



Ref: FOIA Reference 2022/23-310

Royal Stoke University Hospital
Data, Security and Protection
Newcastle Road
Stoke-on-Trent
Staffordshire
ST4 6QG

Date: 16th November 2022

Email foi@uhn.nhs.uk

Dear

I am writing to acknowledge receipt of your email dated 6th September 2022 requesting information under the Freedom of Information Act (2000) regarding leukaemia.

The University Hospitals of North Midlands Trust is committed to the Freedom of Information Act 2000.

However, the NHS is facing unprecedented challenges relating to the coronavirus (COVID-19) pandemic at the current time. Understandably, our resources have been diverted to support our front-line colleagues who are working tremendously hard to provide care for our patients, and to those in need of our services.

We strive to be transparent and to work with an open culture. But at this time, whilst care of our patients and the safety of our staff takes precedent, it is likely that responses to some requests for information will be delayed. We apologise for this position in advance, and will endeavour to provide you with as much information as we can, as soon as we are able.

The Information Commissioners Office has recognised the current situation in the NHS.

As of 1st November 2014 University Hospitals of North Midlands NHS Trust (UHNM) manages two hospital sites – Royal Stoke University Hospital, and County Hospital (Stafford). Therefore the response below is for the two sites combined from that date where appropriate.

Q1 Please can I request answers relating to the below questions. A national collation of this information will be made available to any trust requesting it in reply.

- 1. How many patients in the last 12 months has the Trust treated for metastatic Cholangiocarcinoma (CCA) or Acute myeloid leukaemia (AML)?**
 - a. For each of AML and CCA, how many have IDH-1 mutation?**
 - b. How many CCA are intrahepatic vs extrahepatic?**
 - i. How many of each of these present at 2nd line? How many of these at 2nd line have IDH-1 mutation?**
 - c. For AML, how many patients were not fit for intensive chemotherapy? How many of these AML patients have IDH-1 mutation?**

A1 I can neither confirm nor deny whether the information you have requested is held by the Trust in its entirety. This is because the information requested in this question is not held centrally, but may be recorded in individual health records. In order to confirm whether this information is held we would therefore have to individually access all individual health records within the Trust and extract the information where it is present. We therefore estimate that complying with your request is exempt under section 12 of the FOI Act: *cost of compliance is excessive*. The section 12 exemption applies when it is estimated a request will take in excess of 18 hours to complete. We estimate that accessing and reviewing all individual health records and then extracting relevant information would take longer than the 18 hours allowed for. In addition to the section 12 exemption the Trust is also applying section 14 (1) exemption: *oppressive burden on the authority*

Under section 16 of the FOI Act we are required to provide requestors with advice and assistance where possible. We would therefore like to advise you that your request is shortened to just the questions that we are able to comply within the 18 hour time frame.

Q2 How many patients have been treated with pemigatinib (CCA), venetoclax plus azacitadine dual therapy or azacitadine monotherapy (AML)?
a. **What is the average treatment duration for CCA patients treated with pemigatinib and AML patients treated with azacitadine dual therapy and azacitadine monotherapy? What is the preferred azacitadine product?**

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Q3 What is the real-world dosing for venetoclax (in combination with a CYP3A4)?
a. **What is the antifungal of choice for patients treated with venetoclax?**
b. **What is the antifungal average treatment duration when used in combination with venetoclax ?**
c) **What proportion of patients are treated with an antifungal in combination with venetoclax? In what proportion of patients is the antifungal treatment stopped? In what proportion of these pts is the venetoclax dosage altered following cessation of the antifungal?**

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Q4 Do you routinely test CCA and AML patients for IDH-1 mutation?

- a. If so when does the testing take place? E.g. at diagnosis or following 1st line progression? Is this done using NGS panel? Is this done using PCR testing?**
- b. What is the average turnaround time for these tests?**

A4 See below:

- a. For AML patients this would be tested at diagnosis and also at relapse if clinically appropriate. It would be tested using NGS analysis
- b. turnaround is approximately 4-6 weeks

Q5 Who is responsible for the routine management of patients with CCA and AML?

- a. Clinical oncologist / medical oncologist / specialist nurse etc.?**

A5 Patients with AML routinely get managed by a haematology Consultant and the CCAs were under an Oncology (Clinical Oncologist), CNS will provide support as well.

Q6 How many admissions have occurred in the last 12 months for patients with CCA and AML?

- a. What is their average length of stay?**
- b. How many of these patients were readmissions or readmitted during this time? If readmitted, can you state the main reason?**

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*Please note that any individuals identified do not give consent for their personal data to be processed for the purposes of direct marketing.

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An anonymised copy of this request can be found on the Trust's disclosure log, please note that all requests can be found at the following link: <http://www.uhnm.nhs.uk/aboutus/Statutory-Policies-and-Procedures/Pages/Freedom-of-Information-Disclosure-Log.aspx>

This letter confirms the completion of this request. A log of this request and a copy of this letter will be held by the Trust.

If you have any queries related to the response provided please in the first instance contact my office.

Should you have a complaint about the response or the handling of your request, please also contact my office to request a review of this. If having exhausted the Trust's FOIA complaints process you are still not satisfied, you are entitled to approach the Information Commissioner's Office (ICO) and request an assessment of the manner in which the Trust has managed your request.

The Information Commissioner may be contacted at:

Information Commissioner's Office, Wycliffe House, Water Lane, Wilmslow, Cheshire SK9 5AF or via www.ico.org.uk.

If following review of the responses I can be of any further assistance please contact my secretary on 01782 671612.

Yours,



Leah Carlisle
Head of Data, Security & Protection/ Data Protection Officer



University Hospitals
of North Midlands
NHS Trust

