

## Patient initiated follow up/review

*“This approach could help people with Parkinson’s to actively manage their condition. Having the ability to follow up issues that happen could mean I get an answer to something right away, rather than wait until my next appointment. However it might not be right for everyone, so people should have the choice to be put onto this pathway.”* **Dick, person with Parkinson’s**

### What we believe

People with Parkinson’s should receive high quality health care from diagnosis to the end of their life. They should have regular appointments with their health professionals to manage their symptoms and stay well and should not be discharged from their Parkinson’s service. Our community has told us that some patients are being warned about removal from consultants’ lists. They have also told us that their Parkinson’s nurse provides the most confidence in their healthcare support.

There should be regular conversations about treatment and care options and these should be agreed jointly between the person with Parkinson’s, their carers and health professionals. People with Parkinson’s should be able to choose how they engage with their health appointments and be able to access care and support between appointments, to address any concerns they may have about deteriorating symptoms.

Our Policy Panel suggests the following principles should be met before a patient initiated follow up/review (PIFU/R) pathway is considered:

- Patients and carers should be involved in a discussion or assessment about whether this approach is right for them and ultimately have the choice if they are moved onto this pathway.
- The move to this pathway needs to be in the best interests of the patient and carer.
- There needs to be flexibility in the pathway, rather than a general approach to all patients.
- There must be a recognition that Parkinson’s is different for everyone. As the condition progresses, the needs of individuals will increase and so will the services required.
- There must be clear communication about what to expect if you are moved to this pathway. This should include how to get in touch with your service if you need an appointment, how long you should wait for a response and what to do if you don’t get one within that time frame, and how you provide feedback or complain about the service. The community would welcome a dedicated helpline for the person with Parkinson’s or their family to maintain support.
- Patients, carers and professionals need to be open and honest about the pros and cons of the pathway.
- How the pathway is working for the individual with Parkinson’s should be reviewed at every appointment or at least every 6 months.
- Each service should provide a check-in system for all patients. If a service has not heard from their patient within 12 months, they should contact them to clearly explain how to book appointments and seek advice. Patients should not be discharged from the service. The pathway must make sure that nobody falls through the cracks.
- Fixed appointments should preferably be at 6 month intervals (12 months maximum), supplemented by a patient-initiated intermediate service.

## Background

The NHS is currently facing long waiting lists as it recovers from the pandemic. The NHS in each of the UK countries is developing its own approach to restarting elective care and reducing waiting lists.

While some NHS clinics have been operating a type of patient initiated follow-up (PIFU), or patient initiated review in Scotland (PIR), coronavirus (COVID-19) has meant the NHS is seeking to roll out this approach across many specialities to tackle waiting times and maintain the population's health.

NHS England and NHS Improvement in their restart plans<sup>1</sup> provided guidance on how PIFUs could be used to keep the population healthy, by empowering patients to manage their condition and seek clinical input when required. In Scotland, the Modernising Patient Pathways programme<sup>2</sup> has been investigating the use of patient initiated review, including in neurology.<sup>3</sup>

Neurology is highlighted as a speciality where PIFUs could be used. However, it is made clear in the guidance that an assessment by the service decides whether this approach is suitable for patients.

PIFU is different from patient expedited follow-up. In the former, the patient is put on the PIFU pathway for a set period of time, and then usually discharged to primary care unless they have triggered a follow-up. Under patient expedited follow-up, a patient is given a follow-up appointment sometime in the future (the latest they should be seen by) but given the option to get in touch to trigger an appointment sooner if needed.

Current NICE guidelines state that “people diagnosed with Parkinson's disease should be seen at regular intervals of 6–12 months to review their diagnosis”. The evidence still supports regular reviews to make sure that cases of conditions like Progressive Supranuclear Palsy, Corticobasal degeneration and Multiple System Atrophy are not missed. NICE also states there should be a discussion with a Parkinson's specialist before any medication is started or changed, especially dopamine agonists as it needs to be carefully monitored for side effects.

The Neurological Alliance have also developed guidance on developing PIFUs in neurology for England<sup>4</sup>. Parkinson's professionals who are developing PIFUs have shared that they are not suitable for all of their patients. They added that to operate effectively they need good administration support, a dedicated telephone clinic to triage people with Parkinson's and also clinic slots each week to see urgent cases. This would allow the right treatment to be provided at the right time.

