



# Living with: Parkinson's disease

July 2023

**healthwatch**  
Stoke on Trent

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# Background

Healthwatch Stoke-on-Trent is the city's independent health and social care champion. We are here to listen to the experiences of local people using local health and care services and about the issues that matter to the people of Stoke-on-Trent.

Parkinson's disease is a progressive neurodegenerative condition caused by a loss of nerve cells in the brain, which leads to a reduced level of dopamine in the brain. As dopamine helps to regulate the motor function of the body, when a person has a reduction of this chemical it can impact their movement and ability to carry out their day-to-day activities.

A Parkinson's UK report into the Clinical Practice Research Datalink (CPRD) using primary care data from 2015 found that there were about 137,000 people living with Parkinson's disease in the UK. With the rate of incidents being 33.4 per 100,000 persons, each year there are about 17,300 new diagnoses of Parkinson's disease in people aged 45 years and above.

The lifetime risk of being diagnosed with Parkinson's disease is 2.7%. This is equivalent to 1 in every 37 people being diagnosed at some point in their lifetime. Figures produced by Midlands Partnership Foundation Trust (MPFT) show that there are around 800 people living with Parkinson's in Stoke-on-Trent with an annual incidence of around 90 people newly diagnosed.

In 2015, we published 'Parkinson's Provision', a report analysing the Parkinson's services in Stoke-on-Trent from a user perspective. The report found that despite there being a lot of positive feedback on the care they were receiving, there were some areas that could be improved on, particularly around the provision of information post-diagnosis, and support from a range of services including better training for NHS and related staff in the management of the condition in primary and community care.

Further, in collaboration with Healthwatch Staffordshire and Staffordshire Neurological Alliance, we conducted a largescale study across Staffordshire and Stoke-on-Trent resulting in the 2017 report 'Not NICE Enough'. This study highlighted many areas of good patient care and high levels of satisfaction with neurological services. However, it also identified issues in relation to areas such as delays in being seen by a specialist after

referral to neurologists for diagnosis, access to physiotherapy and palliative care discussions.

Earlier this year, our team engaged with community-led group Living Well with Parkinson's whose stories collectively stressed the lack of support they were receiving through the NHS. As a response to the amount of feedback received, we decided to re-visit our work on Parkinson's care services in Stoke-on-Trent to see what, if anything, has changed.

As a part of our other key projects throughout the 2023 - 2024 work programme, we have included a set of questions titled 'golden threads'. These questions are to remain consistent throughout our projects to gather information about access to services, whether by digital exclusion, accessibility standards or availability of service and the impact of not having access.

## What we did

Healthwatch Stoke-on-Trent received intelligence about the lack of on-going care and support to patients diagnosed with Parkinson's disease. We met with the Living Well with Parkinson's group which are set at local gyms across the area to offer a social group for those with Parkinson's and the carers of, it also encourages regular exercise with specialist support and equipment. Our team visited the group at Base Body Fitness on 3 occasions. We spoke to people on a one-to-one basis using a structured questionnaire.

Living Well with Parkinson's had also been working in tandem with The Stoke-on-Trent City Council to lead 2 additional structured exercise groups at Fenton Manor Sports Complex and Dimensions Leisure Centre. Our staff met with the group at Fenton Manor to collect participants experiences of using local health and social care services when living with or caring for someone with Parkinson's disease.

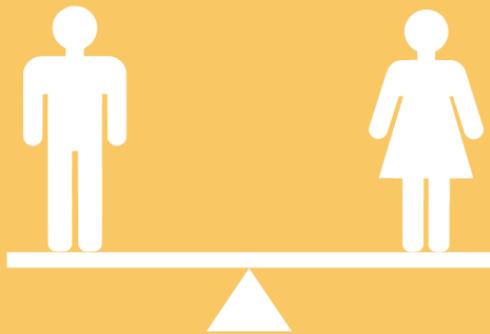
In addition, we were invited to attend a Parkinson's UK support group and spoke to over 40 attendees made up of people living with Parkinson's and their carers, many of whom went on to complete our survey as well as share their experiences as a group.

Alongside the 13 one-to-one interviews with individuals, we had an online version of the questionnaire for people who preferred to provide their response privately or had not attended the groups. The online survey collected an additional 26 responses.

## Who we spoke to



**39**  
respondents



### Gender

Male	14
Female	12
Prefer not to say	13

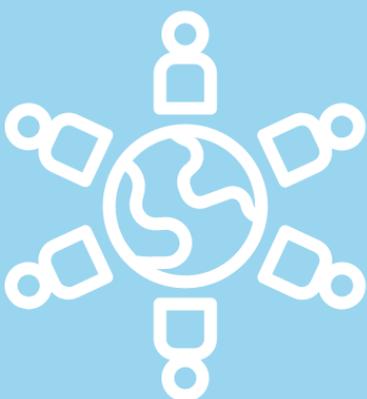
### Age

Under 18	0
18-24	0
25-49	2
50-64	7
65+	15
Prefer not to say	15



### Ethnicity

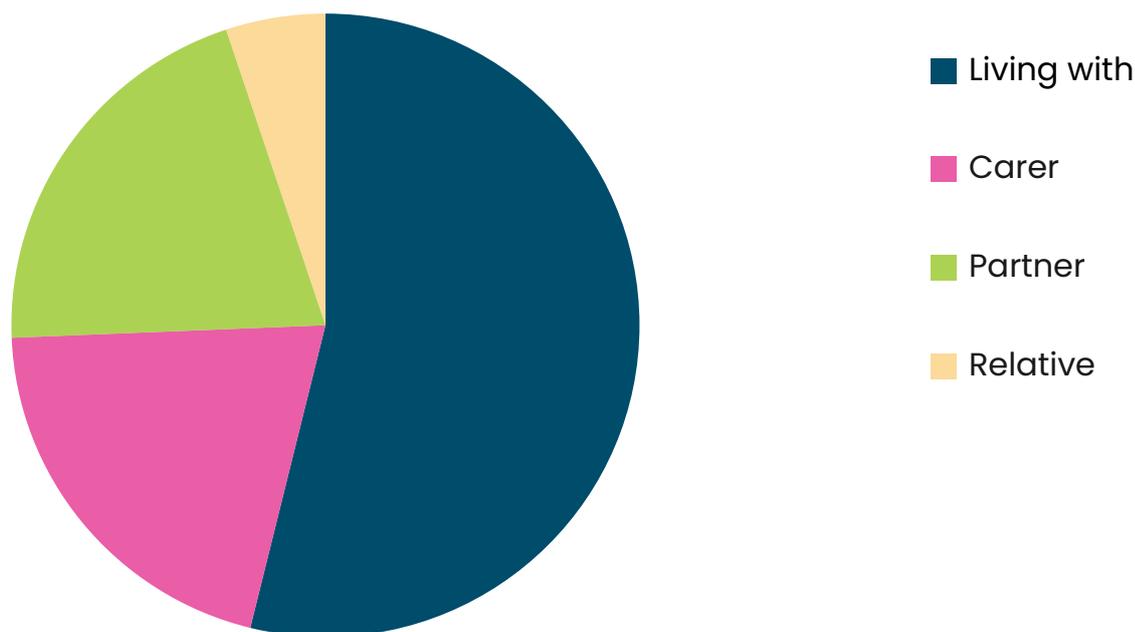
White	21
Asian or Asian British	3
Any other ethnic background	1
Prefer not to say	14



# Key Findings

Through our survey and individual interviews, we asked a mixture of closed and open text questions, so questions have been analysed according to question type. The open questions have been analysed using thematic analysis.

