

Freedom of Information Request

Ref: 22-509

27 September 2022

By Email

Dear Sir/Madam

Thank you for your request for information under the Freedom of Information Act 2000. The Trust's response is as follows:

• We can confirm that we do hold the information you are requesting

1. How many patients in the last 12 months has the trust treated for metastatic Cholangiocarcinoma (CCA) or Acute myeloid leukaemia (AML)?

Metastatic Cholangiocarcinoma (CCA) 10 Acute myeloid leukaemia (AML) 50

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

We do not hold this information, we do not test fro IDH-1

b. How many CCA are intrahepatic vs extrahepatic?

intrahepatic 6

extrahepatic *

Please note: Where the figures are between 1 and 5, this has been denoted by *. Due to the low numbers, we have considered that there is the potential for individuals to be identified from the information provided, when considered with other information that may also be in the public domain. In our view disclosure of these low figures would breach one of the Data Protection Principles set out in Schedule 1 of the Data Protection Act, namely Principle 1. The Trust therefore finds that the Section 40(2) exemption contained within the Freedom of information Act 2000 is engaged. (Section 40 is the exemption for personal information).

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

We do not hold this information; we do not test for IDH-1.

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

We do not hold this information; we do not test for IDH-1.

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 19 Azacitadine monotherapy (AML) 13

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?

We use a generic product- currently stock Seacross and Dr Reddys in stock (depends on contracts).

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

It depends on whether it is combined with a strong or moderate CYP3A inhibitor. We follow the SPC dosing.

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

Posaconazole for AML

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

Please note, the Trust does not hold the data in a format that would enable us to fully respond to your request to the level of detail required and a manual trawl for this information would significantly exceed the 18 hours limit set down by the FOI as the reasonable limit. Section 12 of the FOIA provides that we are not obliged to spend in excess of 18 hours in any sixty-day period locating, retrieving and identifying information in order to deal with a request for information and therefore we are withholding this information at this time.

c) what proportion of patients are treated with an antifungal in combination with venetoclax?

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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?

With regards to when we stop an antifungal (which is a moderate/ strong inhibitor of CYP3A) we would always aim to adjust the dose of venetoclax to ensure optimal dosing, unless any other contraindication or caution in doing so.

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

No

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? Not applicable

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

Not applicable

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

AML - Consultants & Nurses

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

CCA - Consultants and Nurses AML - Haematology/Oncology Consultants, Haematology/Oncology Nurses

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

1684

a. What is their average length of stay?

2.3 days

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

1630 (this is the total number of admissions excluding the first admission where the patient had more than one admission in the year). We do not hold the information regarding reason for readmission.

This concludes our response. We trust that you find this helpful, but please do not hesitate to contact us directly if we can be of any further assistance.

If, after that, you are dissatisfied with the handling of your request, you have the right to ask for an internal review. Internal review requests should be submitted within two months of the date of receipt of the response to your original letter and should be addressed to:

Data Protection Officer University Hospitals Bristol and Weston NHS Foundation Trust Trust Headquarters Marlborough Street Bristol BS1 3NU

Please remember to quote the reference number above in any future communications.

If you are not content with the outcome of the internal review, you have the right to apply directly to the Information Commissioner for a decision. The Information Commissioner can be contacted at: Information Commissioner's Office, Wycliffe House, Water Lane, Wilmslow, Cheshire, SK9 5AF

Publication

Please note that this letter and the information included/attached will be published on our website as part of the Trust's Freedom of Information Publication Log. This is because information disclosed in accordance with the Freedom of Information Act is disclosed to the public, not just to the individual making the request. We will remove any personal information (such as your name, email and so on) from any information we make public to protect your personal information.

To view the Freedom of Information Act in full please click here.

Yours sincerely

Freedom of Information Team University Hospitals Bristol and Weston NHS Foundation Trust