There is currently no guidance on developing PIFU/R in Wales or Northern Ireland. In Northern Ireland, the term patient initiated follow up/review is not used widely and patients' statuses are set to inactive rather than discharged from the service. Northern Ireland was in the midst of a

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<sup>1</sup> NHS England and NHS Improvement (August 2020): Implementing phase 3 of the NHS response to the COVID-19 pandemic - <https://www.england.nhs.uk/wp-content/uploads/2020/08/implementing-phase-3-of-the-nhs-response-to-covid-19.pdf>

<sup>2</sup> See NHS Education Scotland website: <https://learn.nes.nhs.scot/4235/scottish-government-health-and-social-care-resources/modernising-patient-pathways-programme>

<sup>3</sup> See NHS Scotland website: <https://learn.nes.nhs.scot/44390/scottish-government-health-and-social-care-resources/modernising-patient-pathways-programme/speciality-networks/neurology>

<sup>4</sup> The Neurological Alliance, June 2021 - <https://www.neural.org.uk/wp-content/uploads/2021/06/Guidance-20210623-PIFU-principles-June-2021.pdf>

neurology review before the COVID-19 pandemic and there was a whole pathway transformation plan in place and somewhere PIFUs could sit.

The NHS Wales and Welsh Government 3-year strategy and action plan, “Transforming the way we deliver outpatients in Wales 2020 - 2023<sup>5</sup>”, includes patient initiated follow-ups and ‘see on symptoms’ as an integral component of managing outpatient appointments in the future. Health boards across Wales are each tasked with developing and implementing clinical condition pathways as part of transforming the management of outpatients across Wales.

There needs to be a treatment pathway for neurological conditions across borders. Cross-border provision and specialists using hub and spoke clinics do not have the information and local knowledge of services within the local community. Pathways need to be monitored and evaluated for their quality and effectiveness to clients.

### **Why we believe it**

Parkinson’s is a complex, progressive condition that presents differently for everyone and people living with the condition need ongoing long-term multidisciplinary care that flexes to meet their needs as it progresses.

While we know that some people with Parkinson’s would prefer to contact their service when they need to, others may find it difficult to track the progression of their own symptoms and so may not realise that they need a review. Regular reviews make sure that any issues are not forgotten and early access to support and help can often alleviate symptoms.

Particular Parkinson’s symptoms may make it more difficult for people to seek support when they get worse. This could include people living with anxiety and depression, cognitive issues, advanced Parkinson’s, movement related issues, communication issues, or people who live alone with no carer or close relative who can monitor how their condition is progressing.

It’s important that patients are given the time to express themselves. Time constraints can be an issue but sharing a questionnaire before an appointment could highlight any priority issues that need to be discussed.

Parkinson’s medications are vital for managing symptoms of the condition. Optimising Parkinson’s medication is challenging as everyone responds differently to Parkinson’s treatments, and medications become less effective over time as symptoms change.

All Parkinson’s medications have potentially significant side effects and can worsen other symptoms. The risk of impulse control disorders in those taking dopamine agonists must be monitored by professionals. It is also important that professionals review an individual regularly to assess whether the prescribed treatments and therapies (which are equally vital, especially for those newly diagnosed) are still effectively controlling their symptoms.

A move to PIFU/R could be problematic for people who do not already engage with a Parkinson’s service regularly. As well as people from a culture where they don’t want to bother health professionals unless there’s a crisis.

Professionals have also shared that Parkinson’s should be reviewed regularly following diagnosis to make sure the diagnosis is correct. Subtle symptom changes could be missed when they are treatable, such as posture.

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<sup>5</sup> <https://gov.wales/outpatient-services-strategy-and-action-plan-2020-2023>

We're also concerned that PIFU/R could be misused to discharge patients who need a regular review of their care to stay well. PIFU/R must not become a way of bringing down waiting times.

### **What we are doing**

- Working with NHS England and NHS Improvement on developing guidance on rolling PIFUs out across England as a member of the Neurological Alliance.
- Producing guidance and providing support for professionals to make sure they make the most of appointments with their patients.
- Developing guidance for people with Parkinson's and carers to make sure they make the most of appointments with their professionals.

### **Acknowledgement**

We are grateful for the advice and guidance of our Policy Panel in shaping this position paper on patient initiated follow up/review. The Policy Panel consists of people with experience of Parkinson's who meet on a regular basis to help guide the charity's position on a range of policy issues.

We're also grateful for insights from health professionals and Parkinson's UK staff who have shared their experience as we developed this position.

### **Further information**

Please contact the Policy and Campaigns team. Tel: 020 7963 9349 or email: [campaigns@parkinsons.org.uk](mailto:campaigns@parkinsons.org.uk)

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