East Sussex Healthcare
NHS Trust

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FOI REF: 22/531

5th October 2022

FREEDOM OF INFORMATION ACT

I am responding to your request for information under the Freedom of Information Act. The answers to your specific questions are as follows:

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)?

Date range used – 1st September 2021 to 31st August 2022 as discharge date OR episode start date.

Metastatic Cholangiocarcinoma (CCA) - C787	530
Acute Myeloid Leukaemia (AML) - C920	59
Total	589

a. For each of AML and CCA, how many have IDH-1 mutation?

East Sussex NHS Healthcare Trust (ESHT) does not code for this mutation, therefore we do not hold this information.

b. How many CCA are intrahepatic vs extrahepatic?

ESHT does not code whether CCA are intrahepatic vs extrahepatic, therefore we do not hold this information.

i. How many of each of these present at 2nd line? How many of these at 2nd line have IDH-1 mutation?

Not applicable.

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c. For AML, how many patients were not fit for intensive chemotherapy? How many of these AML patients have IDH-1 mutation?

The Trust does not centrally record whether AML patients were not fit for Intensive chemotherapy. To enable the Trust to provide this information would require a manual review of patients' notes. We are therefore, applying Section 12(1) to this part of your request.

Section 12(1) of the Act allows a public authority to refuse to comply with a request for information if the authority estimates that the cost of compliance would exceed the 'appropriate limit', as defined by the Freedom of Information and Data Protection (Appropriate Limit and Fees) Regulations 2004 (the Regulations). These state that this cost limit is £450 for public authorities which are not part of central government or the armed forces. The costs are calculated at £25 per hour per person regardless of the rate of pay, which means that the limit will be exceeded if the work involved would exceed 18 hours. The Trust estimates that the cost of complying with this request would significantly exceed the above limit.

2. How many patients have been treated with pemigatinib (CCA), venetoclax plus azacitadine dual therapy or azacitadine monotherapy (AML)?

pemigatinib (CCA)	0
venetoclax plus azacitadine dual therapy	25
azacitadine monotherapy (AML)	27

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?

The Trust does not centrally record the treatment duration for CCA patients being treated as above. To enable the Trust to provide this information would require a manual review of patients' notes. We are therefore, applying Section 12(1) to this part of your request, please refer to question 1c.

3. What is the real-world dosing for venetoclax (in combination with a CYP3A4)?

The Trust does not centrally record real-world dosing for venetoclax (in combination with a CYP3A4). To enable the Trust to provide this information would require a manual review of patients' notes. We are therefore, applying Section 12(1) to this part of your request, please refer to question 1c.

a. What is the antifungal of choice for patients treated with venetoclax?

No antifungal of choice, this is dependent on patient needs.

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b. What is the antifungal average treatment duration when used in combination with venetoclax?

The Trust does not centrally record the average treatment duration when used in combination with venetoclax. To enable the Trust to provide this information would require a manual review of patients' notes. We are therefore, applying Section 12(1) to this part of your request, please refer to question 1c.

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?

The Trust does not centrally record the proportion of patients that are treated with an antifungal in combination with venetoclax. To enable the Trust to provide this information would require a manual review of patients' notes. We are therefore, applying Section 12(1) to this part of your request, please refer to question 1c.

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

Yes.

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?

AML is at diagnosis. CCA is before initiating treatment. Tests are done with PCR testing.

b. What is the average turnaround time for these tests?

5 day turn around but can be done quicker depending on patient needs.

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

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

Consultant haematologist and specialist nurse

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

There were a total of 3097 admissions in the date range 1st September 2021 to 31st August 2022. This was comprised of 587 individual patients with a number being admitted on more than one occasion.

a. What is their average length of stay?

Adm Type	Total Admissions
DayCase	2337
Elect Ord	51
Emergency	705
Other	4
Grand Total	**3097**

Adm Type	Average length of stay (days)
DayCase	0.00
Elect Ord	11.35
Emergency	6.82
Other	21.25

b. How many of these patients were readmissions or readmitted during this time? If readmitted, can you state the main reason?

Clarification was sought as follows:

We have been looking at the date ranges for admitted patients for 12 months (1st September 2021 to 31st August 2022) but it is not clear from the question what timescales to use for the lengths of time to allow between admission and re-admission, would you therefore please clarify the date range.. Also can it be confirmed if the admission and re-admission needs to be based on the CCA and AML codes only.

Confirmation was received as follows:

If the date ranges could simply being admission and readmission within the same 12 months and the readmissions would only be for the AML and CCA codes.

Numbers of Patients Re-admitted	
Metastatic Cholangiocarcinoma (CCA) - C787	206
Acute Myeloid Leukaemia (AML) - C920	26
Total	**232**

If I can be of any further assistance, please do not hesitate to contact me.

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Should you be dissatisfied with the Trust's response to your request, you have the right to request an internal review. Please write to the Freedom of Information Department (esh-tr.foi@nhs.net), quoting the above reference, within 40 working days. The Trust is not obliged to accept an internal review after this date.

Should you still be dissatisfied with your FOI request, you have the right of complaint to the Information Commissioner at the following address:

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

Telephone: 0303 123 1113

Yours sincerely

Linda Thornhill (Mrs)
Corporate Governance Manager
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