Experiences of Parkinson's care in Gloucestershire

Neighbourhood health and wellbeing insights – February 2026

tcf
the heart of social inclusion

healthwatch Gloucestershire

Contents

About us

Healthwatch Gloucestershire is the county's health and social care champion. We're here to listen to your experiences of using local health and care services and to hear about the issues that really matter to you. We are entirely independent and impartial, and anything you share with us is confidential. We can also help you find reliable and trustworthy information and advice to help you to get the care and support you need.

As an independent statutory body, we have the power to make sure that NHS leaders and other decision makers listen to your feedback and use it to improve standards of care. This report is an example of how your views are shared. Healthwatch Gloucestershire is part of a network of over 150 local Healthwatch across the country. We cover the geographical area of Gloucestershire County Council, which includes the districts and boroughs of Cheltenham, Cotswold, Forest of Dean, Gloucester, Stroud, and Tewkesbury.

Background

There are approximately 1,400 to 1,500 people diagnosed with Parkinson's disease in Gloucestershire. Throughout 2024 Healthwatch Gloucestershire received feedback from patients and carers through our feedback and signposting service, and attendance at events and community groups around the county. We identified several themes that were consistent across the range of people and groups that we had spoken to and presented this to the ICB Board in January 2025. The themes were:

- A lack of information being provided to people at the point of being diagnosed, as well as at follow-up appointments.
- Concerns about access and the frequency of appointments, particularly with the neurologist.
- A lack of coordinated and holistic care which affects their overall experience and outcomes.

This report and the recommendations can be found on our website: www.healthwatchgloucestershire.co.uk/report/2025-03-31/your-experiences-living-parkinsons-disease

This led to a further opportunity with NHS Gloucestershire to co-produce a piece of engagement with those that shared their stories and listen to more patient experiences. The aim was to gain a better understanding of patients' experiences of the services that are provided to ensure that any current and future work is patient centred and focused around feedback.

Who we spoke to

From July to November, we promoted the project through our social media channels, newsletters and our network.

We also visited 11 different Parkinson's UK groups and events around the county to listen to people's experiences of being diagnosed with Parkinson's and the support they currently receive. These were:

- Cirencester
- The Gala Club, Gloucester
- Stroud Road, Gloucester
- Stroud
- Alvington, Forest of Dean
- Cinderford, Forest of Dean
- Cam and Dursley
- Northleach
- Tewkesbury
- Cheltenham
- Parkinson's UK Conference

We used a semi structured interview format which enabled us to gather rich insight into people's experiences.

We spoke to 153 people in total.

97 people were diagnosed with Parkinson's and 56 people were carers of people with Parkinson's. In addition, approximately 70 people attended the Parkinson's UK conference who shared experiences with us but were unable to respond to all our questions due to time pressures.

Key messages

Waiting times for a diagnosis has an impact on people's physical and mental health

- Some people reported visiting their GP repeatedly with symptoms of Parkinson's disease but experienced delays in being referred to neurology
- Given the progressive nature of Parkinson's disease and the impact of symptoms on daily functioning, people reported concerns about waiting times to see a neurologist as they are unable to start medication until this time.

The first three months following diagnosis are 'critical'

- People feel isolated and alone following diagnosis and sense of community, peer support and friendship are crucial.
- There is a lack of information being provided at the point of being diagnosed, leaving people feeling overwhelmed but also left to find things out for themselves. This impacts on access to services if people are not aware of what is available to them, for example, referrals to other professionals, and management of some symptoms such as depression and nightmares.
- There is a lack of information being provided to carers of people with Parkinson's disease about how to care for their loved one and to find support for themselves.

A lack of information and 'vagueness' leads people to feel they need to see a consultant more regularly

- Most people believe that appointments are every six months with either the nurse or consultant or alternating between them – people reported being told this by the neurologist, Parkinson's nurse and Parkinson's UK.
- People need an ability to 'check in' between appointments if there are changes. People don't always know who to go to and whether it is for the patient to book the appointment or wait to receive an appointment letter.
- Many people reported positive experiences with the Parkinson's nurses. However, some are not aware of how 'specialist' the nurses are and are unsure of the role of the GP in prescribing medication.
- Where Parkinson's consultants and nurses have been in attendance at groups and events, people have reported receiving insightful information about the condition, helpful advice and more awareness of available services.