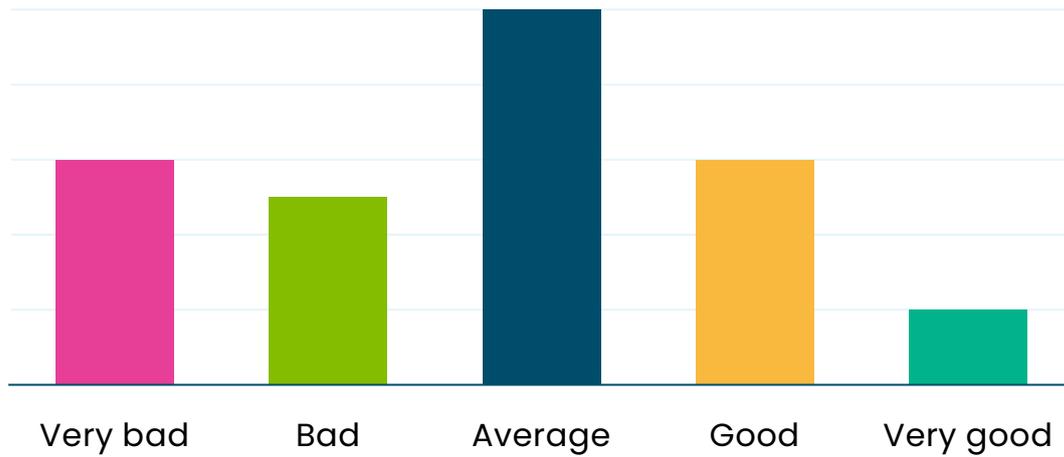
## 1. What is your connection to Parkinson's disease?



Many of our respondents are people who have been diagnosed and are living with Parkinson's disease. However, we are aware that some respondents completed the survey jointly as a couple, and these have only been counted as 1 response in the results. In cases where they were interviewed or completed the survey separately and have been recorded accordingly.

We found that people who identified themselves as a partner or relative were often also carers, and likewise people who identified themselves as carers were often partners or relatives of the person they care for. According to NHS England and Carers UK, many carers do not see themselves as carers, as it can be difficult to separate their caring role from the relationship that they have with the person they care for. It can take carers 2 years to acknowledge their role as a carer.

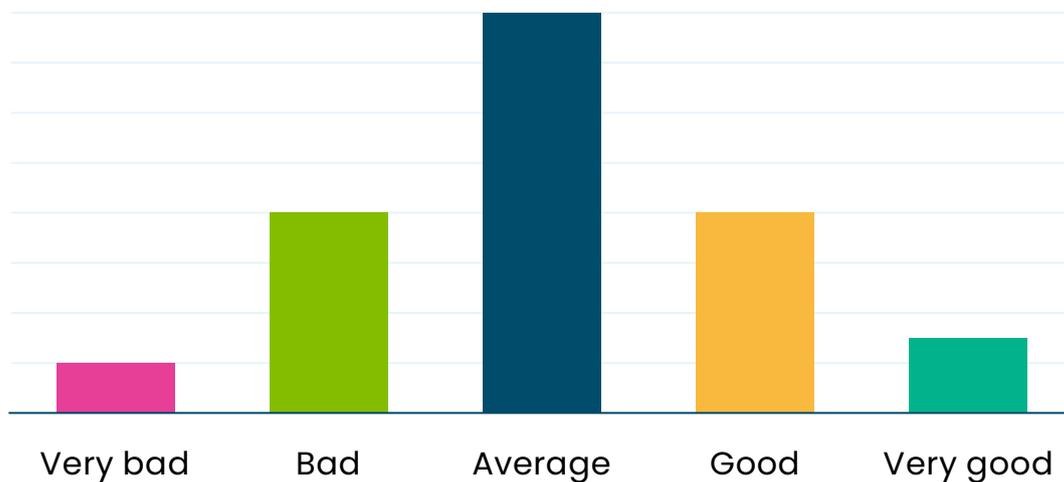
2. How would you rate the overall support you receive from the NHS?



The overall rating for this question is related to the questions that followed where we ask respondents to provide more detail on their experience in each different area of care.

3. How would you rate the support you receive from your:

a. GP?



The main views expressed were that GPs are not Parkinson's specialists and often do not have enough knowledge to provide suitable support. Assumptions are often made that the Parkinson's consultant or specialist nurse is taking care of the patient and so they do not get involved in the day-to-day care of the condition.



“Because my husband has Parkinson's, every other health issue seems to get put down to this. They don't seem to take other health concerns seriously.”



Under a third of respondents found that the best support a GP can offer is a referral to the hospital or a specialist. Other ratings were based on a lack of access to getting an appointment with their GP.

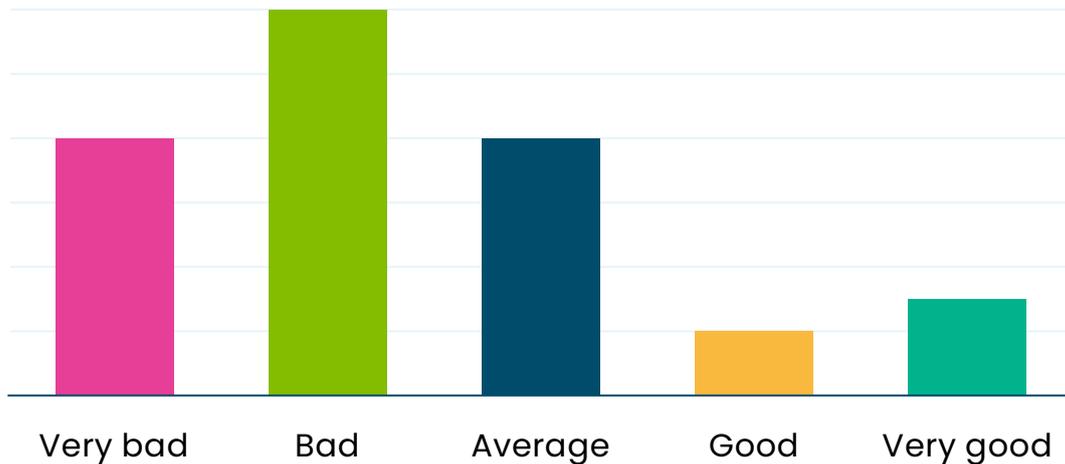
Those that rated the services to be 'good' or 'very good' spoke about how it was their GP that had identified the early symptoms and had referred to specialist services promptly.



