Parkinson's UK's 10 Year Health Plan consultation response (December 2024)

Q1. What does your organisation want to see included in the 10 Year Health Plan and why?

Parkinson’s UK held workshops with people with Parkinson’s, their carers, and health professionals to understand what the three shifts mean for Parkinson’s care, identify the challenges and enablers, and determine the changes needed to improve health care for people with Parkinson’s.

Parkinson’s is a complex condition with complex needs

Parkinson’s is the fastest growing neurological condition in the world. It affects 153,000 people in the UK, and we estimate this will increase to 172,000 by 2030. It costs the UK £3 billion per year and £277 million from unplanned admissions in England. It is seven times more prevalent in the top 5% of primary and secondary care service users by cost in England.

Parkinson’s is a progressive, fluctuating condition that affects all aspects of daily living. There is no cure. There are over 40 symptoms that include both motor symptoms, such as tremors, rigidity and eating and swallowing problems, and non-motor symptoms, such as pain, sleep problems and mental health issues.

Nearly half of people with Parkinson’s experience anxiety and/or depression, with 50%-60% of people with Parkinson’s developing psychotic symptoms as the condition progresses. People with Parkinson’s are up to six times more likely to develop dementia. An audit at UCLH NHS Foundation Trust revealed that people with Parkinson's and mental ill-health had unplanned hospital stays nine times longer on average than those without mental ill-health.

Our evidence submitted to Lord Darzi’s investigation showed how the NHS is failing people with Parkinson’s in terms of waiting times, access to integrated specialist multidisciplinary care and treatments, inadequate in-patient care, and medicine-related patient safety.

The 10 Year Health Plan must therefore prioritise:

1. Growing and developing the Parkinson's workforce - crucial to the success of the 10 Year Health Plan

- People with Parkinson's face unacceptable delays in accessing services that are vital to living well with the condition.
    - Neurology services see only 53.1% of patients within 18 weeks and rank near the bottom for meeting this target, 21st out of 23 specialities.
    - The NHS waiting list for neurology has grown by almost 100,000 patients since the start of the pandemic. And,
    - People struggle to access occupational therapists, physiotherapists, speech and language therapists, and mental health services.
- This is unsurprising given that the UK ranks 44 out of 45 European countries for the number of neurologists per population. There is a shortfall of ~86 whole-time equivalent Parkinson's specialist nurses in England, with 49% of Parkinson's nurses set to retire by 2030/31. There are also just 57 neuropsychiatrist consultant posts in the UK, with a 5% vacancy rate.
- The 10 Year Health Plan must ensure that:
    - Everyone with Parkinson's has access to a core specialist multidisciplinary team (MDT) in line with the NICE guideline on Parkinson's (NG71) and NHS RightCare Progressive Neurological Conditions Toolkit. The Parkinson's Excellence Network published a 'Vision for integrated specialist multidisciplinary care', which sets out what excellent integrated specialist multidisciplinary care looks like for people with Parkinson's.
    - Addresses severe shortages across all professional disciplines constituting a core Parkinson's specialist multidisciplinary team.
- The NHS Long Term Workforce Plan was a positive first step by setting out the building blocks needed to tackle the workforce crisis. However, it lacked the necessary detail to determine if it would lead to everyone with Parkinson's having access to integrated, specialist multidisciplinary care.
- The 10 Year Health Plan must commit to growing and developing the Parkinson's workforce and ensure clarity in how this will be achieved in the refresh to the NHS Long Term Workforce Plan in 2025.
- We look forward to collaborating with NHS England on these plans, and in answer to question 5 below, we offer some key solutions to these workforce challenges.

2. Ensuring that people with Parkinson's receive the right care, by the right professional, in the right place and at the right time

- While people with Parkinson's saw practical benefits in moving care closer to home, this must not be at the expense of access to experts in their condition.
- There should be an assessment of which services can be moved out of hospitals that must centre around the needs of different cohorts of people with Parkinson's.

New models of care need to be co-designed with people with lived experience to meet patients' needs.

- Community-based professionals need training and support to provide excellent care for people with Parkinson's. With the right investment, this could be achieved through 'networks of support' from hospital-based Parkinson's experts providing education, training, advice, and guidance to community-based professionals.
- The success of this shift will depend on culture change, leadership, and workforce growth, development and transformation.