Some people and their carers do not always feel included in discussions around medications and in joint decision making about treatment plans

- Appointments with the consultant can be overwhelming and some people feel they are not long enough to share everything they want to or ask questions.
- Some people reported difficulty managing time critical medications when in hospital environments if admitted as an inpatient.
- Access to, and accessibility of, services can vary depending on where people live, and whether they live on their own or have a carer supporting them.

Recommendations

The following recommendations have been developed based on the feedback and ideas received from contributors to this report.

- Ensure that GPs have the tools to recognise signs and symptoms of Parkinson's at the earliest opportunity, and to identify appropriate pathways for support, e.g. reviewing information available on G-care.
- If the GP has referred a person to neurology because Parkinson's disease is suspected, review the ability for GPs to prescribe medications to manage some of the presenting symptoms while the person is waiting to see the neurologist. The GP can also provide information on diet and exercise, things to prepare for, and signpost to the Parkinson's UK advice line.
- At the point that people receive a diagnosis of Parkinson's, they should be referred to Parkinson's UK who can provide information about the condition itself, information on support groups around the county and how carers can also access support for themselves.
- In addition, the Parkinson's team to provide information on the roles and responsibilities of the Parkinson's nurses and consultants, what other services are available and the process for making referrals (see p. 6 for more details).
- People need to be given consistent messaging about how often they should expect to see a Parkinson's specialist - either a Parkinson's nurse or a consultant (see above re: clarity on roles and responsibilities).
- Consistent and clear information also needs to be provided about who is responsible for booking ongoing appointments and how people can book appointments in-between as required.

- Gloucestershire Adult Social Care to consider how they meet the specific needs of different carers. For example, a support group for those who are caring for people with degenerative neurological conditions.
- Parkinson's nurses and consultants to take an active role in engagement within the community e.g. visiting community groups on a six-monthly basis to gather feedback and to respond to questions about Parkinson's and the Parkinson's service.
- When sending out appointment letters or notifications, these should include information on who the appointment is with and 'how to make the most of your appointment' to help people prepare. e.g. what questions will the consultant or nurse ask, what to bring, such as a diary of symptoms, and to write down what questions the patient wants to ask.
- Conversations about people's wishes for their treatment and long-term care should be documented in "What matters to me" ('Orange') folders. This will enable more personalised care and support joint decision making between the clinician and patient. This would also aid communication about medication and support needs during hospital admissions.
- At appointments, people should be asked whether they would like to receive a copy of their notes in case people aren't able to bring someone to support them or people need to refer back to what was discussed.
- In line with plans to move more services into the community, people should have more choice about where they would prefer to have in-person appointments where possible, to overcome issues with transport, disabled parking access and parking charges, and for people who don't have a carer to support them to appointments.

What we heard

Experience of being diagnosed

Most people we spoke to had been diagnosed for between 2 and 5 years, although the newest diagnosis had been received in September 2025 and the longest was 23 years ago. Many reported experiencing, or being advised of, long waits (up to 15–16 months) for diagnosis, prompting some to seek private consultations. This was mainly so that they could start medication at the earliest opportunity.

The impact of receiving a diagnosis and starting medication is described by one person below.

> “I'm grateful to have been able to get a diagnosis and start the medication because it has allowed me to attain a higher level of well-being and to develop my own strategy for coping.”

People explained that they had often been having various symptoms for years before receiving their diagnosis. Parkinson’s symptoms present in a range of ways, and it is not always easy to diagnose. As a result, some reported being misdiagnosed or not referred promptly by their GP to neurology. These people felt that GPs may need more information about Parkinson’s symptoms and pathways to aid getting a referral at the earliest opportunity.

Of those who had been diagnosed recently, once referred to neurology, people were typically seen within 3 months.

> “I waited for 3 months from referral to see someone.”
>
> “My wife had lots of strange symptoms, so we had lots of visits - 8 or 9 over a 3-month period.”

