

Cyflwynwyd yr ymateb i ymgynghoriad y [Pwyllgor Iechyd a Gofal Cymdeithasol](#) ar [Gynllun Llywodraeth Cymru i drawsnewid a moderneiddio gofal a gynlluniwyd a lleihau rhestrau aros](#)

This response was submitted to the [Health and Social Care Committee](#) consultation on the [Welsh Government's plan for transforming and modernising planned care and reducing waiting lists](#)

PCWL 21

Ymateb gan: | Response from: Parkinsons UK Cymru



Transforming and modernising planned care and reducing waiting lists

1. This submission serves to highlight the issues impacting the Parkinson's community that we feel need to be emphasised in light of this plan and acknowledging the recent publication of the ['My Neuro Survey' Wales report](#).

Issues include:

- people living with worsening symptoms post lockdown.
 - reduced access to all aspects of healthcare to manage the condition.
 - our position on Patient Initiated Follow-Up (PIFU) for people with Parkinson's.
2. We welcome the plan to transform and modernise planned care and reduce waiting lists and acknowledge that this is an opportunity to shape how we deliver healthcare effectively in the future.
 3. However, we are also aware that services for people with Parkinson's were inconsistent throughout Wales prior to the pandemic and, with such an enormous multifaceted task ahead over the next four years, as set out in this plan, we must ensure that the needs of people living with Parkinson's in Wales are consistently considered.

4. We would seek assurances from Welsh Government that the findings presented here from the Parkinson's community, in the 'My Neuro Survey Wales' report and the report of the Cross Party Group on Neurological Conditions: Building the foundations for change: The impact of the Welsh Government's Neurological Delivery Plan are considered alongside the developments outlined in this plan.
5. The impact of the lockdown restrictions and reduced access to regular healthcare reviews, physiotherapy, speech and language therapy and occupational therapy since the start of the pandemic has had a significant impact upon people living with the condition being able to manage their Parkinson's symptoms.
6. Coupled with reduced access to regular physical activity and exercise as well as the negative mental health implications of reduced social interaction, isolation and loneliness the impact of the past two years on those living with Parkinson's means we must ensure those living with the condition are not left behind as we seek to rebalance and modernise.

7. About Parkinson's

Parkinson's is the fastest growing neurological condition in the world¹, and currently there is no cure. Parkinson's is what happens when the brain cells that make dopamine start to die. There are over 40 symptoms, from tremor and pain to anxiety. Some are treatable, but the drugs can have serious side effects.

8. In Wales, around 7,600 people are already living with Parkinson's. This is forecast to rise by around a fifth to approximately 9,000 by 2030.

9. What matters most to people affected by Parkinson's

¹ Dorsey, E. et al. (2018). Global, regional, and national burden of Parkinson's disease, 1990–2016: a systematic analysis for the Global Burden of Disease Study 2016. *The Lancet Neurology*, 17

The views and needs of people affected by Parkinson's are central to both the work that Parkinson's UK Cymru does, and our ultimate ambition, which is to find a cure and improve life for everyone affected by the condition.

10. In 2020 we asked people affected by Parkinson's - those living with the condition, their families and carers - what are the most important issues for us to campaign on through our [‘What matters most?’ survey and our coronavirus poll](#). As the pandemic hit halfway through our survey, causing a great deal of uncertainty, we used the poll to validate the views of our community. More than 2,300 people in the Parkinson's community responded to both surveys across the UK with 5% of responses from Wales.

11. People affected by Parkinson's in Wales told us they need:

- High quality health and social care
- Access to the right treatments at the right time
- To be able to access financial benefits
- To get their Parkinson's medication on time when in hospital or a care home

12. Cross Party Group on Neurological Conditions inquiry into the impact of the Neurological Conditions Delivery Plan

13. Prior to COVID-19, the [Cross Party Group on Neurological Conditions inquiry on the impact of the Neurological Conditions Delivery Plan \(NDCP\)](#) heard that people with neurological conditions had experienced poor access to treatments, services and support. In spite of the NDCP being in place since 2014.

14. In the first half of 2022, the Wales Neurological Alliance (WNA) has, for the first time, collaborated with the Neurological Alliances of Scotland, England and Northern Ireland to gather evidence from people living with neurological conditions across the UK.

15. The [My Neuro Survey](#) provides an important insight into whether people living with neurological conditions in each of our nations are getting the treatment and support they need. Over 8,500 people shared their experiences in the survey, 503 from Wales.

16. The [findings from the neurological community in Wales are presented in this report](#) alongside the Neurological Conditions Implementation Group's (NCIG) Position Statement for Neurological Services across NHS Wales report of March 2022.

17. The report concludes that: "People living with neurological conditions in Wales continue to report substantial barriers to accessing the treatment, services and support that they need from health and social care services."

18. The impact of coronavirus on people affected by Parkinson's: July 2020

Parkinson's UK and Lancaster University collaborated on a survey in April-May 2020 to find out the impact of the coronavirus restrictions on the Parkinson's community. Over 2,000 people across the UK affected by the condition completed it - 1,491 people with Parkinson's and 540 family members, friends and carers. 6.6% (116) of respondents were from Wales.

The full report is available [here](#).

19. Access to healthcare: For those in regular contact with health services, many had appointments cancelled and alternatives were not routinely offered via telephone or online.

The statistics for Wales do not compare favourably to the other three nations or to the UK as a whole.