3. Realising the potential of the shift from analogue to digital to transform Parkinson's care from fragmented and chaotic to joined-up and personalised while ensuring that no one is left behind.

- Digital health technologies should not replace face-to-face interactions with health professionals; instead, they should be used to improve the quality of care and free up more time for people with Parkinson's.
- There needs to be a focus on "getting the basics right". Existing digital technology and systems often fail people with Parkinson's and health professionals.
- Digitised systems in the NHS need to support healthcare delivery and enhance the productivity, efficiency, and quality of care (e.g. universal access to patient records across the NHS).
- Digital health technologies hold promise for enhancing Parkinson's care and symptom management, yet challenges of safety, effectiveness, and NHS adoption need to be addressed.
- The NHS workforce requires training and support to maximise the benefits of a digitally transformed NHS. Investment in data staff and infrastructure will also be needed to embed these new technologies in routine care.
- People with Parkinson's should always be offered a choice in how digital health technologies are used in their care. Considering limitations like dexterity or cognition and digital exclusion, their use might not always be appropriate or practical.

4. Providing people with Parkinson's the right support to keep them well for longer and out of hospital

- Although Parkinson's cannot be prevented, focusing on physical activity, exercise and early intervention could reduce the impact of symptoms and improve quality of life.
- People with Parkinson's need more information and support on diet, physical activity, and exercise at the point of diagnosis. Health professionals should also receive more training and support to empower them to discuss these strategies and

tailor their advice to the stage of the condition.

- Access to specialist multidisciplinary care from the point of diagnosis is vital to providing proactive care for people with Parkinson's and reducing avoidable hospital admissions. This includes physiotherapy, occupational therapy, speech and language therapy, and mental health support.

5. Recognising the true value of the Voluntary Community and Social Enterprise (VCSE) sector to the NHS and being seen as integral to its success

- The VCSE sector plays a crucial role in health and care, offering unique insights, data on the communities they serve and services that should be incorporated into broader health and care planning and delivery.
- Involving VCSEs in the co-design and co-delivery of services is essential to ensure interventions are person-centred.
- Social prescribers should consistently link with VCSE organisations to improve access to peer support, physical activity, and exercise opportunities.
- Addressing barriers such as a lack of awareness of the VCSE sector, data management and governance issues, and the need for improved accountability mechanisms is crucial for maximising the sector's contribution to the NHS.
- Our Parkinson's Connect programme exemplifies successful VCSE-NHS collaboration. It allows health professionals to connect people with Parkinson's at diagnosis to Parkinson's UK's information and support services. Parkinson's Connect is working with seven NHS healthcare teams and planning to roll out to 10 new NHS sites in 2025.

Q2. What does your organisation see as the biggest challenges and enablers to move more care from hospitals to communities?

Practical benefits of moving care from hospitals to communities

People with Parkinson's saw practical benefits in moving care from hospitals into communities, including:

- Feeling more comfortable receiving care in their own homes or communities than in a hospital.
- Not having to travel as far to access care, especially given mobility issues and a lack of accessible transport options.
- The potential for more occupational therapy assessments to be conducted in their home environment to understand better the support they need.

Receiving the right care from the right professional in the right place and at the right time is paramount

However, people with Parkinson's saw access to an expert in their condition as more important than where services are based. They worried about community services' ability to meet rising demand due to funding, recruitment, and the scarcity of Parkinson's experts, fearing that shifting to community-based care could worsen access to specialists in Parkinson's and increase fragmentation.

Health professionals warned that many community-based professionals do not regularly see enough people with Parkinson's to have the critical mass needed to develop the skills and competency to provide high-quality care. Therefore, community-based professionals require targeted training to deliver excellent Parkinson's care, especially considering its growing prevalence and increased demand this shift entails.

Receiving a Parkinson's diagnosis can be emotionally challenging. It is essential that community-based professionals understand Parkinson's and can signpost to information and further support. This is also why more NHS-VCSE integration is vital, as initiatives like Parkinson's Connect (see question one) can make it as easy as possible for health professionals to connect people to information and support when it is needed most.

Structures and systems built around the needs of the person, not the system

In assessing which services can be moved out of hospital and into the community, the needs of different cohorts of people with Parkinson's must be considered. This will give the best indication of what care needs to be provided where and for whom. New models of care should be co-designed with people with Parkinson's so that changes in the structure and design of services are built around their needs.

