

<b>Reference:</b>	FOI.9796.22
<b>Subject:</b>	Metastatic Cholangiocarcinoma (CCA) and Acute myeloid leukaemia (AML)
<b>Date of Request:</b>	6 September 2022

**Requested:**

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?
2. 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?
3. 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?
4. 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?
5. Who is responsible for the routine management of patients with CCA and AML?
  - a. Clinical oncologist / medical oncologist / specialist nurse etc?
6. 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?

**Response:**

Hywel Dda University Health Board (UHB) is unable to provide you with the information requested, as it is estimated that the cost of answering your request would exceed the “appropriate limit” as stated in the Freedom of Information and Data Protection (Appropriate Limit and Fees) Regulations 2004. The “appropriate limit” represents the estimated cost of one person spending 18 hours (or 2 ½ working days) in determining whether the UHB holds the information, and locating, retrieving and extracting the information.

The ChemoCare Team, which holds a central record of cancer treatments, is based within Swansea Bay University Health Board (SBUHB). In order to provide you with the information requested, the UHB would be required to conduct a manual trawl of all cancer patients’ medical records, to establish the type of cancer diagnosed and therapies used to treat the patients. It is estimated that conducting this search would take longer than the 18 hours ‘appropriate limit’ as stated within the Freedom of Information Act 2000 (FoIA).

The UHB is therefore applying an exemption under Section 12 of the FoIA, which provides an exemption from a public authority’s obligation to comply with a request for information, where the cost of compliance is estimated to exceed the appropriate limit.

However, under Section 16 of the FoIA, we are required as a public authority, to provide advice and assistance so far as it is reasonable, to individuals who have made a request under FoIA. We therefore recommend that you redirect your request to the Freedom of Information Team in SBUHB, who may be able to help you with your enquiry. The contact details are as follows:-

[FOIA.Requests@wales.nhs.uk](mailto:FOIA.Requests@wales.nhs.uk) or alternatively, you can contact: FOIA Team, Swansea Bay University Health Board, Health Board Headquarters, 1 Talbot Gateway, Port Talbot, SA12 7BR.