- 48% had appointments with their Parkinson's Nurse cancelled in Wales (33% across UK) and of these, 53% were not offered a phone or online appointment (53% across UK.)
- 57% in Wales had appointments with their Parkinson's Consultant cancelled (34% across UK) and of these, 80% in Wales were not offered a phone or online appointment (68% across UK.)
- Cancellation rates were also high for those accessing physiotherapy at 78% across Wales (70% across UK), speech and language therapy (76% in Wales, 57% across UK) and occupational therapy (78% in Wales, 55% across UK.)

20. Wales had the lowest number of respondents who decided to cancel appointments because they were worried about the coronavirus (8% for Wales, 15% for the UK.) Cancelled appointments were seen by many as a contributor to deterioration of the

condition and some were worried they were storing up future difficulties.

21.Symptoms: Many said their Parkinson's symptoms got worse since the restrictions began. Over a third experienced increased slowness of movement, stiffness and fatigue and over a quarter experienced increased tremor, anxiety and sleep problems. Stress and isolation and reduced access to health care and exercise (see below) were seen as causes of deterioration of their condition.

The impact of coronavirus on people affected by Parkinson's: August 2021

We again worked with Lancaster University in August 2021 to survey the Parkinson's community. This enabled researchers to measure the change in symptoms over the course of the restrictions and the pandemic. The full report is available [here](#).

Worsening symptoms: The findings show that both motor and non-motor symptoms were heavily impacted. Overall, 8 in 10 people with fatigue (86%), stiffness (83%) and slowness of movement (88%) reported a decline in these symptoms.

Anxiety and depression also increased considerably with 7 in 10 people reporting that their anxiety had worsened in 2021, more than doubling the percentage from the previous year. And almost 4 times as many people with the condition said their depression got worse (rising from 13% to 48%).

Slowness of movement, fatigue and sleeping issues all doubled year-on-year, while muscle cramps increased threefold. We believe these significant declines could be in part because of government restrictions that limited people's access to physical activity.

Limited access to services: As well as a deterioration in symptoms, our community shared that they weren't able to access their healthcare services in quite the same way.

In the 3 months before our 2021 survey, over half (54.3%) of people with Parkinson's had an appointment with their care provider cancelled, with consultants cancelling slightly more frequently than nurses (31% compared to 28%).

Other appointments that had been cancelled include physiotherapist (18%), speech/language therapist (18%), occupational therapist (14%) and psychologist (6%).

Virtual appointments: Almost 3 in 5 people with Parkinson's (58%) had a phone or online appointment with their Parkinson's nurse and over a third (35%) had had one with their consultant. While aspects of these were seen positively, only 4 in 10 (40%) said they were pleased with the outcome of their consultant appointment.

Just under half (46%) of people with Parkinson's surveyed felt their doctor could understand them well, and fewer than a quarter (23%) felt the connection with their doctor was comparable to that of a face-to-face appointment.

Only 1 in 10 (12%) would recommend online or phone appointments to another person with Parkinson's.

Noting this low number who would recommend online or phone appointments to another person with Parkinson's, we are concerned by the inclusion of targets: "35% of new appointments and 50% of follow up appointments are delivered virtually." People living with Parkinson's, as individuals, must be a part of the decision making process as to whether this type of appointment is suitable for them, it cannot be a default position across services or patient groups.

Patient Initiated Follow Ups

Based on what people with Parkinson's have told us, we believe there are some key principles that should be met before a Patient Initiated Follow Up/ review (PIFU/R) pathway is considered for someone as follows:

- Patients and carers should be involved in a discussion/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 needs to be a recognition that Parkinson's is different for everyone, and that as the condition progresses the needs of individuals will increase and therefore the progression of the services required will need to change to meet this.
- There needs to be clear communication about what to expect if you are moved to this pathway - how to get in touch with your service if you need an appointment, timescales for 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.
- 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, but at least on an annual basis.
- Each service should instigate a check-in system for all patients. If a service has not heard from their patient within 12 months they should contact them.
- Fixed appointment intervals should be preferably at 6 month intervals (12 months maximum) supplemented by a patient-initiated intermediate service.

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 England².

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 as the need arises, others may find it particularly challenging to assess the progression of their own symptoms and therefore identifying that they need a review would be particularly difficult.

² The Neurological Alliance, June 2021 - <https://www.neural.org.uk/wp-content/uploads/2021/06/Guidance-20210623-PIFU-principles-June-2021.pdf>

Particular Parkinson's symptoms may make it more difficult for an individual to seek support when they get worse. This could include those living with anxiety and depression, those with cognitive issues, those with advanced Parkinson's, those who experience movement related issues, have problems with communicating or those who are more frail and those who live alone or have no carer or close relative who can assess the progression of an individuals' condition.

Parkinson's medications are vital at 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 are still effectively controlling their symptoms.

A move to PIFU/R could be problematic for those who do not already engage with a Parkinson's service regularly and also people from a tradition/culture where they don't wish to bother health professionals unless there's a crisis.

Professionals have also shared that Parkinson's should be reviewed regularly following diagnosis to ensure the diagnosis is correct. Subtle symptom changes could be missed when they could be more easily correctable, for instance posture.

We are also concerned that PIFU/R could be misused to discharge patients who need a regular review of their care to stay well.

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Submitted on behalf of Parkinson's UK Cymru