“The GP was very good. He was the first to notice a change in walking pattern and referred us to the hospital straight away. We had never heard of Parkinson's disease until then”



b. Hospital consultant?



Just under half of the respondents said that they do not know who the consultant is, do not have one or do not see one anymore. Some specified how the hospital consultant was good in the beginning, but as time went on, particularly since the pandemic, there have been few to no appointments.

There are mixed responses about the information and advice given by consultants.

2 respondents did not rate this service due to not having yet seen a hospital consultant for a formal diagnosis.

4 of the respondents had rated their consultant to be 'good' or 'very good' but had confirmed they were paying privately for this service. One shared how now that they are paying for private healthcare it has made access to appointments easier and consultant monitoring more consistent. These responses were not included in the above data due to the fact that these are not related to NHS services.



"I haven't seen a consultant for 5 years since my diagnosis. I only see the Parkinson's nurse but even that is not on a regular basis. I have to call them to get an appointment"

"I pay privately to see a Parkinson's consultant. I could not get an appointment through the NHS and was worried about the deterioration in my health."

"Got a diagnosis after a long wait for an appointment and then nothing..."

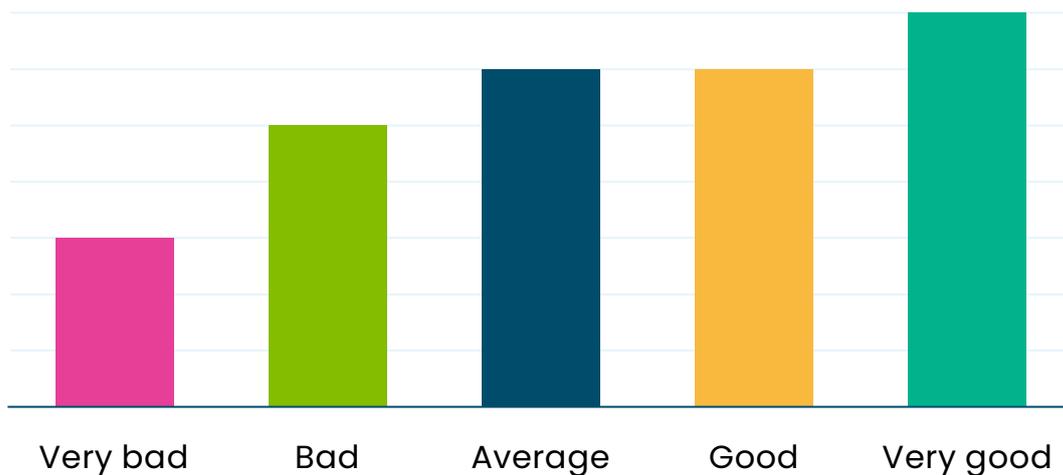
"I had to go private as I could see my husband's condition worsening and there were no NHS appointments available. I could not let things slide any longer so decided we would have to pay to go private to see a consultant."

"Follow up appointments are no longer available to see a consultant, so I haven't seen one since the start of the pandemic. I used to see one at least annually before that."



People were asked why they felt they needed to see a consultant following diagnosis and what they felt a consultant could do that the specialist Parkinson's nurse could not. Those who responded felt that it was around medication review, monitoring of the condition and most respondents believed that they should, as a matter of good practice, see a consultant at least annually if not every 6 months. There was a view of a small number that only a consultant could change the medication.

c. Specialist nurse?



Parkinson’s nurses are overwhelmingly regarded as the primary source of help and advice, and were seen as approachable, helpful, and knowledgeable in meeting their treatment needs.



“My Parkinson’s nurse has been great, and I can ring up if I have any issues and they are responsive.”

“I have appointments with the Parkinson’s Nurse every 6 months and to be honest they’ve been very helpful with reviewing the medication. I can’t fault the service I have had, especially when I hear of other people’s experiences. I feel very lucky but wish the service were more consistent so that everyone was able to have my experience.”



However, some find that the frequency of contact is inconsistent and is not enough. Some participants have regular appointments every 6 months whilst others do not. 3 people said that they were waiting for an appointment which usually is a telephone call instigated by the nurses themselves. Most people reported that contact is mainly through telephone appointments, but most would prefer face-to-face consultations.



"I had a telephone consultation with the Parkinson's nurse last October.

They promised to call again in January, but no-one has been in touch to date."



Respondents perceived that there is a long waiting list for an appointment with a Parkinson's nurse and that getting a referral to them was not automatic as you would have to ask for one. Based on the responses, there was evidence of inconsistencies in the service received both from the point of referral, to waiting times, face-to-face versus telephone appointments, and frequency of appointments.

Waiting times were cited as being a significant cause of concern as this was at a time following diagnosis when the patient feels most vulnerable and in need of advice and guidance.



"I always insist on a face-to-face appointment and make an appointment straight after the last one to make sure I get one. They have tried to put me off doing that and tell me that they will ring me, but I insist on having a date in advance so that I know it will happen."

"I had a diagnosis fairly recently and am still waiting for an appointment with the Parkinson's Nurse. I am told there is quite a waiting list so I don't know when I might get an appointment. In the meantime, I just have to get on with it but at least have the fitness group where people are really helpful."

"I was not sent an appointment to see a Parkinson's nurse. I found out about them from someone here (at the gym). They will respond if called but there is no automatic appointment given."



One patient told us that they did not think there were specialist nurses who only dealt with Parkinson’s patients as they had been seen and diagnosed by a different neurological specialist nurse.



