Parkinson's UK's submission to Health Bill call for evidence

6 July 2026

1. Summary

1.1. Around 166,000 people in the UK are living with Parkinson's, and with population growth and ageing, we estimate this will increase to 173,000 people by 2030[1]. Parkinson's cannot currently be prevented, and there is no cure or treatment to stop or slow its progression. Parkinson's is a complex, progressive and incurable condition, with over 40 physical and mental health symptoms affecting all aspects of daily living. As such, it requires specialist, integrated multidisciplinary care.

1.2. Our submission focuses on the areas of the Bill that are a priority for the Parkinson's community, and often, the 1 in 6 people who live with a neurological condition[2]. In summary:

- **Clinical leadership and advice following the abolition of NHS England (Clause 1):** We are concerned about whether NHS England's existing clinical leadership and expertise will be retained when it merges with the Department of Health and Social Care (DHSC). The legislation lacks provisions guaranteeing clinical involvement in high-level decision-making. We ask the Committee to consider mechanisms to ensure that expert clinical advisory roles are transferred to DHSC.
- **Single Patient Record (Clause 47):** We support the establishment of a secure Single Patient Record (SPR). Current NHS systems for sharing patient information records across settings and providers are inadequate and contribute to fragmented care. Done right, a SPR will be essential for delivering safer, integrated care. To succeed, the new system must overcome existing data flaws, ensure strict privacy safeguards, and maintain strong public trust before, during and after its rollout. We ask the Committee to consider if the provisions in the Bill are sufficient to enable the successful implementation of the SPR, including the necessary data privacy and security safeguards.

[1] Parkinson's UK website 'Parkinson's statistics' https://www.parkinsons.org.uk/information/about-parkinsons/statistics [accessed 3/7/26]

[2] Neurological Alliance (2019) 'Neuro numbers 2019' https://www.neural.org.uk/wp-content/uploads/2021/04/neurfromo-numbers-2019-1.pdf

- **Healthwatch and patient voice (Clauses 64 and 65):** The proposed abolition of Healthwatch organisations and transfer of their responsibilities to the same bodies that plan, fund and deliver health services risks compromising the independence of patient voice and the ability of local people to hold the NHS to account. The Committee must ensure any new arrangements guarantee true independence, transparency, and public trust.

2. Clinical leadership and advice following the abolition of NHS England (Clause 1)

2.1. The abolition of NHSE and the planned integration into the DHSC by April 2027 raises critical questions about which of NHSE's activities and expertise will be maintained through the merger. The success of the remodelled DHSC, patient safety and optimal outcomes all rely on high-quality decision-making. Although the Bill contains provisions on patient involvement, there are none on clinical involvement in decision-making.

2.2. It is essential for DHSC to retain the national clinical leadership NHSE has provided through national clinical directors and specialty advisers, to inform decision-making and ensure the continued vital advice and support across distinct conditions and service areas.

2.3. For the Parkinson's community, and the 1 in 6 people living with a neurological condition in the UK, the National Clinical Director for Neurology has provided invaluable national leadership in a specialty that has been underprioritised for decades. The role has successfully established clear priorities for service transformation and national standards through the adult neurology service specification[3]. Losing or diminishing this role would threaten progress in spreading best practice, advising on specialised commissioning, and delivering the high-quality care that people with Parkinson's rely on.

2.4. **We ask the Committee** to consider mechanisms to ensure that the National Clinical Directors' expert clinical advisory roles are transferred to DHSC to inform strategic planning and decision-making, promote service

[3] NHS England (2025) 'Specialised neurology (adults) service specification' https://www.england.nhs.uk/publication/specialised-neurology-services-adults/

improvement, advise the Department and commissioners, and help ensure oversight of the widespread implementation of national standards.

3. Single Patient Record (Clause 47)

3.1. We welcome efforts to improve information sharing, to enable more timely, coordinated and integrated care for people with complex, long-term conditions like Parkinson's.

