

Our Reference

North East and North Cumbria ICB\ FOI ICB 24-240

NECS - John Snow House **Durham University Science Park** Durham DH13YG

Tel: 0191 301 1300

E-mail: necsu.icbfoi@nhs.net

By Email 27 September 2024

Dear Applicant

Freedom of Information Act 2000 - Request for Information - NHS North East and North **Cumbria Integrated Care Board (NENC ICB)**

Thank you for your request received by North of England Commissioning Support (NECS) on 9 September 2024 for information held by NHS North East and North Cumbria Integrated Care Board (the ICB) under the provisions of the Freedom of Information Act 2000.

The ICB covers the areas of County Durham, Gateshead, Newcastle, North Cumbria, North Tyneside, Northumberland, South Tyneside, Sunderland, and Tees Valley (which covers the five local authorities of Darlington, Hartlepool, Middlesbrough, Redcar and Cleveland and Stockton-on-Tees).

Please find the information you requested on behalf of the ICB as follows.

Your Request

I am writing to request the following information about alopecia care under the Freedom of Information Act 2000.

If it is not possible to provide the information requested due to the information exceeding the cost of compliance limits identified in Section 12, please provide advice and assistance, under Section 16 obligations of the Act, as to how I can refine my request.

If any of this information is already in the public domain, please can you provide details of where it can be found together with page reference and URLs as appropriate.

Please do not hesitate to contact me for any queries or clarifications; I will be very happy to discuss the request in further detail.

Section 1: Patient pathways and prescription

- 1. Do you have a patient pathway for alopecia?
 - a. If yes, what does it say, and when was it last reviewed, does it include referral from primary to secondary care?

www.northeastnorthcumbria.nhs.uk











- b. If no, please explain any reasons for what has prevented this (e.g. budgets, other priorities, other organisations' responsibility).
- c. If no, do you prescribe some off license treatments (e.g. topical steroids) in your area (area is defined as all the local Trusts that are relevant to your ICB, serve your ICB area, or are commissioned by your ICB, for which you are responsible to fund or commission treatment?
- 2. Are patients with alopecia areata in your ICB area able to be prescribed ritlecitinib, as approved by NICE technology appraisal guidance TA958 (area is defined as all the local Trusts that are relevant to your ICB, serve your ICB area, or are commissioned by your ICB, for which you are responsible to fund or commission treatment)?
 - a. If yes, could you provide information on any policy or limitations on the number of patients with alopecia areata that can be prescribed ritlecitinib?
 - b. If no, or if any limitations are present, please explain any reasons for not adhering to NICE's mandatory guidance (e.g. budgets, other priorities, other organisations' responsibility).

Section 2: Clinics and referrals in your area

- 3. Are you currently referring alopecia patients to secondary/tertiary care?
 - a. If yes, please explain the referral criteria, including whether referrals are for virtual or in person appointments?
 - b. If no, what is preventing this? (e.g. budgets / other priorities / other organisations' responsibility)
- 4. What is the average time for a patient with alopecia to be referred to secondary/tertiary care within your ICB area?

Section 3: Wigs

- 5. Do you have a wig policy for patients with alopecia in your ICB area (area is defined as all the local Trusts that are relevant to your ICB, serve your ICB area, or are commissioned by your ICB, for which you are responsible to fund or commission treatment)?
 - a. If so, what does your policy state regarding the provision of wigs for alopecia patients? Specifically, please address the following:
 - Are all types of alopecia eligible for a wig?
 - How many wigs are provided to patients per year?
 - Are there any limitations on the type of wig available (e.g. acrylic or human hair wigs)?
 - Do patients have a choice of supplier? And if so, how many?
 - How do patients pay for their wigs?
 - Are patients allowed to pay a top-up to the prescription to get a wig that costs more?
 - b. If no, what has prevented this so far?

Section 4: Mental Health

- 6. Are the associated mental health or psychological challenges of patients with alopecia assessed in your ICB area (area is defined as all the local Trusts that are relevant to your ICB, serve your ICB area, or are commissioned by your ICB, for which you are responsible to fund or commission treatment)?
 - a. If yes, please explain what specific support is available, whether people are signposted to relevant support organisations, and if there is any criteria to receive support (e.g. percentage of hair loss, type of alopecia)?
 - b. If no, please explain what has prevented this so far?