The VCSE sector is uniquely placed as an enabler to support the co-design of services involving people with lived experience. Parkinson's UK has extensive experience of this through our service improvement grants and working directly with services on service redesign. We also offer unique insights and data about the Parkinson's community, which can help inform decision making in a way that helps to meet their needs.

With the right investment, networks of support from hospital-based Parkinson's experts could provide education, training, advice, and guidance to community-based professionals on an ongoing basis so that they can provide excellent care to people with Parkinson's in the community. This would allow hospital-based specialists in Parkinson's to focus on more complex cases that require their direct input. It will remain crucial that a specialist in the condition diagnoses Parkinson's.

The shift from hospital to community must not inadvertently reduce productivity and efficiency, negatively impact care, or increase the already long delays people with Parkinson's experience in accessing care. For example, if a clinician sees twelve patients in a hospital clinic setting and then changes to home visits, they may only be able to see four patients in a day. Health professionals noted the lack of estate and facilities in the community setting as a challenge in the move to community.

Delivering care in the community also provides an opportunity to undertake research closer to home. This would improve accessibility to research studies and could enable more people with Parkinson's to participate in clinical research. We support the Association of Medical Research Charities' (AMRC) call to champion decentralised clinical trials and enable research delivery in settings such as GP surgeries in the 10 Year Plan.

Health professionals highlighted the need to review contracting models to allow more time with patients and ensure contracts promote collaboration among health professionals across different settings. We support the points made in the King Fund's 'Making care closer to home a reality' report that the transition from hospital to community requires sufficient time to achieve the desired outcomes. It will require culture change, leadership, reform to contracting models in different settings, and workforce growth, development and transformation to succeed.

Q3. What does your organisation see as the biggest challenges and enablers to making better use of technology in health and care?

People with Parkinson's, their carers, and health professionals were very clear that digital health technologies should not replace interactions with health professionals but should be used to improve the quality of care and free up more time to care for patients, which aligns with the Topol review findings.

Getting the basics right

We heard multiple examples where even basic digital technology and systems are not working for people with Parkinson's or health professionals and are negatively impacting care and health service delivery, including:

- A lack of secretarial support led to consultant letters, including medication changes and referrals, taking up to five months to type and send, creating unacceptable delays in care and treatment.

- A person receiving news of their Parkinson's diagnosis through a letter in the NHS App.
- People receiving appointment letters only in the NHS App with no notification leading to missed appointments.
- Neurology consultants having to waste time being held in a telephone queue to speak to a GP to ask quick and simple questions about a patient.

Implementing systems that enhance healthcare delivery can improve productivity, efficiency, and quality of care provided. This includes supporting better connectivity for professionals working remotely, effective dictation tools, a better communication platform between primary and secondary care, and the appropriate use of the NHS App.

One consultant highlighted the efficacy of AI-based voice recognition software, in contrast to others using multiple different tools, none of which were fit for purpose. National coordination is needed to identify effective solutions, rather than relying on procurement decisions made purely on a Trust-by-Trust basis, to enhance standardisation, efficiency, productivity, and collaboration.

The Darzi review also reflects the need to get the basic administration of services right for patients (p.112, point 6). The review references a poll by the Patients Association that found that 55% of respondents had communication issues with their healthcare services in the last five years. These issues also resonate with findings from a joint project by National Voices, The Kings Fund, and Healthwatch England highlighting the detrimental impact of deprioritising improving NHS administrative processes on worsening ill health and the inefficient use of NHS resources. Despite this, improving administrative processes is seldom prioritised.

A single point of truth to transform care from fragmented and chaotic to joined-up and personalised joined-up and personalised

People with Parkinson's, their care partners, and health professionals alike saw the shift to digital as an opportunity to transform care from fragmented to joined-up and personalised and as an enabler for continuity of care. The Darzi review (p.104, point 16) agrees that "there is a greater need for information systems that work across different settings."

Patient records and notes should be easily accessible by different healthcare providers, which the Topol review agrees is also needed to fully benefit from digital medicine. People with Parkinson's hoped this could enable more frequent access to health professionals and mean not having to repeat their clinical history, allowing more time to focus on care during appointments.