However, one person who was diagnosed in September 2025 reported issues trying to access an appointment with a consultant following a referral from their GP.

> “My GP referred me to see an NHS consultant but when I tried to get an appointment at Gloucester through choose and book they said there were no appointments available, and Cheltenham said the earliest appointment was May 2026. So I arranged a private appointment which was paid for through a workplace scheme.”

Information

Only one person we spoke to said that they had received any information packs or leaflets at the point of being diagnosed. They said that they had been given some leaflets. The remainder describe feeling left to look on the internet and find things out for themselves, or with support from family if they are digitally excluded.

What information people told us it would be useful to have

- Information about medication – how it will affect the person, potential side effects, and how and when to take it e.g. not with milk or with a meal
- Diet, sleep and exercise
- Information about Parkinson’s UK
- About keeping a diary to document side effects, ups, downs, sleep patterns etc - this can be very useful when seeing the Consultant
- Benefits advice
- Information about what to expect for the future, e.g. possible symptom progression
- General information about the service with contact details– roles and expectations - who to contact for what
- Signposting to useful and trusted websites
- Information about support available for people living alone
- Information for Carers and how to access support
- Information on local peer support groups
- The places where clinics are run, so people can choose the best place for them to see someone
- Information on how to give feedback on services e.g. Healthwatch, PALS
- A manual that newly diagnosed people are given which ensures all the information they need is in one place to enable people to dip in and out of the information provided. It is easy to mislay leaflets.
- The Parkinson’s UK Information Pack at the point of diagnosis
- An opportunity for people to be given both online and paper options

> “There's a book 'My Grandad's got Parkinson's', it is really good - it describes it so well!”

People felt the three months following diagnosis are a critical time to be receiving information and support as “you do not know what to expect.”

> “I initially had my head in the sand and did not want to know”

Frequency of appointments

The most common response we heard was that people expected to have appointments every six months, to see either a nurse or a consultant, or alternating between a nurse and a consultant.

> “The neurologist told me that it would be every 6 months, alternating between seeing him and seeing the nurse”
>
> “Parkinson's UK said it should be once every 6 months”
>
> “The Parkinson's nurse said it should be every 6 months”

Feedback about actual frequency of appointments ranged from seeing a Care of the Elderly consultant every 3 or 4 months, to going several years between appointments.

Expectations were shaped by:

- Information from neurologists, Parkinson’s nurses, and Parkinson’s UK.
- NICE Guidelines, which recommend reviews every 6–12 months.
- Some people were unsure of the expected frequency or had experienced long gaps (up to 4 years) between appointments.
- Concerns were raised about “slipping through the net”, with some needing to chase for appointments.
- Some people felt annual appointments were sufficient, especially if symptoms were stable.
- Others emphasized the need for appointments based on individual needs, especially for newly diagnosed patients.
- People were unsure how the process works - whether they should wait to hear or be proactive and chase appointments themselves. Some people told us they feel uncomfortable chasing appointments because they appreciate how busy everyone is.
- Others shared they have had several appointments cancelled at short notice, or with no notice at all.
- Some people reported that they have more in-depth tests with the Consultant, which is why it can be useful to see one occasionally.

“I have my appointments once a year. I see a nurse. I’ve got several health problems so when I last saw a doctor it was about something else. I don’t see the neurologist very often. I feel that once a year suits me – it’s fine”

“I realised I hadn't seen anyone for about 18 months, so I rang up, and got an appointment for a couple of months later. I didn't realise it had been so long.”

Medication reviews

Feedback about people’s experiences of medication reviews was very mixed. If symptoms were changing, most people responded that they would contact the Parkinson’s nurses and felt confident that they would be able to get an appointment with them within a few weeks. Where people didn’t feel confident contacting the Parkinson’s nurse, they said they would contact Parkinson’s UK instead. Many people told us that they were able to speak to the Parkinson’s nurse who could make some changes to medication, or the nurse could book people in to see the Consultant if required. However, this was not reflective of everyone’s experience.

There appears to be uncertainty over the role of the Parkinson’s nurse and the GP in terms of who can prescribe different medications.

