FOINHSD26/1872

NHS Devon
Aperture House
Pynes Hill
Rydon Lane
Exeter
EX2 5AZ

d-icb.foi@nhs.net

Tel: 01392 205205

Dear,

Re: Request for information under Freedom of Information Act 2000

Thank you for your request under the Freedom of Information Act 2000.

NHS Devon Integrated Care Board (ICB) is confirming in accordance with Section - (1) (a) of the Act, whether it holds the information requested and (b) is supplying it unless otherwise specified.

NHS Devon can confirm it holds part of the requested information.

You requested the following information.

We're writing to you as part of a comprehensive review of neuromuscular healthcare provision. Together, we want to understand the problems it faces and build a future where everyone can access the highest standard of care.

We cover more than 60 neuromuscular conditions, including myopathies, peripheral nerve disorders, neuromuscular junction disorders and spinal muscular atrophy (SMA). Please note our remit, and thus the remit of this FOI, does not include Motor Neuron Disease (MND). A full list of relevant conditions and ICD-10 codes is attached for your reference.

If you have any questions while retrieving the below information, please contact us at 020 7803 2871 or professionals@musculardystrophyuk.org and we will be happy to provide clarification.

We are writing to seek access to the following information:

- **Please confirm whether your ICB has any strategies or transformation programmes relevant to neurological services.**
    - **If so, please provide the relevant strategy documents.**

- **Please confirm the total number of children and adults with a known diagnosis of a neuromuscular condition within the population covered by your ICB.**

  The ICB does not hold a central database of patients and their diagnoses.

  Data can be held on clinical systems in primary care, secondary care (Inpatient and Outpatient) and in community services.

  From our acute hospital inpatient records a total of 2200 patients with an ICD 10 code from the list had a hospital admission since January 2023. This is the only diagnosis data we can access.

- **Please provide the total annual funding provided for neuromuscular care for the financial year 2025-26. If exact figures are not available, please provide an approximation based on the records you hold.**

  NHS Devon does not hold this information. Funding is not set at this specific level.

- **Please provide the total annual funding provided for adults specialised neuroscience neurology (service code NCBPS08O) and specialist neuroscience services for children (service code NCBPS23M) for the past three financial years, or since their delegation from NHS England.**

  NHS Devon does not hold commissioning responsibility for these specialities.

- **Please confirm whether your organisation has held discussions about implementing the National Neurosciences Advisory Group's (NNAG) optimal clinical pathway for neuromuscular conditions, since its publication in September 2024.**
    - **If 'yes' to the above, please confirm whether your organisation is delivering the optimal pathway. If you are not delivering the optimal pathway, please outline reasons that prevent you from delivering it.**
    - **If 'no' to the above, please confirm whether your organisation plans to consider the implementation of the optimal clinical pathway for neuromuscular conditions. If not, please outline reasons that prevent you from implementing it.**
    - **Please supply any papers or discussion records about the NNAG optimal pathway for neuromuscular conditions.**
    - **Has your organisation discussed or received communications about the optimal clinical pathway with/from the former NHSE Specialised Commissioning team?**

- **Does every place in your ICB have a community neuro team?**

Yes, each locality has a community neuro team.

- Royal Devon University Healthcare NHS Foundation Trust.
  Email: rduh.foi@nhs.net

- Torbay and South Devon NHS Foundation Trust.
  Contact information: Freedom of Information

- Livewell Southwest via the Integrated Care Partnership with University Hospitals Plymouth NHS Trust.
  Email: plh-tr.foi-requests@nhs.net

    - **If not, please provide a list of the places which do not.**

      Not applicable.

- **Can you confirm whether each of the community neuro teams in your ICB treats people with neuromuscular conditions? Please provide the referral criteria used by each team, including a list of conditions which are accepted/covered by the team.**

  NHS Devon does not hold this information. You may wish to have direct communication with the trusts listed above.

- **Please confirm whether your ICB includes people with lived experience of neurological conditions in decision-making about the commissioning of neurological services. If yes, please provide further details. If not, please outlines the barriers.**

  Yes. Please see our One Plan for Devon - One Devon

Satisfaction

We trust this matter has been dealt with to your satisfaction but if there is anything you need clarifying, please do not hesitate to contact the office on 01392 205205 or emailing d-icb.foi@nhs.net Please remember to quote the reference number at the top of this letter in any future communications.

If you are unhappy with the service you have received in relation to your request and wish to request a review of our decision or make a complaint, you can write to the office and arrangements will be made for an independent review. You can write directly to the NHS Devon Chief Executive Officer if you prefer using the "contact us" details displayed on the NHS Devon website.

If you remain dissatisfied with the outcome of the independent review, you have the right to appeal again to the Information Commissioner at:
Information Commissioner's Office, Wycliffe House, Water Lane, Wilmslow, Cheshire

SK9 5AF
Tel: 01625 545 700
Fax: 01625 524 510

Yours sincerely,

The Freedom of Information Office
NHS Devon Integrated Care Board