

Freedom of Information request 454-22

Request

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

Please note: NHS Borders does not treat CCA patients. NHS Borders offer treatment for AML patients not eligible for intensive treatment and non-transplant eligible- none of the patients treated here have NGS done on reflex. The main Cancer Centre in NHS Lothian's Western General Hospital treat our intensive patients. Therefore, please note under Section 25 of the Freedom of Information (Scotland) Act 2002 this data is accessible elsewhere – NHS Lothian.

1. In the last 12 months NHS Borders has not treated any patients for Metastatic Cholangiocarcinoma (CCA) and 11 patients have been treated for Acute Myeloid Leukaemia (AML).
 - a) None of these patients have IDH-1 mutation.
 - b) n/a
 - c) 6 of the AML patients were not fit for Intensive Chemotherapy. None of these patients have IDH-1 mutation.
2. No NHS Borders patients have been treated with Pemigatinib (CCA). <5 patients have been treated with Venetoclax/Azacitidine and <5 patients have been treated with Azacitadine single agent.
 - a) NHS Borders do not treat CCA patients, therefore there is no average treatment duration for Pemigatinib. The average treatment time for AML patients treated with Azacitadine Dual Therapy is 3 months. The average treatment time for AML patients treated with Azacitadine Monotherapy is 6 months. The preferred Azacitadine product is Seacross Pharmaceuticals / Tillomed Laboratories Ltd.
3. The real-world dosing for Venetoclax (in combination with a CYP3A4) is 100mg.
 - a) The Antifungal of choice for patients treated with Venetoclax is Posaconazole.
 - b) Posaconazole is used throughout Venetoclax treatment, if compliant.
 - c) All patients are treated with an Antifungal in combination with Venetoclax. In the last 12 months, <5 patient(s) stopped the Antifungal treatment, and the dosage was not altered due to non-compliance.
4. NHS Borders do not routinely test CCA and AML patients for IDH-1 mutation unless the patient is transplant eligible.
 - a) Testing takes place at diagnosis and 1st progression. This is done using NGS panel and not using PCR testing.
 - b) The average turnaround time for these tests is 4 weeks.
5. The NHS Borders Haematologist is responsible for the routine management of patients with CCA and AML.
6. NHS Borders had 33 admissions in the last 12 months for patients with CCA and AML.
 - a) Their average length of stay was 6 days.
 - b) There was a total of 33 admissions across the 11 patients and the main reason for admission was infection.

As the number of events in some areas are very small and in accordance with the Code of Practice for Official Statistics any number that is less than five, actual numbers and potentially identifiable information is withheld to help maintain patient confidentiality due to potential risk of disclosure. Further information is available in the [ISD Statistical Disclosure Control Protocol](#).

If you are not satisfied with the way your request has been handled or the decision given, you may ask NHS Borders to review its actions and the decision. If you would like to request a review please apply in writing to, Freedom of Information Review, NHS Borders, Room 2EC3, Education Centre, Borders General Hospital, Melrose, TD6 9BS or foi.enquiries@borders.scot.nhs.uk.

The request for a review should include your name and address for correspondence, the request for information to which the request relates and the issue which you wish to be reviewed. Please state the reference number **454-22** on this request. Your request should be made within 40 working days from receipt of this letter.

If following this review, you remain dissatisfied with the outcome, you may appeal to the Scottish Information Commissioner and request an investigation of your complaint. Your request to the Scottish Information

Commissioner should be in writing (or other permanent form), stating your name and an address for correspondence. You should provide the details of the request and your reasons for dissatisfaction with both the original response by NHS Borders and your reasons for dissatisfaction with the outcome of the internal review. Your application for an investigation by the Scottish Information Commissioner must be made within six months of your receipt of the response with which you are dissatisfied. The address for the Office of the Scottish Information Commissioner is, Office of the Scottish Information Commissioner, Kinburn Castle, Doubledykes Road, St Andrews, Fife.