“I'm on the same medication since the start. I spoke to the nurse who recommended we spoke to the GP, but he couldn't do anything - so we're going to have to wait until we see the doctor”

“I wonder how specialist the nurses are and how much do they know about Parkinson’s?”

A lack of information and ‘vagueness’ around medications were cited as being the main reason why people feel a need to have an appointment with the consultant at least once a year.

One person also highlighted how other factors such as co-morbid health conditions, and different situations and environments can impact on symptom presentation and severity. This can make it hard for the person or their carer to assess how the disease is progressing and when to seek support.

“My husband's Lewy Body dementia probably started about a year after his Parkinson's and I didn't know. He's now in care and his stress levels are lower, so his 'on' and 'off' times are less noticeable. Stress and anxiety and different situations affect the symptoms as much as the medication”

Duration of appointments

Most people who responded to this question felt that appointments were long enough for them. We found good satisfaction with appointment length with Parkinson’s nurses who were generally described as not rushing and providing ample time.

“The nurse is very good, she tells us everything we need to know, and we can ring them and leave a message and they call back”

There was more variation in responses when people spoke about appointments with the consultant.

“Dr XXX is wonderful. He’s got all the time in the world when you’re with him. If you need an hour, you get it.”

“I have enough time. I don't have a lot of questions. I just want to keep tabs on how things are”

For some people however, appointments were felt to be too short, with limited time to digest and respond to information. This meant that some people reported not feeling included in decisions being made about their care and treatment.

“I'd like to be able to talk to the doctor about things that aren't strictly Parkinson's but which I think have an impact on my Parkinson's, but there isn't time.”

> “We have 20 minutes. Last time, the doctor used that doing tap tests. We wanted to ask about medication but we didn't have time.”

- 23 people reported being under the care of a neurologist.
- 14 people were under a Care of the Elderly (COTE) Consultant.
- The remainder were either unsure or did not respond to the question.

People under a COTE consultant said they preferred the holistic approach and felt that they were not rushed in appointments. COTE consultants are also typically seen within Community hospitals, whereas neurology consultants are based within Cheltenham General hospital and Gloucestershire Royal Hospital. Age is also a factor in determining which type of consultant people will see as well as if a person has other co-morbid health conditions.

A number of people described being visited at home, by COTE doctors, nurses, or other therapists, and how helpful they found them if they don’t have the mobility to travel to clinics.

> “We had a care of the elderly psychiatrist come to see us at home. It was only a week after the Parkinson’s nurse requested the appointment for my husband, we were very impressed. Because he came to the house he saw my husband as he is in his own environment – it made such a difference. He was brilliant”

Phone appointments were seen as less effective though, especially for complex issues like vision problems. One person had been informed of their diagnosis over the phone and felt that this was ‘immoral’.

Some people reported feeling anxious or overwhelmed before appointments. Preparation strategies included making lists of questions and bringing someone along for support and to take notes, so nothing is missed.

> Appointments have been the right length so far. I take my son with me too, as I'm a bit hard of hearing

Referrals to other clinicians besides the doctor and the Parkinson’s nurses

Some people reported being referred to or accessing other services, including:

- Physiotherapy
- Speech and Language Therapy
- Occupational Therapy
- Frailty Nurses
- Psychiatrists
- Later Life Team at Weaver’s Croft (mental health and other services)
- Managing Memory team
- Dietitians
- These services were seen as highly beneficial, but:
- Awareness of these services was low among many.
- Referrals were inconsistent, with some people self-referring.
- Long wait times were acknowledged for some services.

People expressed a desire for a more integrated approach, where the Parkinson’s service would proactively refer and inform them about available support.

Raising concerns

Of those that responded, the majority of people said that they did not know what they would do or who to contact if they felt unhappy with the service being provided. One person said that they had tried to make a complaint to the Gloucestershire Hospitals NHS Foundation Trust six months ago but was told it would take 21 days to respond. “That's no good if you've got an urgent problem.”

Use of technology to help monitor and manage symptoms

In general, people were interested in finding out more about how technology can help them to manage and monitor their symptoms.