Digital tools such as e-prescribing and administration systems (EPMAs) are used to significant effect to improve care in some parts of the country but not others. EPMAs can be transformative in improving inpatient medication management, yet nearly a fifth of NHS Trusts are still operating on paper-based systems. Our report 'Every Minute Counts' cites the example of NHS Ayrshire and Arran, where administration of time critical Parkinson's medication improved from 41% in (2014) to 87% (2022/23) of doses given on time through targeted interventions enabled by auditing EPMA data.

Digital health technologies - a potential catalyst for the transformation of Parkinson's care

Digital health technologies (DHTs), including wearable technology and apps, offer significant potential to improve Parkinson's care and symptom management. However, challenges around safety, effectiveness, and nationwide NHS adoption must be overcome.

Last year, NICE conditionally recommended five remote monitoring devices for Parkinson's for the NHS in England. These devices remotely monitor changes in Parkinson's motor symptoms, helping to provide data directly to clinicians to give an objective view of symptom progression and inform clinical decision-making.

The Home Based Parkinson's Care (HBC) pathway project at University Hospitals Plymouth NHS Trust, funded by the Parkinson's Excellence Network and the Health Foundation, represents a pioneering use of wearable technology in the care of People with Parkinson's. The project introduced a digitally enabled care pathway using a Personal Kinetigraph (PKG^{TM}) smartwatch for remote monitoring, empowering patients to self-manage their condition and identify complications early.

This innovative approach has led to significant benefits, including improved patient engagement and understanding of their Parkinson's, enhanced staff morale and workload management, and better clinical outcomes with reduced need for in-person clinic visits.

People with Parkinson's shared with us how devices like the PKG watch could help personalise their care and give health professionals a more complete picture of how they're doing. They also valued apps that help track their symptoms to make the most of often short appointment times. Voice-activated and voice-recognition software were seen as particularly helpful.

Ensuring digital health technologies are safe, effective, accessible and equitable

However, health professionals and people with Parkinson’s cautioned against the use of wearable technology and other digital innovations as a replacement for face-to-face care. For example, wearables can provide data on motor symptom progression but cannot pick up on mental ill-health or cognitive decline. Health professionals also warned that the use of wearables to aid self-management was not suitable for all, especially people with dementia or cognitive decline.

Concerns were raised about the rapid influx of apps and devices outpacing existing regulatory and approval processes’ ability to evaluate their safety, clinical, and cost-effectiveness (e.g., MHRA, and NICE). Unless this is urgently resolved, this risks money spent on tech that doesn't work, and delays to promising tech being adopted and available on the NHS.

Fit for purpose and fit for the future - workforce transformation and data

Health professionals highlighted the need for improved digital and data literacy among the NHS workforce more broadly to maximise the use of DHTs, an issue highlighted by the Topol review. There was a clear consensus on the need to equip the workforce with the skills, knowledge, and experience required to maximise the benefits of a digitally transformed NHS.

There are well-recognised data quality issues within NHS data collection, for example in the coding of outpatient data or the problem for training AI tools on data unrepresentative of patient populations. Health professionals worry that current hospital systems and processes are not ready to handle data flows with digital innovations happening now and in the near future. Investing in data staff and infrastructure is crucial if DHTs are to be embedded in routine care.

Virtual consultations - ensuring quality of care and maintaining choice

Health professionals highlighted the importance of face-to-face consultations for conditions like Parkinson’s, where assessing motor and cognitive decline requires a holistic approach. People with Parkinson’s said they prefer face-to-face appointments, with very few exceptions, such as avoiding long-distance travel to see a specialist.

As stated in our policy position on virtual consultations, people with Parkinson’s should be able to choose whether their appointments are face-to-face, on telephone or via video.

Ensuring no one is left behind

Digital exclusion was a major concern for both people with Parkinson’s and health professionals. Without addressing the digital divide, the NHS’s founding principle of “a comprehensive service, available to all” is at risk. Several barriers to engaging with digital healthcare were identified, including the inability to afford devices or broadband, low levels of digital literacy for some groups, and the impact of a disability or health condition on the ability to use devices - dexterity, tremor and cognitive decline making it particularly problematic for people with Parkinson’s.

Q4. What does your organisation see as the biggest challenges and enablers to spotting illnesses earlier and tackling the causes of ill health?