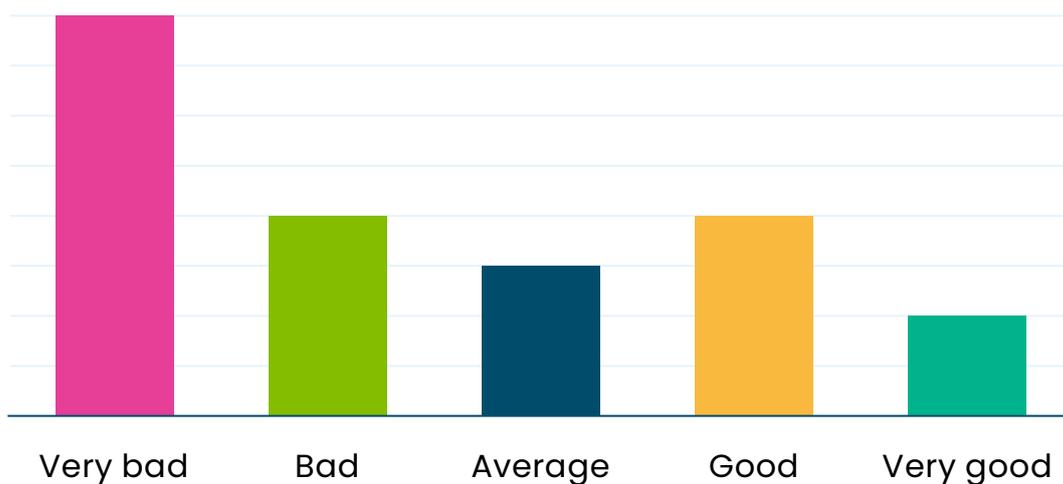
“Although the nurse diagnosed me, they are really an MS (Multiple Sclerosis) Specialist. I haven't been referred to a Parkinson’s disease consultant. I’m still waiting for an appointment.”



A total of 3 respondents did not rate this service due to not having seen a specialist nurse.

As part of this study, we made an attempt to contact the Parkinson’s nurse team but received no response to our emails to the neurosciences team at University Hospital North Midlands (UHM). We were unable to locate any specialist Parkinson’s nurses via that avenue or other alternative methods we tried. Therefore, we were not able to listen to both perspectives or learn about the service and the process of accessing it, any issues or problems relating to staffing or waiting times; so, this analysis is based on patient feedback only.

d. Physiotherapist?



A total of 18 respondents did not rate this service due to not having ever seen a physiotherapist nor having been offered any physiotherapy treatments through the NHS.

Others had seen a physiotherapist previously but have not received any follow-up or are still waiting on the referral process. Those who have a physiotherapist, or commented on their previous treatment, found it to be helpful and praised the support.



“I had a 6 week course at Burslem clinic. It was useful and helped me but then ended and nothing in terms of follow-up to see how I am getting on.”

“I have not heard of a Rehab service. I don't need it right now as I have the gym, but it would be good to know about it in case, I need it any time in the future.”

“The physio I had was very good and kind and I got a lot out of it. It was only a short course however and it would be nice to have been able to have continued with this.”

“I have never been offered any physio and have had to find and fund this myself. No one told me that there was a rehab service available in Stoke-on-Trent.”

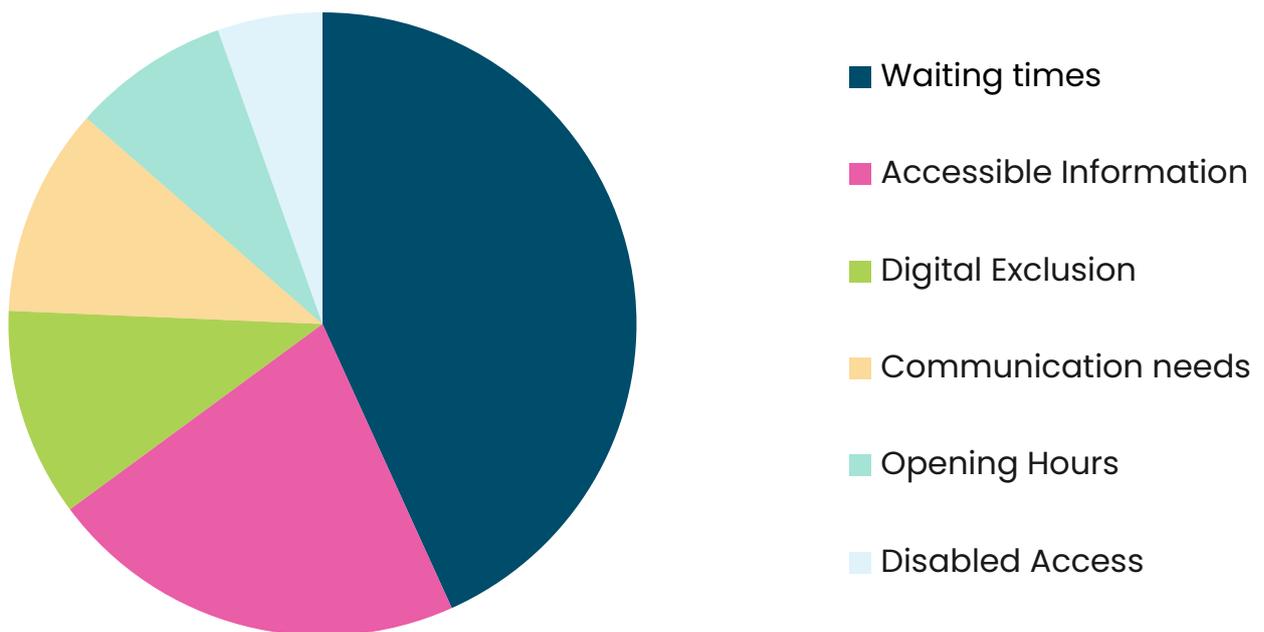
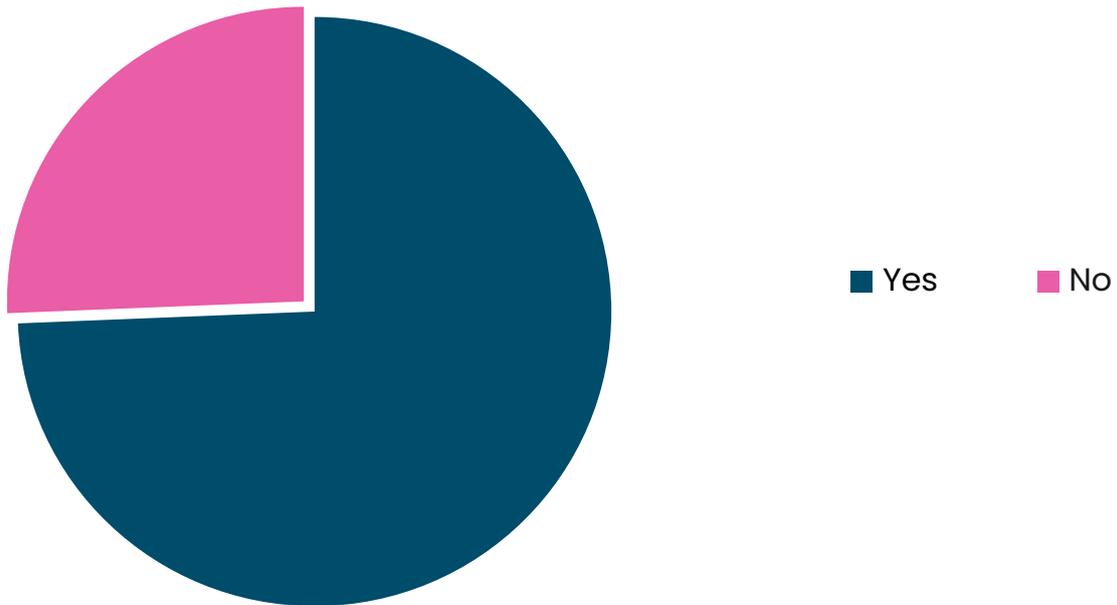