Some people wore Beech Bands which have recently become available, and they pay for these. These are wrist bands which emit “regular rhythmic vibrations transmitted to a person’s body which can help stimulate and sharpen natural brain function”. We were told that Parkinson’s UK are investing and supporting the development of the Beech Bands.

One person we spoke to who was recently diagnosed was taking part in the Parkinson’s Kinetograph (PKG) trial, a wearable device used to monitor motor symptoms, including tremors, dyskinesia, bradykinesia and immobility. This is being used to revolutionize the Parkinson’s care by enabling remote assessment of patients' conditions and facilitating timely adjustments to medications or other interventions.

It gives the Consultant precise information on an hour-by-hour basis about the patient and enables them to see precisely how their Parkinson's is presenting, whether the medications are working and how long it takes for them to wear off. This will allow them to see if and when they need adjusting and the times they should be taken.

Other people present in this group discussed how beneficial this would be. Often in appointments the Consultant will ask for timescales relating to symptoms, and unless you keep a diary of these, it is difficult to remember when it may have happened.

Support for unpaid carers

A shared theme that came across from carers of people with Parkinson's disease was that they feel they have a full-time responsibility to look after their loved ones. Which can be isolating and overwhelming. Awareness of support for carers varied. Carers told us that they felt overlooked and wanted more proactive engagement.

> "We are told that we can ask for help if we need it, but I would like someone to take the time to speak to me and ask how I am."

Some people felt it would be useful to have a group just for carers and we shared details of groups run by the Carers Hub.

> "You have to battle for everything, and it would be nice not to have to do this all the time."

Services like the Carers Hub, counselling, and respite care were appreciated when accessed. Below are some of the things that carers said they found beneficial:

- The Carers Hub
- Attendance allowance – "useful for things we can't do any more like the gardening"
- The Carers Hub Emergency Scheme
- Carers breaks

- Respite through day care centres supporting their loved ones, however not everyone can afford this
- Dance with Parkinson’s sessions
- Carers ‘cafes’
- Registering as a carer with their GP practice
- Telecare
- Counselling
- Support from family and friends

> “It helps to hear from people going through similar experiences, whether it’s advice or just someone to talk to.”

What would help people be able to access the right care and support more easily?

Much of the feedback can be summarised by the comment made by one individual below:

> “Seeing the consultant more often? Although I don't know whether I need to. I just don't know what to expect”

Information providing

- Knowing who to go to for information. Is it the nurse, the GP, or the neurologist?
- “It would have helped in the beginning to be allocated a nurse at the point of diagnosis.”
- “When someone is diagnosed with cancer, at the diagnosis everything is ‘switched on’, and the individual is given information, allocated a nurse, given contact numbers etc. … why does that not happen when someone is diagnosed with Parkinson’s?”
- “If the GP could do the signposting to Parkinson's UK, that would be really good”
- “I wanted information from the GP about how to go private since the wait for a NHS consultant was 10 months. I got nothing from the GP”

- “A 6-monthly group meeting, like this, where a doctor and nurse are there, to give us a chance to ask questions. This happened at the Parkinsons conference at the rugby club and it was so useful”
- “The 'Parky Charter' is a very useful tool - it sets out the five key aspects of our basic needs”

Appointments

- “Certainty about frequency of appointments”
- “Making the next appointment at the point of your last one, so you'll know when you'll next see someone. Like we do at the dentist”
- “Currently it feels very much self-assessment and self-service appointments, rather than being directed by the service”
- “I receive a letter about my next appointment and I know who I am seeing. I get the letter very close to the appointment time though, so it would be useful to have a little more notice.”
- “Someone answering the phone, instead of having to leave a message. If you've worked up the courage to make a call, it's awful if you then have to leave a message as you have to think about what you need to say - you worry that you haven't given all the information, your name, your number, etc.”
- “Gloucestershire needs an NHS Parkinson’s administrator. There are people like XXX, who is a Parkinson’s Local Adviser, but more help is required.”

