¹⁰ <https://www.nhs.uk/conditions/parkinsons-disease/>

¹¹ Wickremaratchi et al (2009) 'Prevalence and age of onset of Parkinson's disease in Cardiff: A community based cross sectional study and meta-analysis' Journal of Neurology, Neurosurgery, and Psychiatry

The hidden disease

Each person diagnosed with Parkinson's has a different experience, with their own combination of symptoms and side-effects. This makes treating Parkinson's difficult.

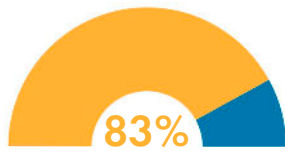
One of the biggest issues identified by Cure Parkinson's is the widespread belief that most people with Parkinson's experience tremors or shaking. 67% of UK adults believe this to be the case. While tremor and shaking are fairly common, they are only two of a wide range of debilitating symptoms of the condition, many of which are unknown to the majority of the UK public.

Continued...

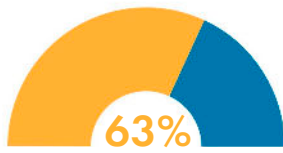


It was movement on my right side that was first affected. Gradually my symptoms progressed and I struggled to write, work and even carrying out everyday tasks became a problem."

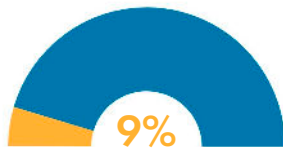
Alison, person living with Parkinson's



Unaware that loss of smell is a symptom.



Don't connect memory problems with Parkinson's.



Only 9% know that constipation is a symptom.

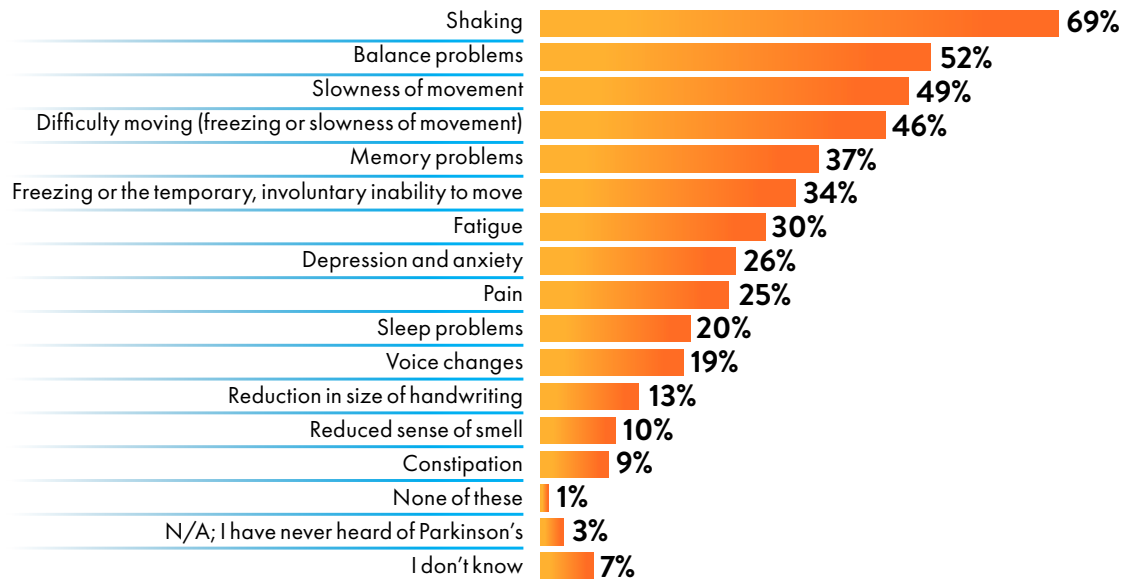


The hidden disease (cont.)

83% of Brits are unaware that loss of smell is a symptom. 81% don't know that changes in voice could be an indicator of Parkinson's and 87% had no idea that a reduction in handwriting size could also be a sign of the life-changing disease.