Parkinson’s cannot be prevented

Although developing Parkinson’s cannot be prevented, people with Parkinson’s saw benefits in focusing on prevention and early intervention - reducing the impact of symptoms and improving quality of life. However, people worried that a large-scale shift to prevention could come at the expense of improving access to high-quality care and treatment.

Keeping people well for longer

Physical activity and exercise help people with Parkinson’s build strength and better posture, improve mental well-being, avoid falls, and avoid hospital admissions. This also helps prevent other preventable long-term conditions from developing, like heart disease and type two diabetes.

People with Parkinson’s emphasised the need for more personalised advice around making healthy lifestyle changes adapted to the stage of their condition and accounting for personal preferences. Many people with Parkinson’s highlighted a lack of information and support on diet, physical activity and exercise at the point of diagnosis, despite this being recommended in NICE guidance on Parkinson’s (1.7.2, p.20.)).

Health professionals emphasised the need for increased funding to deliver appropriate exercise opportunities and the physical space to deliver these. They recommended that ICBs be held accountable for ensuring there is space available in the community to provide physical activity and exercise activities. We also agree with the Richmond Group’s recommendations in the Millions More Moving report and its submission to this consultation.

Three in 10 people with Parkinson’s live with Parkinson's-related dementia at any one time. People with Parkinson's must be included in any new intervention programmes for modifiable dementia risk factors, including exercise and physical activity (as this helps to improve cognitive health).

Promoting physical activity and exercise should be part of every health professional's role. However, many professionals feel they need more confidence in having these conversations. We must empower health professionals to have those conversations and maximise opportunities to promote physical activity and exercise. There is also a need for social prescribers to consistently link with VCSE organisations to improve access to peer support, physical activity, and exercise opportunities.

Keeping people out of hospital

Health professionals and people with Parkinson's support early access to specialist care after diagnosis, as recommended by NICE guidelines, to help prevent symptom worsening and reduce unnecessary hospital admissions. This includes access to physiotherapy, occupational therapy, speech and language therapy and mental health support.

Health professionals noted that due to current pressures on services, generic therapy services often only accept referrals when a patient reaches a crisis, such as in physiotherapy after a fall or experiencing freezing (suddenly not being able to move).

Early access to services like speech and language therapy can prevent hospital admissions by addressing common issues in people with Parkinson's, such as pneumonia and swallowing difficulties. Parkinson’s UK has pump-primed a Speech and Language Therapist in Gateshead, where they've initiated a rapid access service to advise people with swallowing difficulties to help prevent chest infections and avoid subsequent hospital admissions.

People with Parkinson's are significantly more likely to have osteoporosis and fractures, with worse outcomes, yet often aren't assessed for fracture risk. The Parkinson’s Excellence Network implemented a national project using an algorithm for bone health assessments, showing promising results from 2021 to 2023 across 74 UK services. Phase 2 assessed over 1,800 individuals' bone health, potentially preventing up to nine fractures. Building on this success, the initiative is now offering resources to all aimed at reducing falls.

Future-ready - the NHS needs to be prepared to handle advances such as the use of biomarkers in prodromal diagnosis and the adoption of disease-modifying therapies for Parkinson’s

Disease-modifying therapies for Parkinson's are emerging, and research on biomarkers, like blood tests and the alpha-synuclein seed amplification assay, for early detection before symptoms appear (known as prodromal diagnosis) is rapidly progressing.

Given the pace of these advances, the NHS needs to be system-ready for earlier diagnosis of Parkinson's, the rollout of disease-modifying therapies and potential preventative interventions. Health professionals we spoke to expressed scepticism about the NHS system's preparedness, particularly in light of the recent experience with Lecanemab for early-stage Alzheimer's dementia where NICE said "substantial investment in infrastructure and training for NHS care pathways to be redesigned to accommodate new treatments" was one of the reasons it was not seen as cost-effective.

Both people with Parkinson's and health professionals agree on the need for more research into the causes of Parkinson's, the impact of lifestyle on its progression, and how treatment effectiveness varies across ethnic groups.