3.2. Current systems are failing both people with Parkinson's and health professionals, negatively impacting care and service delivery. For example:

- Parkinson's is complex, requiring multidisciplinary care across multiple settings. Due to the lack of or poor information and record sharing across settings, people with Parkinson's have to repeat their medical history over and over again. This wastes precious clinical time and relies on a person's recall, which can result in an incomplete overview and thereby impact care. We have also heard how neurology consultants' time is wasted in phone queues to reach GPs for simple patient queries.
- The inability of different NHS Trusts to share medical records can also compromise patient safety. The following two illustrative examples demonstrate the potential risks of inaccessible records on Parkinson's care:
    - Mental health professionals may miss that a person with Parkinson's hallucinations or impulsive behaviours is experiencing side effects of their Parkinson's medication, compromising their care.
    - A&E staff treating an uncommunicative patient with Parkinson's might inadvertently delay giving them their time-critical medication and risk severe health deterioration that could have been avoided.

3.3. The Darzi review[4] and a joint project by National Voices, The Kings Fund, and Healthwatch England[5] both stress the need for efficient NHS administration and cross-setting information systems to prevent people's health deteriorating and wasting NHS resources.

3.4. The Topol Review[6] also highlights that patient records accessible to all health professionals involved in their care are key to realising the benefits of digital health. This will be vital to maximise the potential of new digital technologies being developed for Parkinson's, thereby transforming patient care as set out in the government's 10 Year Health Plan.[7]

3.5. Done right, a Single Patient Record (SPR) will therefore be a crucial enabler for delivering safer, more connected clinical care, and for delivering the 10 Year Health Plan's ambitions for digital transformation and a neighbourhood health service.

3.6. The successful implementation of the SPR will rely on seamless sharing of high-quality information across NHS settings. It is vital to recognise that the SPR is only as good as the data feeding into it. We know, for example, that there is a paucity of outpatient data in neurology and that inconsistencies exist in how this data is recorded[8,9]. Without careful development and implementation, there is a distinct risk that these existing data issues will simply be transferred into the new system.

3.7. Public trust is also essential for the SPR to deliver its intended benefits. Maintaining this trust during the rollout requires transparent safeguards,

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[4] Darzi, A. (2024). Independent Investigation of the National Health Service in England. Available at: https://www.gov.uk/government/publications/independent-investigation-of-the-nhs-in-england (Accessed: 3 July 2026).

[5] Ewbank, L., Lamming, L., Cream, J. and Wenzel, L. (2021) Admin matters: the impact of NHS administration on patient care. The King's Fund. Available at: https://www.kingsfund.org.uk/insight-and-analysis/long-reads/admin-matters-nhs-patient-care (Accessed: 3 July 2026).

[6] Topol, E. (2019) *The Topol Review: Preparing the healthcare workforce to deliver the digital future*. Health Education England. Available at: https://topol.digitalacademy.nhs.uk/ (Accessed: 3 July 2026)

[7] Department for Health and Social Care (2025). *Fit for the Future: 10 Year Health Plan for England.* https://assets.publishing.service.gov.uk/media/6888a0b1a11f859994409147/fit-for-the-future-10-year-health-plan-for-england.pdf (Accessed: 6 July 2026)

[8] Biggin F, Knight J, Dayanandan R, et al (2023) 'Outpatient neurology diagnostic coding: a proposed scheme for standardised implementation' Practical Neurology 2023;23:317-322. https://pn.bmj.com/content/23/4/317

[9] Biggin, F., White, L. M., Ashcroft, Q., Howcroft, T., Chandrabalan, V. V., Emsley, H., & Knight, J. (2025). Density of routinely collected neurology data depends on patient visit type: an investigation using the observational medical outcomes partnership common data model. BMJ neurology open, 7(2), e001202. https://doi.org/10.1136/bmjno-2025-001202

clear accountability, strict oversight of data privacy, and continuous public dialogue.

3.8. **We ask the Committee to** consider if the provisions in the Bill are sufficient to enable the successful implementation of the SPR, and deliver the benefits of more joined up care while providing appropriate and proportionate safeguards in relation to data security and data privacy.