We met with the Operational Manager of the Parkinson's Rehabilitation Therapy team to learn more about the work that they do and to understand the pathway for accessing their service. We were told that the part-time therapy team is made up of occupational therapists, physiotherapists, and therapy assistants who provide a service to North Staffordshire and Stoke-on-Trent. There is no consultant within the team, but they aim to work closely with the neurology team at UHNM.

The team has an inclusion and exclusion criteria which is based upon a diagnosis of Parkinson's, location of the person, the ability to benefit from rehabilitation and be able to attend the assessment session

Few respondents were aware of the physiotherapy service provided by Midlands Partnership Foundation Trust (MPFT) as part of the Rehabilitation Therapy Team. There was interest in knowing more about this service and some had wished they had known about it sooner as they felt they might have benefitted from this service.

4. Did you experience any issues when accessing the services, you need?

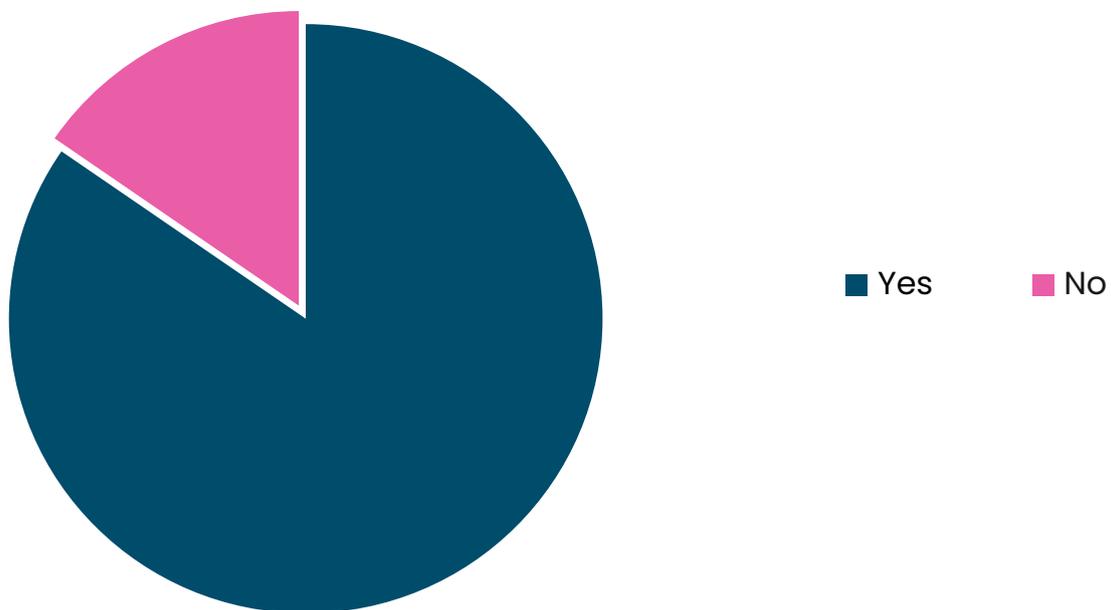


Those who faced digital exclusion noted that they were heavily reliant on other members within their local groups to pass any information on as they were unable to do their own research via the internet. Although most of the digital exclusion faced was internet-based, some highlighted how Parkinson’s has affected their ability to communicate over the phone and felt that they have become excluded from most services because of this.

Additional issues faced were with parking and transport to the hospital. Some shared how lack of nearby available parking reduces accessibility as walking is difficult. Others commented on how they must request and pay for wheelchair accessible taxis, which again impacts their access to the hospital.

These issues have impacted respondents' mental health and wellbeing, as some respondents shared their increase in anxiety and frustrations due to the amount of effort they put in to finding information and making appointments.

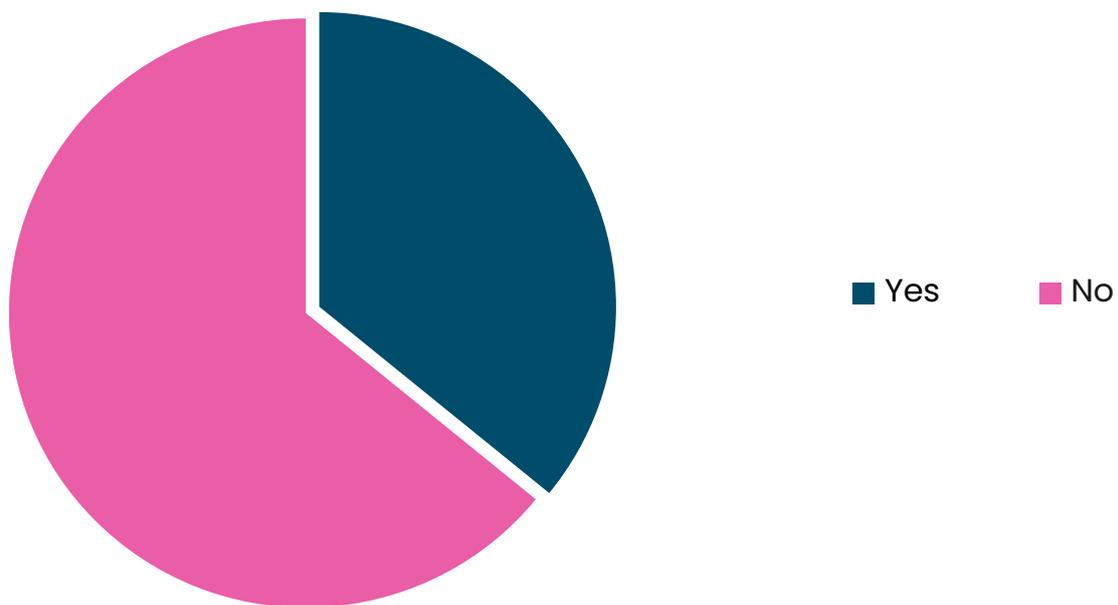
5. Have you considered or are you getting support or treatment from anywhere else? (e.g., charities, community support groups, private healthcare)