Joined up holistic support

- “An integrated approach, so we know what additional support we can get from the NHS. I did a self-referral to physio and got a specialist Parkinson's physio that way. Couldn't the Parkinson's nurse have arranged that? Why couldn't we be told about what's available and have it arranged by the Parkinson's team?”
- “There used to be 6 Parkinson’s nurses and now this has been reduced to four. Gloucestershire is a large area for them to cover and if one is off sick or on holiday, it puts pressure on an already busy department.”
- “Physiotherapy should be tied into the Parkinson’s patient requirements as standard and should be available consistently.”
- “Speech Therapy should be freely available.”
- “I think a lot of consultants only look at motor symptoms but there are lots of other symptoms that the medication can help with”
- “I would like to receive more intelligent information on Parkinson’s and what new initiatives are being brought in to help people in the future.”

- “I phoned the Parkinson's nurses as I wasn't able to get my meds as usual from the pharmacy in Tewkesbury - they were able to arrange for me to get them through the pharmacy at Cheltenham General which was useful”

Hospital experiences

- “If you're not on a neurology ward, general nurses don't understand the urgency of getting Parkinson's medication on time. You deteriorate really quite quickly if it's late.”
- “Staff in hospital are still resistant to people having their own drugs and administering them.”
- “I use Wendy Lett [satin sliding] sheets which enable me to turn over in bed, which I couldn't do otherwise. When I was in hospital I took them in with me, and I had to sign a special disclaimer in order to use them, to say that I wouldn't blame them if I fell out of bed.”
- “Arrangements for disabled people at Gloucestershire Royal is just awful. It is really difficult to find a disabled space, and last time we went I couldn't find a wheelchair to help get us to where we needed to go”

Stakeholder response

Gloucestershire Integrated Care Board

As part of our shared commitment to improving the health and wellbeing of patients with Parkinson's disease and their carers, we are responding directly to the insights shared through a joint project Healthwatch Gloucestershire (HWG) undertook with the support of NHS Gloucestershire ICB's engagement and experience team. We would like to take this opportunity to thank HWG for highlighting the experiences of people with Parkinson's disease and their carers of accessing care in Gloucestershire.

One Gloucestershire Integrated Care System's vision is to make Gloucestershire the healthiest place to live and work – championing equity in life chances and the best health and care outcomes for all. To achieve this vision, in line with the national neighbourhood health ambitions, we are committed to providing evidence-based care close to home.

We have provided a themed response below to the recommendations in the report.

1. Support for Primary Care and Access to Specialist Advice

Neurology consultants remain committed to supporting GPs through advice, training, and clinical guidance when requested. G-Care, the local online clinical information platform, provides up-to-date information on the Parkinson's Specialist Team, including access to Parkinson's Disease (PD) Nurse Specialists, and links to Neurology Advice & Guidance. Regular teaching opportunities for GPs and GP trainees such as the String of Pearls sessions (teaching conducted by the Gloucestershire GP Education Trust) continue to be offered. The Neurology and Care of the Elderly teams will ensure that G-Care guidance on Parkinson's disease remains current.

2. Diagnostic Accuracy and Initiation of Treatment

There are recognised challenges in initiating Parkinson's medication in primary care without specialist assessment. Evidence shows that diagnostic accuracy in primary care is approximately 50%. Two critical components of specialist assessment are:

Reviewing any existing PD medication, and

Assessing clinical response to treatment.

Skipping these steps can compromise diagnostic accuracy and long-term management. For this reason, diagnosis is made by Neurology consultants, with long-term management delivered collaboratively by consultants and Parkinson's Specialist Nurses.

3. Multidisciplinary Support and Patient Education

Advice on diet, exercise, and lifestyle is provided by Physiotherapists and Dietitians following a referral. Consultants at Gloucestershire Hospitals NHS Foundation Trust have recently partnered with Parkinson's UK to refer all newly diagnosed patients to Parkinson's Connect, which offers tailored education and support. A standard operating procedure is being finalised with the local Data Protection team to ensure appropriate referral pathways. Parkinson's UK leaflets are routinely used in outpatient clinics, and Parkinson's Specialist Nurses also discuss Parkinson's UK resources at the first nursing appointment, typically within four weeks of diagnosis. This process will be reinforced at the upcoming local Parkinson's Strategy Day.