4. Abolition of Healthwatch England and Local Healthwatch organisations (Clauses 64 and 65)

4.1. The Dash Review[10] of the patient safety landscape recommended simplifying and streamlining it to improve the user experience. However, we believe that the abolition of Healthwatch and Local Healthwatch organisations could worsen patient experience and weaken patient voice.

4.2. Indeed, abolishing them removes an effective and, crucially, independent voice advocating for patients and facilitating unfiltered feedback. This is key to improving health services for local populations.

4.3. Box 1 provides examples from across England of how Healthwatch has built trust with the Parkinson's community and improved local health services, thanks to its dedicated staff and independence from those services.

4.4. Moving the patient voice functions of Healthwatch and Local Healthwatch organisations into the same organisations that plan, fund and deliver services (DHSC, Integrated Care Boards (ICBs) and local authorities) would dramatically change this dynamic, creating a conflict of interest and allowing health organisations to 'mark their own homework'. We support the safeguards of transparency, accountability, equity and resourcing that National Voices set out in its second reading briefing on the Health Bill[11].

4.5. **We ask the Committee to** consider whether the changes set out in the Bill can deliver independence, public trust, transparency (including the

[10] Dash, P. (2025) *Review of patient safety across the health and care landscape*. Department of Health and Social Care. Available at: https://www.gov.uk/government/publications/review-of-patient-safety-across-the-health-and-care-landscape/review-of-patient-safety-across-the-health-and-care-landscape (Accessed: 3 July 2026)

[11] National Voices (2026). *Health Bill: Second Reading Briefing.* https://s42139.pcdn.co/wp-content/uploads/Health-Bill-National-Voices-Second-Reading-Briefing-on-Patient-Experience-1.pdf (Accessed: 6 July 2026

publication of patient experience data), and accountability in the exercise of the functions of patient voice and patient accountability.

Box 1: Examples of Healthwatch's critical support for the Parkinson's community across England

In the Northwest
Healthwatch helped in South Cumbria when a neurology provider announced it was decommissioning the service. The ICB had to look for a new provider, and Healthwatch supported Parkinson's UK locally and other neurological charities to facilitate patient meetings with the ICB and the new provider. Healthwatch meetings certainly helped patients to build trust in the new provider and feel listened to in South Cumbria. Healthwatch's involvement meant the meetings carried more weight in conversations about patient involvement. The new provider has been very open to patient feedback so far and has made changes based on this. Patients are generally really happy with the service, having had no neurologists in the area for several years.

In the South West
Volunteers in the Parkinson's UK Cirencester and Stroud Branch said: "We have had a great relationship with [Healthwatch]. They have visited all our groups on a regular basis, both for collating information for surveys and informing us of the findings and actions taken as a result. We feel that it has been an important contact, which has enabled our members to have a voice and share their experiences in order to improve services for everyone in our area. At this point in time, we have no understanding of how things will work going forward, and if we will have the same level of input. We would be looking for the same level of service as we have had with Healthwatch."

The Parkinson's UK Area Development Manager in the South West said: "I have worked with Healthwatch in Gloucester for years. They have supported Parkinson's UK and the local community positively. It will leave a big gap if they close down, negatively impacting the community."

In Yorkshire
Healthwatch East Riding of Yorkshire worked with Parkinson's UK on a report that is likely to inform a local project on how support can be improved. Throughout the process, the community was listened to and given a chance to share their experiences, which many people said they didn't feel they'd ever had before.

5. About Parkinson's UK

5.1. Parkinson's UK is the charity that's here to support every Parkinson's journey, every step of the way. We don't wait for change, we make it happen. We believe that together we'll find a cure. But that's not all we're working for. We campaign for better health and care, fund research into groundbreaking new treatments, and run life-changing support services. Families, volunteers, campaigners, fundraisers, scientists, and health and care workers. We're a powerful community united by one mission: improving life with Parkinson's.

5.2. For further information about this submission, please contact Parkinson's UK on campaigns@parkinsons.org.uk.