NHS
Nottingham and Nottinghamshire
Integrated Care Board

07/05/2025

NN-ICB/25-1150

Dear Requestor

Re: Freedom of Information Request

Thank you for your request for information, received on 9 April 2025, regarding Nottinghamshire Area Prescribing Committee Joint Formulary and in particular to Chapter 20: Unlicensed Medicines. We have processed your request in accordance with the Freedom of Information Act 2000 (FOIA).

Under the FOIA, public authorities like ours are required to respond to requests for information within 20 working days. In response to your request, I can confirm that we do not hold the information requested.

Details of your request:

1. Please could you let me know in the section titled Sirolimus Ointment/Cream as available (0.1%, 0.5%) how you diagnose the Facial Angiokeratomas in patients with tuberous sclerosis?
2. Secondly what clinic evidence is used for the unlicensed ointment to treat Facial Angiokeratomas in patients with tuberous sclerosis.
3. Finally what diagnostic tools do you use to distinguish between Facial Angiokeratomas in patients with tuberous sclerosis and Facial Angiofibroma's in patients with tuberous sclerosis.

Our response to your request:

The ICB does not hold this information. You may wish to contact Nottingham University Hospitals NHS Trust (NUH) to request this and how to submit a Freedom of Information request to NUH can be found on their website - https://www.nuh.nhs.uk/freedom-of-information.

If you are unhappy with the way in which your request has been handled, NHS Nottingham and Nottinghamshire Integrated Care Board (ICB) has an internal review procedure through which you can raise any concerns you might have. Further details of this procedure can be obtained by contacting Lucy Branson, Director of Corporate Affairs via lucy.branson@nhs.net or by writing to FOI Team at NHS Nottingham and Nottinghamshire ICB, Sir John Robinson House, Sir John Robinson Way, Arnold, Daybrook, Nottingham NG5 6DA.

If you remain dissatisfied with the outcome of the internal review, you can apply to the Information Commissioner's Office (ICO), who will consider whether the organisation has complied with its obligations under the Act and can require the organisation to remedy any problems. Generally, the ICO cannot make a decision unless you have exhausted the complaints procedure provided by NHS Nottingham and

Nottinghamshire ICB. You can find out more about how to do this, and about the Act in general, on the Information Commissioner's Office website at: https://ico.org.uk/for-the-public/.

Complaints to the Information Commissioner's Office should be sent to:

FOI/EIR Complaints Resolution, Information Commissioner's Office, Wycliffe House, Water Lane, Wilmslow, Cheshire, SK9 5AF. Telephone 0303 123 1113 or report a concern via https://ico.org.uk/concerns/.

Yours sincerely

Freedom of Information (FOI) Officer on behalf of NHS Nottingham and Nottinghamshire Integrated Care Board

nnicb-nn.foi@nhs.net

All information we have provided is subject to the provisions of the Re-use of Public Sector Information Regulations 2015. Accordingly, if the information has been made available for re-use under the Open Government Licence (OGL) a request to re-use is not required, but the license conditions must be met. You must not re-use any previously unreleased information without having the consent of NHS Nottingham and Nottinghamshire Integrated Care Board. Should you wish to re-use previously unreleased information then you must make your request in writing (email will suffice) to the FOI Lead via nnicb-nn.foi@nhs.net. All requests for re-use will be responded to within 20 working days of receipt.