Early symptoms of Parkinson's can include loss of taste, changes in voice and handwriting and memory problems. Likewise, nearly three quarters of adults (74%) don't associate depression, anxiety, and pain as potential signs of the disease. Two thirds (66%) don't know about the temporary inability to move and 63% don't connect memory problems with Parkinson's either. Many people who have Parkinson's notice difficulties with constipation before they notice motor symptoms such as tremor or stiffness and yet only 9% of people are aware that this is an issue.

Q. Which of the following, if any, do you associate with Parkinson's? [Select all that apply]





In the dark over a cure

Currently there is no cure for Parkinson’s – a statistic unknown to 49% of the population. In fact, a quarter of the population (25%) believe there is a cure. Standard treatments for Parkinson’s have not actually changed since the introduction of levodopa in the 1960s – more than 60 years ago. Current treatments do nothing to impact the progression of the condition, they simply help with the symptoms by masking them, often temporarily.

Dig deeper into the research and men are more likely to think there is a cure than women (30% vs 21% respectively), which is especially noteworthy as men are more often affected than women.

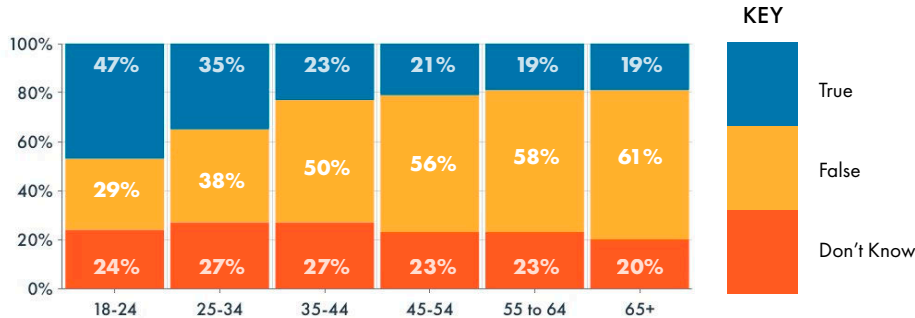
Looking at age profiles, there isn’t too much variance in the percentage of “don’t knows” but, it is clear from the research, the younger you are the more likely you are to think there is a cure.

49%
of adults are unaware that there is currently no cure for Parkinson’s

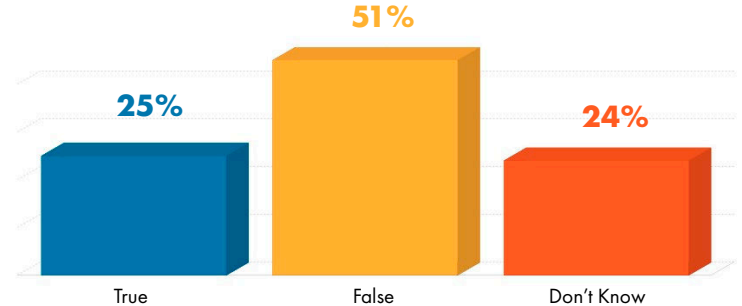
Q. Do you think the following statement is true or false?
“There are treatments available that can cure Parkinson’s.”

A cure is a treatment that restores health.

Results by Age Range



Results in Total





Living well with Parkinson's

Over three quarters of the population (78%) do not know there are ways of managing the symptoms of Parkinson's beyond the use of medications.

The World Health Organisation promotes healthy lifestyle as does Parkinson's UK¹² which, among other behaviours, advises maintaining a healthy diet can be helpful. Being active with Parkinson's can help improve mental and physical wellbeing as well as balance, strength and coordination. Equipment, living aids and technology can all make daily life with Parkinson's easier.

A number of studies are also currently looking at whether exercise can slow progression of Parkinson's including a clinical trial¹³ which is investigating the impact of high and low intensity exercise on untreated people with Parkinson's.



A cure would wind back the clock. It would give me back my life as I imagined it would be. The emphasis on finding a cure, that's the most important thing to people living with this day in, day out."