Q5. Please use this box to share specific policy ideas for change. Please include how you would prioritise these and what timeframe you would expect to see this delivered in, for example:

- **Quick to do, that is in the next year or so**
- **In the middle, that is in the next 2 to 5 years**
- **Long term change, that will take more than 5 years**

The 10-Year Health Plan must ensure the following are achieved for each of the three shifts:

Moving care out of hospital into the community

1. Critical

- Assess which services can be moved out of hospital and into the community. This assessment needs to centre around the needs of different cohorts of people with Parkinson's. (Quick to do)
- Work with the VCSE sector utilising their unique insights, data on the communities they serve and services and incorporating them into broader health and care planning and delivery. (Quick to do)
- Involve VCSEs in the co-design and co-delivery of services to ensure interventions are person-centred. (Quick to do)
- Co-design new models of care with people with Parkinson's so that the changes in the structure and design of services are built around the needs of the patients. (In the middle)

2. High-priority

- Assess and map people with Parkinson's current regional and local access to specialists in Parkinson's to identify variation and gaps in access. This would help inform the creation and implementation of new models of care and workforce requirements needed to close these gaps. (Quick to do)
- Explore alternative models of care where hospital-based specialists can provide a network of support to community-based health professionals in terms of education, training, advice, and guidance. This would need significant investment in these services to work; it cannot be added on top of existing work plans. (In the middle)
- We support the Association of Medical Research Charities' (AMRC) call to champion decentralised clinical trials and enable research delivery in settings such as GP surgeries.

Analogue to digital

1. Critical

- Focus urgently on "getting the basics right" to increase productivity and quality of care by addressing the administrative and communications processes that delay and prevent access to care. (Quick to do)
- Ensure the use of virtual consultations and digital health technologies is appropriate and tailored to the needs and preferences of patients. (Quick to do)
- Enable all health professionals in all settings to have access to patient records and notes. Enhance digital communication channels between different NHS providers, especially between primary and secondary care. (In the middle)
- Ensure that training curricula across professions are regularly reviewed so that they are fit for purpose in a rapidly changing care delivery landscape, especially concerning digital and data literacy, in line with the Topol Review. (In the middle)
- Commit to tackling the barriers that lead to digital exclusion. (Long term change)

2. High priority

- Supercharge the rollout of electronic prescribing and administration systems to ensure the remaining NHS Trusts use these systems by the end of 2025. (Quick to do)
- Ensure the use of digital health technologies is evidence-based and clarify regulatory processes. (In the middle)
- Assess the need to streamline and standardise processes such as information governance across NHS Trusts in England to improve the adoption and spread of digital health technologies across the NHS. (In the middle)

Sickness to prevention

1. Critical

- Ensure training and support are provided to empower all health professionals to focus on preventative action. This includes:
  - Providing support right from the point of diagnosis to enable people with Parkinson's to live well (e.g. physical activity and exercise). (In the middle)
  - Identifying and addressing Parkinson's risk factors for worsening illness.
- Ensure early access to specialist integrated multidisciplinary teams, including crucial therapies (physiotherapy, speech and language therapy and occupational therapy) to enable a proactive approach to care, implementing early interventions to prevent avoidable hospital admissions.
- Social prescribers should consistently link with VCSE organisations to improve access to peer support, physical activity, and exercise opportunities. (Quick to do)

2. High priority

- Develop a clear strategy to futureproof services so that they can cope with earlier diagnoses and are ready to administer disease-modifying therapies. (In the middle)
- Ensure that ICBs working in collaboration with local authorities are held accountable for funding and provision of space in the community to enable space for physical activity and exercise. (In the middle)

The 10 Year Health Plan must also prioritise **growing and developing the workforce**, which is fundamental to transforming care. It must ensure that detailed plans are set out in the forthcoming refresh to the NHS Long Term Workforce Plan, including:

1. Critical

- Conducting an assessment of the specialist neurological workforce as a matter of urgency. (Quick to do)
- Addressing regional variation in workforce supply and demand to ensure equitable access to Parkinson's care and end the postcode lottery. (Long term change)
- Incentivising and supporting nurses to specialise in underserved areas, including Parkinson's. (In the middle)
- Ensuring healthcare professionals are given protected time and space to engage in condition-specific learning, including Parkinson's, to deliver the best possible care. (In the middle)

2. High priority

- Closing the 'data blackhole' of publicly available NHS workforce data. We need to know how many specialist health professionals there are and where in the country so gaps can be identified and filled. (In the middle)

For more information contact campaigns@parkinsons.org.uk or call 020 7963 9349