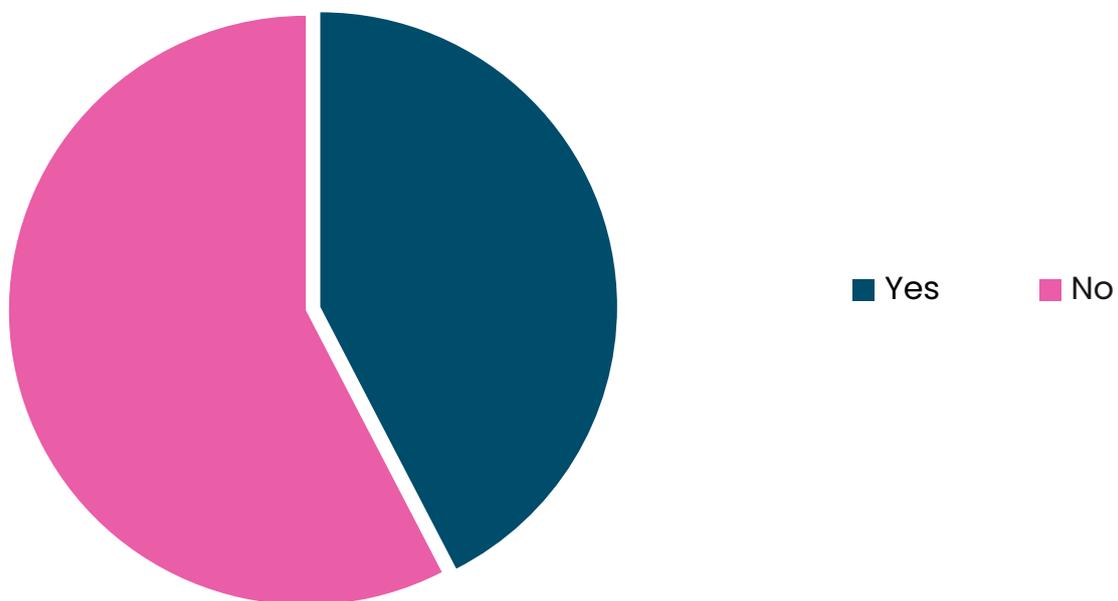
Just under half of respondents had reported either paying for private healthcare (even for a one-off appointment) or would consider it if they could afford it.

Most respondents, we spoke to were receiving support through attending local community support groups through Living Well with Parkinson's and Parkinson's UK.

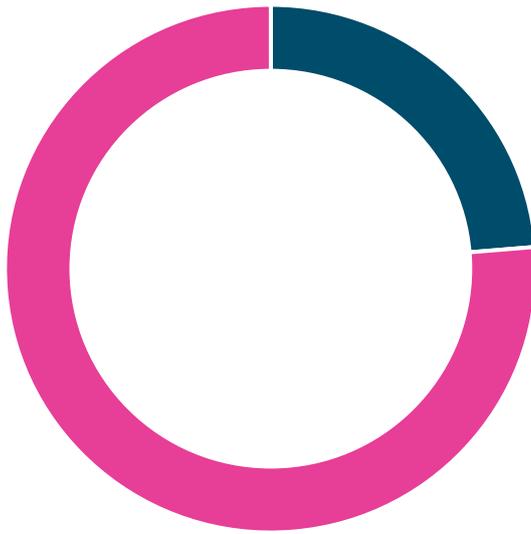
6. Were you given enough information on available treatment and support?



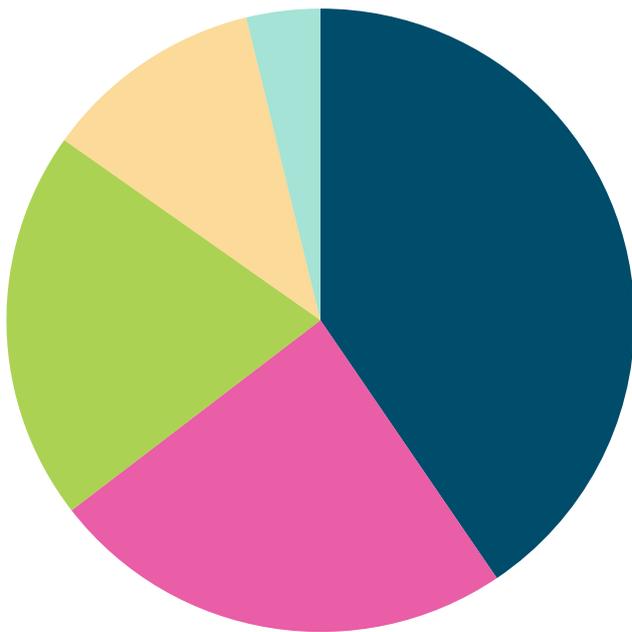
7. Was the information you received clear and easy to understand?



8. Did you need to find information elsewhere?

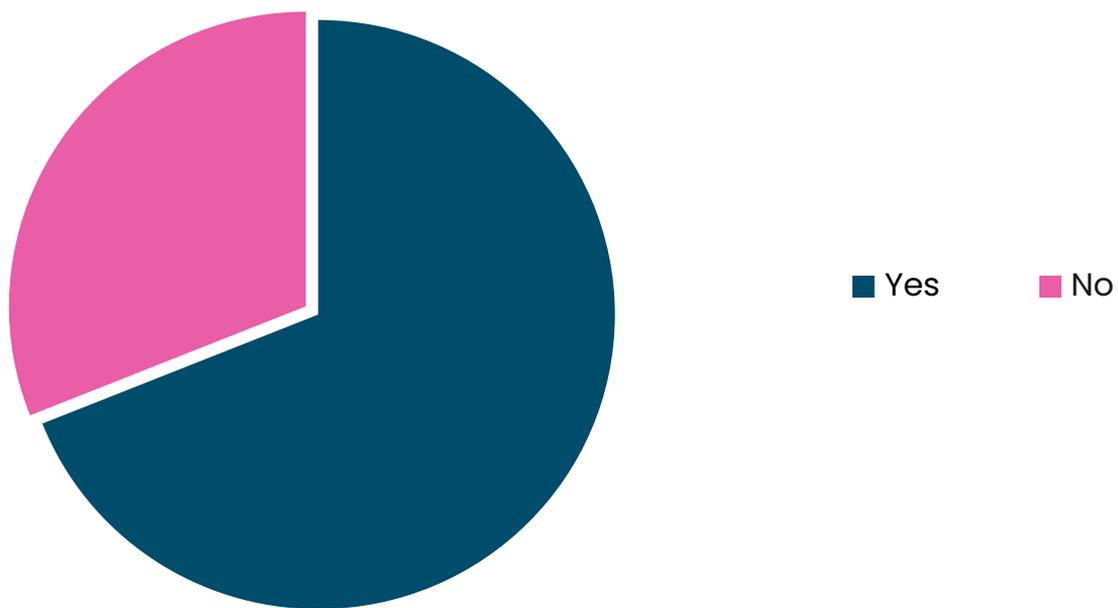


- No
- Yes



- Local support groups
- Parkinson's UK
- Online searches
- Carers groups
- Other

9. Is there any support that you would find helpful that is not currently available?



Most respondents felt that there was support they could be offered that was not currently available to them. However, we found that some respondents had suggested services that are already available, but they were unavailable to them, or they were unaware of them.