Alison, person living with Parkinson's

78%
don't know Parkinson's
can be managed beyond
the use of medication.

¹² <https://www.parkinsons.org.uk/information-and-support/everyday-life>

¹³ <https://www.sparx3pd.com/>



The cost to society and finding a cure

The cost of healthcare for the estimated 145,000 people living with Parkinson's in the UK is over £728m⁶ per year. But considering the wider cost of out-of-pocket expenditures by patients, caregiving costs or social costs, for example, the total economic impact rises to over £3.6bn per year. Over time the costs will increase, highlighting the importance of finding treatments which will slow the disease's progress and ultimately, cure it.

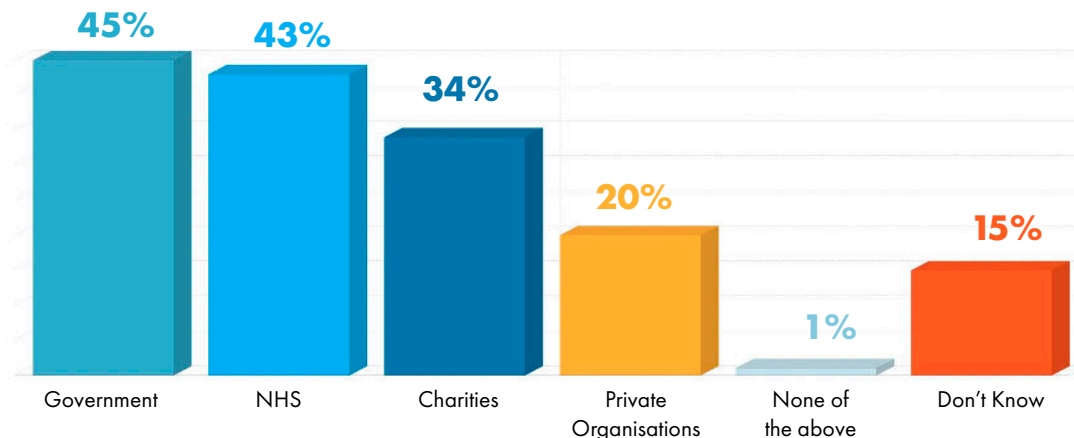
The surest and quickest way to achieve this is through greater funding and according to the research, UK adults believe that should be the responsibility of government and of the NHS. Charities and private organisations should also bear the funding brunt but, without greater support and focus from governing bodies, the journey to a cure will be a lot slower.

The public is willing to get behind the search for a cure with only 12% saying they wouldn't donate to that cause. Although when asked "which of the following areas of human medical research have you donated to in the past 12 months", only 10% said Parkinson's. 40% supported cancer, 24% heart disease and 16% dementia.

£3.6bn

is the annual economic impact of Parkinson's.

Q. Which of the following bodies in the UK, if any, do you think has the most responsibility to help fund the search for a cure for Parkinson's? [Select up to 2 options]





06

RECOMMENDATIONS

The research clearly identifies a need for greater understanding and awareness to prepare us for the Parkinson's pandemic that is looming unless we take action. The only way to truly avert it is to find a cure.

As a small, independent British charity, Cure Parkinson's has managed to fund millions of pounds of research, make scientific discoveries and open new avenues of research. To accelerate towards a cure the following four actions must be taken:



1. Funding to increase from central government as a priority

We appreciate there are many pressures on central government funding, particularly in challenging economic times. But the reality is, without a cure for Parkinson's, the economic and social impact that accompanies a Parkinson's pandemic will be devastating. The current cost to healthcare is already estimated to be over £728m per year with the total economic impact rising to over £3.6bn per year. If the current projections are correct, of people with Parkinson's more than doubling by 2040², the economic impact will double to over £7.2 billion.

In its technical brief, Parkinson's disease: A public health approach¹⁴, the WHO is clear on the political commitment required to "develop strategies, programmes and services that are effective for people with Parkinson's disease". Furthermore, it highlights the need to "increase investment in biomedical, clinical, implementation and translational research into new diagnostics and treatments in direct response to the needs of people with Parkinson's disease".

