

Reference: FOI.ICB-2425/231

Subject: People living with Progressive supranuclear palsy (PSP) and Corticobasal degeneration

I can confirm that the ICB does hold the information requested; please see responses below:

QUESTION	RESPONSE
<p>I am writing from the XXXX to request information under the Freedom of Information Act 2000 on NHS Continuing Healthcare in the NHS Bristol, North Somerset and South Gloucestershire ICB area in respect of people living with Progressive supranuclear palsy (PSP) and Corticobasal degeneration (CBD, sometimes referred to as corticobasal syndrome or CBS).</p> <p>My specific questions are below:</p> <ol style="list-style-type: none"> 1. Please confirm the number of people in the NHS Bristol, North Somerset and South Gloucestershire ICB area with PSP and CBD who were receiving NHS Continuing Healthcare in the years 2021, 2022, 2023 and 2024. <ol style="list-style-type: none"> i. People with PSP ii. People with CBD 2. Please confirm the number of applications for NHS Continuing Healthcare that the NHS Bristol, North Somerset and South Gloucestershire ICB received in the years 2021, 2022, 2023 and 2024 in respect of: <ol style="list-style-type: none"> i. People with PSP ii. People with CBD 	<p>The ICB does not hold the data in the format requested as CHC assessments are not held by the PSP, CBD or CBS characteristics requested in the FOI.</p> <p>The ICB receives over 3300 referrals each year. To source this data would require a case-by-case review of each assessment.</p> <p>The ICB has calculated that this would take over 100 hours to provide the response which is more than the 18 hours appropriate under the FOI Act, therefore the ICB has exempted the information under Section 12 (Cost compliance exceeds appropriate limit).</p>

3. Of the above applications for NHS Continuing Healthcare in respect of people with PSP and CBD, please confirm the number which were:
 - i. Approved (found eligible for Continuing Healthcare)
 - ii. Rejected (found ineligible for Continuing Healthcare)
4. Of the above applications for NHS Continuing Healthcare in respect of people with PSP and CBD that were approved, please confirm the number which were for Fast Track Continuing Healthcare.
 - i. People with PSP
 - ii. People with CBD
5. In respect of applications for Continuing Healthcare in respect of people with PSP and CBD that were rejected, please confirm the number of applications that rejected due to:
 - i. Failed initial assessment (NHS Continuing care checklist)
 - ii. Failed full assessment (CHC Decision Support Tool)
 - iii. Other (please specify)

To assist you in fulfilling this request, in ICD-10 (2019) PSP is coded as G23.1, and in ICD-11 (2024) it is coded as 8A00.10.

CBD does not have a distinct ICD code but may be recorded as corticobasal degeneration or corticobasal syndrome.

The information provided in this response is accurate as of 2 October 2024 and has been approved for release by Denise Moorhouse, Director of Nursing/Deputy Chief Nurse for NHS Bristol, North Somerset and South Gloucestershire ICB.