4. Information on Roles, Services and Referral Pathways

The Parkinson's team will provide clear information on the respective roles of consultants and specialist nurses, available services (Physiotherapy, Speech and Language Therapy, Continence Services, etc.), and referral pathways. National guidelines recommend at least an annual review by a specialist with an interest in Parkinson's disease. Locally, the aim is to review patients every 6–12 months, or more frequently if clinically indicated. Referrals to other services are based on clinical need and patient preference. A new Neurology team leaflet is being finalised to improve clarity for patients.

5. Appointment Processes and Communication

New Parkinson's appointments are 30 minutes and follow-ups are 20 minutes, reflecting the multisystem nature of Parkinson's disease. Patients are encouraged to bring their top concerns to appointments. The team is exploring the option of sending letters outlining appointment duration, clinicians involved, and what to bring.

Neurology appointment letters are now issued via central administrative teams. Parkinson's nurses will liaise with administrators to ensure letters clearly state whether the appointment is with a consultant or specialist nurse. Standard templates include guidance on preparing for appointments, such as bringing an up-to-date medication list and identifying key issues to discuss. The Neurology team will review processes to ensure clarity and consistency.

All appointments are booked through the booking office rather than by clinicians. We acknowledge that there is some streamlining required in the appointment booking systems for consultant and specialist nurse appointments and we are committed to improving this.

Letters from both departments are routinely copied to patients, and all clinic letters are available via the NHS App or upon request.

6. Community Engagement and Carer Support

The Gloucestershire Carers Hub, commissioned by Gloucestershire County Council, provides support to carers across the county. Support is tailored to individual needs and may include information, advice and guidance (IAG), activities, workshops, carers assessments, counselling, peer support, and signposting to a wide range of additional services that can help carers in their role.

The Carers Hub actively listens to carers' feedback. If carers request a peer support group for a specific community of carers, such as those supporting someone with a degenerative neurological condition, the Hub will help facilitate the development of that group.

Gloucestershire County Council also maintains strong links with Parkinson's UK through the Neurology Subgroup, which provides a forum for sharing information, updates, and training opportunities.

The Neurology service runs a newly diagnosed patient group in the community and has attended local Parkinson's groups in Cheltenham, Gloucester, Cam, and other areas. Staff continue to attend community events, including upcoming sessions in Northleach and Cirencester. Both consultants and nurses are willing to attend local meetings when invited, balancing this with clinical workload and county-wide commitments. Mapping of community groups and planning for equitable coverage will be included on the Parkinson's Strategy Day agenda.

7. Frailty, Advanced Care Planning and Home Visits

Gloucestershire has adopted the Proactive Care Model, with a frailty matron assigned to each Primary Care Network. Moderate to severely frail individuals with Parkinson's may come under their oversight. While some aspects of advanced care planning can be discussed in outpatient clinics, comprehensive planning is often better suited to frailty or palliative care teams. Appropriateness depends on the individual, for example, it would not be suitable for a healthy 42-year-old but is relevant for frail older adults with comorbidities.

Advanced care planning discussions may occur during home visits where appropriate. The teams will liaise with community colleagues to clarify the use of orange folders and other documentation systems. The aim is to avoid duplication whilst contributing to existing paperwork when needed.

8. Access, Transport and Locality-Based Care

Consultant-led clinics are offered across the county, including: Gloucestershire Royal Hospital, Cheltenham General Hospital, and Forest of Dean, Tewkesbury, North Cotswolds, Cirencester, and Stroud Community Hospitals. Parkinson's Nurse Specialists routinely refer patients to consultants when transport, distance, or multimorbidity make Neurology follow-up challenging. Home visits are provided for housebound patients.

Thank you

Thank you to the individuals who shared their experiences and provided invaluable insights. We are also grateful to everyone who supported us to raise awareness of the project and ensure that these voices could be heard through this report. Thank you to the ICB Engagement team who supported us with the engagement.

Healthwatch Gloucestershire
The Vassall Centre
Gill Avenue
Fishponds
Bristol
BS16 2QQ

www.healthwatchgloucestershire.co.uk
t: 0800 652 5192
e: info@healthwatchgloucestershire.co.uk
𝕏 @HealthwatchGlos
f Facebook.com/HealthwatchGloucestershire