Other suggestions included: more support with exercise, respite and over-night carer support, help at-home for daily activities and household chores, a wider range of 'just in case' information, and additional community support groups to help cover more areas of Stoke-on-Trent.



"I have enough help at this time, but I would like to be prepared by knowing more about what is available to me in case I need help in the future."



# Themes of Findings

## Emerging Themes

From the responses overall in the survey and in individual and group discussions, some common themes emerged relating to responses from the questions around access and waiting times, options for treatment and services, availability and user friendliness of information, and awareness of support systems, prevention and support groups post diagnosis.

## Information and Advice

Despite information about Parkinson's disease being available in different forms in various places, there is no consistent way in which this is given to patients. 64% of our respondents said that they were not given any or enough information at nor following diagnosis. Compared to the recent Parkinson's Excellence Network 2022 national audit where only 40% of patients felt that they were not given enough information about Parkinson's at diagnosis, the experience of participants in this survey was significantly worse. There is a myriad of ways in which information and advice can be obtained, but for many this depends upon word of mouth or being in the right place, at the right time, and with the right person. Information was seen by many as being key to enabling them to consider their options and take more control over their health, making choices and decisions about management of the condition and seeking appropriate help when needed.

## Access to Treatment and Support

There were several issues highlighted in relation to access to treatment and support. Patients have an expectation that they should have access to a specialist consultant in Parkinson's on a 6 monthly or annual basis to monitor and review their condition and medication. However, very few have this service. 4 respondents have resorted to arranging private appointments. Best practice guidance suggests that all patients with a diagnosis of Parkinson's should be reviewed every 6 - 12 months by either a specialist consultant or nurse.

The analysis of our survey suggests that in Stoke-on-Trent this is a role mostly undertaken by a nurse, but from a patient perspective, many believed it should be a consultant. It was evident that patients were not clear about the referral and treatment

pathway and therefore their expectations were not being met. Even though most people were happy with the service provided by a Parkinson's nurse on a practical level, their expectation was that they should be having some contact with a consultant, and therefore the perception was that the service was not as good as it should be. The lack of consistency of service provision was also a factor in satisfaction levels, as people with Parkinson's speak to each other about their service and cannot understand why service levels are so different when symptoms and issues faced are similar.

In comparison to our 2017 report on neurological conditions, delays in being seen by a specialist, whether this is a consultant, a specialist nurse or physiotherapist is significantly worse. It is also shown to be worse than the national audit, with 74% of people reporting delays in accessing services. Respondents mentioned waiting times for all levels of the service, access to information and specialist care as being a problem for them.

It was also notable how very few people we spoke to were aware of the existence of the Parkinson's rehabilitation service, which included the physiotherapy service. Very few had had access to any form of rehabilitation. These included the members of the Base Body Fitness group who were very committed to maintaining their physical wellbeing through fitness training. The NICE guidance recommends that people with Parkinson's disease should be referred to physiotherapy early, for assessment and advice on activities and exercise. It also indicated the lack of a multidisciplinary approach to working with Parkinson's patients holistically across all specialisms.

## **Prevention and Self-help**

85% of our respondents reported seeking help and information from alternative sources about what support and help they could access to help manage their condition and prevent deterioration in their health. A small number had sought this through a private healthcare route but the majority through other local and national organisations, through word of mouth and through internet searches. The type of help that people sought could be broken down into categories which covered:

- Information about Parkinson's the condition and its progression and treatment options.
- Information and support to maintain an active healthy lifestyle and how diet and exercise might help the condition.
- Information about emotional and practical support for the person with Parkinson's and their carer's /family members.

- Information about finances and support with understanding and claiming appropriate benefits.
- Information about the emotional aspects of the condition including mental health support for the person with Parkinson's and the carer separately.
- Applying for a blue disabled person's badge.
- Help and support in the home with practical issues such as aids to daily living and adaptations to the home, personal care, and respite care.
- Support groups available for patients and carers to meet like-minded people.

As suggested earlier, there is a myriad of information available to support people but most of it is not held by one organisation. Therefore, people must know where to find it or how to search for it through several organisations. Respondents sourced most of their information from: Parkinson's UK, North Staffordshire Carers, Carers UK and other members of local support groups.

Respondents were asked to if there was any support that they would find helpful that is not currently available. An information directory of all the sources of help and information in one place was mentioned as being something that would really help people manage their condition better, as they would not have to spend hours searching and contacting many different organisations to get help for the many aspects of life that Parkinson's impinges on.

# Our Conclusions

When we compare this work to the work undertaken previously on Parkinson's services by ourselves, and in collaboration with Healthwatch Staffordshire and Staffordshire Neurological Alliance, there were many similarities in the issues faced by people accessing services.

Our findings show that when people are accessing services, they are generally happy with the quality of the care they receive if not the quantity. Similar issues around waiting times for all aspects of the service have been highlighted in this study with some people experiencing long waits for services including diagnosis, assessment, therapy, review, and ongoing monitoring of Parkinson's. This is reflected in the low ratings of satisfaction with the service which is lower than the data gathered in the Excellence in Parkinson's audit 2022, where satisfaction levels are higher than in Stoke-on-Trent. This has led some people to seek the help they need through private healthcare, but due to the costs this is not an option for many of our respondents. Service levels and resource restraints may account in part for the perceived long waiting times, but there also appears to be a lack of a multidisciplinary approach to provision that may mean some people are falling through the net or are experiencing longer waits due to a lack of a clear pathway that patients are aware of and understand.

As well as access to services, lack of consistency in the provision of information about all aspects of the Parkinson's journey has had a significant impact upon the perception of the service and support people have received. There is a lot of information out there in various places, but no joined up way of getting it to people in way that is helpful to them at the time of diagnosis and beyond. There are a lot of services in the community who can help people achieve their goal of living well and managing well with their Parkinson's, but they can only access these if they know about them and currently this is often by chance rather than design.