Cure Parkinson's is asking for £90million to be urgently allocated to finding a cure. To put that in context it is less than 3% of the economic impact of the disease. How would it be allocated?

- £10m to be invested in screening to identify at risk populations, so that trials can be funded that look at prevention as the cure.
- £25m to fund grants for researchers to run those trials with the at risk groups.
- £10m over 5 years to fund 40 more Clinical Research Nurses so that more trials can take place.
- £45m for multi-arm research which allows multiple drugs to be tested in one trial, speeding up the search for a cure.



£90M
urgently needs
to be allocated to
finding a cure.

This is just
3%
of the total
economic impact
of Parkinson's.

¹⁴ www.who.int/publications/i/item/9789240050983



2. Getting more people to participate in trials

To improve access and participation in clinical trials in the UK, Cure Parkinson's is calling for the Clinical Research Network to fund and enlist a dedicated team of Parkinson's specialist clinical research nurses to deliver cutting edge Parkinson's studies.

Clinical trials are often delayed because of the difficulty in enrolling participants. Research has indicated that 45% of clinical studies are held up due to this¹⁵.

Other research points to 30% of a timeline for drug development process is dedicated to recruitment and 45% of clinical studies are delayed because of difficulty enrolling participants¹⁶.

¹⁵ Rising to the Challenges of Clinical Trial Improvement in Parkinson's Disease - IOS Press (Rallying, 2014)

¹⁶ <https://content.iospress.com/download/journal-of-parkinsons-disease/jpd150541?id=journal-of-parkinsons-disease%2Fjpd150541>



45%
of clinical trials,
struggle to enrol
participants.

80%
are 'unlikely'
to participate in
clinical trials.

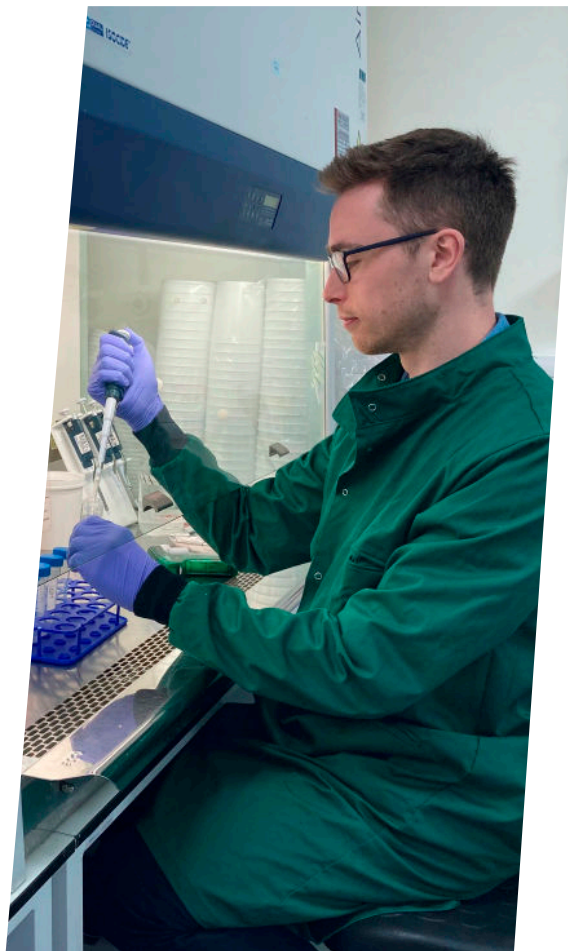


3. Filling a recruitment gap to secure more scientists working on a cure

The House of Lords Science and Technology Committee recently wrote to the Minister of State for Health and Social Care with the findings of its short inquiry into clinical academics in the NHS¹⁷. It concluded “clinical research is on a precipice” and strongly recommended the government “should urgently address inequalities in total remuneration that disincentivise clinical academia as a career path. It should work with universities, governmental and non-governmental research funders, and NHS trusts, to ensure that clinical academics are not financially disadvantaged by pursuing research compared to what they could earn as full-time clinicians”.