Section 5: Awareness of local population

7. Have you reviewed the alopecia needs of your local population (e.g. numbers of people living with alopecia who are diagnosed and not yet diagnosed, gender, ethnicity, socio-economic groups)?

- a. If yes, please give details.
- b. If no, what has prevented this and are there plans to do so?
- 8. Are you aware of local inequalities of access to care services for people with alopecia amongst any groups (e.g. by gender, ethnicity, socio-economic groups)?
 - a. If yes, please give details of the inequalities and any work you are doing or planning to do to address this.
 - b. If no, are there plans to do so?

Our Response

We can confirm, as per Section 1(1) of the Freedom of Information Act 2000, the ICB holds some of the information you have requested.

- 1. NENC ICB does not have a specific pathway for alopecia. This is due to other priorities and referral onward to a dermatologist is at the discretion of the clinician. In, addition, there is no policy on prescribing off licence medication this is down to individual clinician discretion.
- 2. Ritlecitinib has been recommended for addition to formulary as a hospital only drug by the NENC ICB medicines sub-committee in line with NICE guidance: Search Results for "ritlecitinib" NTAG No other restrictions on its use are in place.
- 3. Referral of patients is at the discretion of the clinician involved in the patient's care.
- 4. Waiting times specifically for Alopecia is not available; the ICB monitor the waiting times for Dermatology which Alopecia forms part of this speciality.
- 5. We can confirm, as per Section 1(1) of the Freedom of Information Act 2000, the ICB holds some of the information you have requested. However, this is available within the NENC ICB Value Based Clinical Commissioning policy which can be accessed on the ICB website: icp040-value-based-clinical-commissioning-policy-v13-0.pdf (northeastnorthcumbria.nhs.uk) In accordance with s.21 of the FOIA, we are not required to provide information in response to a request if it is reasonably accessible to you by other means.
- 6. Alopecia distinct mental health pathways are not commissioned specifically within the NENC ICB Mental Health NHS Provider contracts, as this is not a recognised mental health condition. However, mental health conditions that could be caused or associated with people experiencing alopecia (such as anxiety and/or depression) or emotional support and wellbeing services, are commissioned across the North East and North Cumbria across a range of different providers, depending on the level of need and severity of the condition. A link to alopecia support groups can be located on https://www.nhs.uk/conditions/hair-loss/
- 7. No, NENC ICB has not reviewed the alopecia needs of the local population. With limited resources, the ICB has priority areas which will be reviewed first. This will be based on areas where patient safety issues have been identified or capacity issues are seeing services really struggle. The ICB are not aware of risks being identified in Alopecia services.
- 8. The ICB is not aware of any work currently being undertaken to understand inequalities in access to care for people with alopecia, or any plans to do so.

In accordance with the Information Commissioner's directive on the disclosure of information under the Freedom of Information Act 2000 your request will form part of our disclosure log. Therefore, a version of our response which will protect your anonymity will be posted on the NHS ICB website https://northeastnorthcumbria.nhs.uk/.

If you have any queries or wish to discuss the information supplied, please do not hesitate to contact me on the above telephone number or at the above address.

If you are unhappy with the service you have received in relation to your request and wish to request a review of our decision, you should write to the Senior Governance Manager using the contact details at the top of this letter quoting the appropriate reference number.

If you are not content with the outcome your review, you do have the right of complaint to the Information Commissioner as established by section 50 of the Freedom of Information Act 2000. Generally, the Information Commissioner cannot make a decision unless you have exhausted the complaints procedure provided by the North of England Commissioning Support Unit.

The Information Commissioner can be contacted at:

Information Commissioner's Office Wycliffe House Water Lane Wilmslow Cheshire SK9 5AF

www.ico.org.uk

Any information we provide following your request under the Freedom of Information Act will not confer an automatic right for you to re-use that information, for example to publish it. If you wish to re-use the information that we provide and you do not specify this in your initial application for information then you must make a further request for its re-use as per the Re-Use of Public Sector Information Regulations 2015 www.legislation.gov.uk. This will not affect your initial information request.

Yours faithfully

S Davies

S Davies
Information Governance Officer