Although the sample of people engaged with for this study was relatively small, we were provided with some rich and detailed information about their experiences which we hope will help and enable service providers to address these and seek ways to find solutions to the concerns raised.

The people we spoke to whether they were people living with Parkinson's, or their carers/family members, were engaged with the ethos of 'living well with Parkinson's' whether through keeping fit through physical activity, keeping well through lifestyle

changes or mental stimulation, and the concerns and issues raised were done so to enable them to take control of the management of their condition to enable them to lead active lives for as long as possible. The professional staff we met who are providing services for people with Parkinson's and their carers have the same motivation, so it is hoped that this report can bridge some of those gaps.

## Recommendations

Based on our feedback and findings, we have the following recommendations to help improve Parkinson's services in Stoke-on-Trent:

- **Accessibility** - Each part of the NHS healthcare system to look at ways to work together to improve equality and accessibility of services for all people across Stoke-on-Trent.
- **Information** - Develop a clear pathway for the diagnosis, treatment, review, and on-going care of patients that is clear to patients and sets out what treatments are available, including access to rehabilitation and therapy so that patients and carers know what options might be available to them. This may help with managing expectations. Participants reported that many of them had no idea what to expect after their diagnosis as they did not have the information provided. Patients could be provided with an information pack that has relevant contacts and up-to-date information.
- **Inclusion** - Service providers to consider further engagement with patients and families living with Parkinson's to address their issues of concern and seek ways to improve response times to enable access to services in a timelier manner.
- **Support** - Support during and after diagnosis and while waiting for a diagnosis was highlighted as a key issue for patients, the lack of support and information while awaiting diagnosis or during diagnosis is a source of great stress. Presence of a family member during diagnosis, or presence of their specialist nurse will provide additional support to patients to manage the shock of a diagnosis. Collaborations with the Parkinson's UK and local support groups will enable patients to be able to seek support while awaiting an official diagnosis. Furthermore, these collaborations will also provide an additional contact point for patients who have questions about their conditions but are unable to be seen by clinical staff quickly.

# Next Steps

This report has been shared with the providers of local Parkinson's services and were invited to respond to our findings in this report, and how the service providers have taken into account the recommendations for improvement.

## **A response from The Midlands Partnership University NHS Foundation Trust**

The Parkinson's Rehabilitation Therapy Team at Midlands Partnership University NHS Foundation Trust (MPFT) recognised that this report highlights the key issues across the Parkinson's pathway and the need to integrate more closely with University Hospitals of North Midlands NHS Trust (UHNM) so that patients have access to resources and rehabilitation as early as possible in the pathway.

It was shared that due to there being a total of 4 part-time staff in the MPFT Parkinson's Rehabilitation Therapy team, who cover the whole of North Staffordshire and Stoke-On-Trent, the teams focus is on patients who have the most need for support and treatment.

During the Covid-19 pandemic the service became significantly reduced in the number of group-based sessions available, to a domiciliary based service, but the team have worked tirelessly to resume the original services provided and now offer the Parkinson's Programme (Physio and SALT), 1 x Physio only group, 1:1 sessions, domiciliary visits, community rehabilitation, plus the valuable addition of 1 day of physio clinic assessments.

They actively encourage patients take up activities, such as the Living Well with Parkinson's fitness groups hold, for their physical wellbeing and would consider the service as a safety net for support when the patients experience deterioration of their condition.

The team are continuously looking at ways to improve the experience for patients including the pathway to access, treatment, follow-up, and discharge which many of our respondents were unaware of. We were informed that patients are triaged by the team within 24-48 hours of referral and patients are sent a baseline pack of information outlining some of the services and support groups available.

We found that whilst there is an acknowledgement of some shortfalls in the service in some areas, there was a genuinely expressed passion and enthusiasm to improve the service.

Although at current, their service is predominantly for those in more advanced stages of Parkinson's, they recognise the need for support as early as possible for those diagnosed with Parkinson's. In their bid to become a 'Centre of Excellence' the team are exploring ways to bridge some of the gaps by providing better and more consistent information at point of diagnosis and to carer support networks, where they and patients can engage with the team and ask questions. The team are exploring lots of ideas on how there can be a joint approach with specialist nurses to ensure that patients do not fall through the net and are now in the final stages of submission to set up a clinic for the newly diagnosed.

 "This report really highlights the key challenges our Parkinson's patients currently face and will strengthen our funding submission to Parkinson's Disease UK for additional workforce to deliver a newly diagnosed clinic across the region."

**- Dominic Ellington**

Operational Manager & Associate Chief Clinical Informatics Officer  
at Midlands Partnership University NHS Foundation Trust (MPFT)



# Thank You

We are grateful to everyone who helped shape this document by sharing their stories, thoughts, and reflections.

A special mention to:

Roy Clarke and the members of Living well with Parkinson's

Dominic Ellington and the Parkinson's North Therapy Team at MPFT

Lorraine Vernon and The Parkinson's UK Support Group

## References

1. Parkinson's UK. (2017). *The Incidence and Prevalence of Parkinson's in the UK: Results from the Clinical Practice Research Datalink Reference report*. [https://www.parkinsons.org.uk/sites/default/files/2018-01/Prevalence%20%20Incidence%20Report%20Latest\\_Public\\_2.pdf](https://www.parkinsons.org.uk/sites/default/files/2018-01/Prevalence%20%20Incidence%20Report%20Latest_Public_2.pdf)
2. Healthwatch Stoke-on-Trent. (2015). *Parkinson's Provision report*. <https://www.healthwatchstokeontrent.co.uk/report/2015-05-01/parkinsons-provision>
3. Healthwatch Staffordshire, Healthwatch Stoke-on-Trent & Staffordshire Neurological Alliance. (2017). *Not NICE Enough: A qualitative study of MND, MS and Parkinson's Pathways in accordance with the National Institute of Health and Care Excellence (NICE) Guidance report*. <https://healthwatchstaffordshire.co.uk/wp-content/uploads/2019/11/Not-NICE-Enough-%E2%80%93-The-Neurology-Report.pdf>
4. Parkinson's Excellence Network. (2023). *2022 UK Parkinson's Audit – Summary Report*. <https://www.parkinsons.org.uk/sites/default/files/2023-06/2022%20Summary%20Report%20-%20FINAL.pdf>

The contract to provide the Healthwatch Stoke-on-Trent service is held by

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We are committed to the quality of our information. Every three years we perform an in-depth audit so that we can be certain of this.

# healthwatch

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