Alder Hey Children's NHS
NHS Foundation Trust

Reference Number: FOI202223/277
From: Private Individual

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Subject: Number of patients with and treatments options for metastatic Cholangiocarcinoma (CCA) and Acute myeloid leukaemia (AML)

Q1 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 Zero patients for CCA

Five for AML
a. Two not tested for – treated within context of clinical trial and trial does not release this information to local centres. Three have no IDH mutation present. Please note, patients for AML are routinely tested for it, if not on a trial.
b. Information not held – Zero CCA patients
c. Zero – all fit and no IDH-1 mutations

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?
b. What is the preferred azacitadine product?

A2 Information not held for CCA, as per A1

One venetoclax plus azacitadine dual therapy
a. Information not held – no average available as only one patient being treated
b. Injection Vial

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 Wenetoclax? 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?

A3
a. We don't have antifungal of choice as this will depend on clinical requirement. If azole is required venetoclax dose would be reduced. We have only used in one patient so cannot contribute to real – world dosing data.
b. Information not held - no average available as only one patient being treated

c. Information not held – data not available as only one patient being treated

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 Information not held for CCA, as per A1

Yes (for AML)
a. At diagnosis. NGS and WGS (whole genome)
b. 2-3 weeks for NGS, ~6 weeks for WGS

Q5 Who is responsible for the routine management of patients with CCA and AML?
a. Clinical oncologist / medical oncologist / specialist nurse etc?

A5 Information not held for CCA, as per A1

For AML – Haematologist or Leukaemia-specialist Oncologist

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?

A6 Information not held for CCA, as per A1

98 recorded admissions for AML since September 2021, between 8 patients in total
a. Average length of stay 4.4 days
b. All readmissions.
Reasons for readmissions - Information not held. The Trust does not routinely collate or hold this information centrally as part of its management or performance data. In order to ascertain the data the Trust would be required to access personal data of the individuals and as such the data is exempt under Section 40: Personal data.