Research from the Association of Medical Research Charities (AMRC) also revealed four in ten (40 per cent) charity-funded early career scientists have also considered leaving research due to funding concerns since the coronavirus hit the UK¹⁸.

It is a simple picture. Without more scientists to work on finding a cure, the pathway to success will be greatly slowed and a Parkinson’s pandemic will almost certainly not be averted. We need urgent action from the government to address this workforce crisis.



40%
of early career
scientists have
considered
leaving over
funding concerns.

¹⁷ <https://committees.parliament.uk/committee/193/science-and-technology-committee-lords/news/175630/the-future-of-clinical-research-in-the-nhs-is-under-threat/>

¹⁸ <https://www.amrc.org.uk/news/pandemic-threatens-future-of-research-as-early-career-scientists-look-to-leave>

4. Speeding up the clinical trial process

Cure Parkinson's welcomes the recent announcement from the UK's Medicines and Healthcare products Regulatory Agency (MHRA) that, with support from partners, it will make it faster and easier to gain approval and to run clinical trials in the UK. The announcement has been a long time coming and it must be actioned without further delay. We also ask regulators to look at what more can be done to speed this up including identifying innovative ways of collating data across multiple trials.

In 2022 Nicola Perrin, MBE, CEO of the Association of Medical Research Charities (AMRC) said of a report from the British Pharmaceutical Industry that showed a drastic decline in the number of clinical trials, "a drop of this magnitude in access to clinical trials in the UK is damaging both to the UK's position as a world leader in research, but also for the many patients that benefit from participating in clinical research".

Cure Parkinson's has been championing a new type of clinical trial process, called multi-arm, multi-stage (MAMS) studies, which involve testing multiple therapies at the same time. This type of trial can create a conveyor belt-like process of clinical testing that will enhance the standard of care and drive us faster towards a cure.

Another avenue of focus for Cure Parkinson's research is on drugs already approved for human use or already being developed for treating other conditions. This means some steps have already been taken, enabling trials in people with Parkinson's to start faster than would be possible without previous clinical testing. However, we regularly hear from people with Parkinson's that the process is still not fast enough.

The three stages of clinical trial can take anywhere between 15 and 20 years in Parkinson's, but in that time, those living with the condition are considerably worse off.



15-20YRS
is the time it
currently takes to
do the three stages
of a clinical trial.

Rachel, living with Parkinson's



05

METHODOLOGY

Methodology

The findings in this study are based on quantitative data collected from 2,000 adults across the U.K. OnePoll, a survey-led market research company – managed the research in collaboration with Cure Parkinson's. The survey was fielded between 8 -14 February 2023.

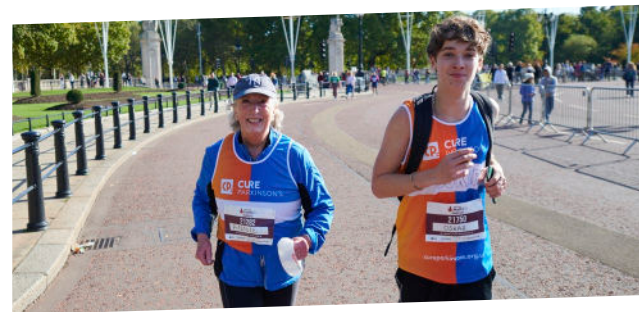
This survey was undertaken in the UK only, to a nationally representative sample. Our nationally representative samples are representative on the basis of age, gender, and region.

For a statistic of 50% the margin of error for sampling on a sample of 2,000 respondents is $\pm 2.2\%$. For smaller or larger statistics, the margin of error will decrease and falls to 1.9% for a statistic of 10% or 90%. This margin of error is small making the data highly reliable.



I have to relearn how to tie a pair of shoelaces, every single day. My body has reorganised itself and it's not the way you think it should be."

John, person living with Parkinson's



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