

17 January 2025

Our Ref: FOI 395

Dear

**Freedom of Information Act 2000
Information in Relation to Myeloproliferative Diseases**

I am writing to confirm that the South Eastern Health & Social Care Trust (the Trust) has now completed its search for information relating to the above, which you requested on 28 November 2024. Please accept my apologies for the delay in responding to your request. Thank you for your understanding and forbearance.

A response to the questions you have raised has been provided by the Surgery Elective Maternity and Paediatrics Directorate and is attached in Appendix A.

If you are unhappy as to how this request has been handled, you have the right to seek a review within the Trust in the first instance. You should write to the Information Governance Department, Lough House, Ards Community Hospital (informationgovernance@setrust.hscni.net) within two months of the date of this response and your complaint will be considered and a response provided, within 20 working days of receipt.

If, after receiving a response, you remain unhappy, you can refer your complaint to the Information Commissioner at The Information Commissioner's Office –Northern Ireland, 3rd Floor, 14 Cromac Place, Belfast, BT7 2JB. It is important to note that if you refer any matter to the Information Commissioner, you will need to show evidence of having gone through the Trust's internal review procedure to try to resolve the matter with the Trust in the first instance.

If you have any queries about this letter, please do not hesitate to contact me. Please remember to quote the reference number above in any future communications.

Yours sincerely

Keith McCollum
Information Governance Team

Q1. How many patients were treated in total, regardless of diagnosis, with the following medicines in the 3 months between the start of July 2024 and end of September 2024, or latest 3-month period available?

- 1.1 Fedratinib (Inrebic)**
- 1.2 Momelotinib (Omjjara)**
- 1.3 Ruxolitinib (Jakavi)**
- 1.4 Hydroxycarbamide**

Q2. How many patients were treated for the following myeloproliferative diseases in the 3 months between the start of July 2024 and end of September 2024, or latest 3-month period available?

- 2.1 Polycythaemia vera**
- 2.2 Myelofibrosis**
- 2.3 Essential thrombocythemia**
- 2.4 Myeloproliferative Disease, Chronic**

Q3. How many patients with Myelofibrosis (ICD10 codes = C944 or D474; OR morphology codes = 9931/3 or 9961/3) were treated with the following medicines in the 3 months between the start of July 2024 and end of September 2024, or latest 3-month period available?

- 3.1 Fedratinib (Inrebic)**
- 3.2 Momelotinib (Omjjara)**
- 3.3 Ruxolitinib (Jakavi)**
- 3.4 Hydroxycarbamide**
- 3.5 Peginterferon Alfa-2a (Pegasys)**
- 3.6 Roppeginterferon Alfa-2b (Besremi)**
- 3.7 Epoetin alfa (Eprex, Binocrit)**
- 3.8 Epoetin beta (NeoRecormon, Mircera)**
- 3.9 Epoetin zeta (Retacrit)**
- 3.10 Darbepoetin (Aranesp)**

Q4. How many patients with Polycythaemia Vera (ICD10 codes = D45, D450, D45.0, D45X OR morphology code = 9950/3) were treated with the following medicines in the 3 months between the start of July 2024 and end of September 2024, or latest 3-month period available?

- 4.1 Ruxolitinib (Jakavi)**
- 4.2 Hydroxycarbamide**
- 4.3 Peginterferon Alfa-2a (Pegasys)**
- 4.4 Roppeginterferon Alfa-2b (Besremi)**

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- Q5. How many patients were treated with ruxolitinib (Jakavi) in combination with epoetin in the 3 months between the start of July 2024 and end of September 2024, or latest 3-month period available? Please include all types of epoetin – epoetin alfa, epoetin beta, epoetin zeta, darbepoetin alfa**
- Q6. How many patients were treated in total, regardless of diagnosis, with the following medicines in the 3 months between the start of July 2024 and end of September 2024, or latest 3-month period available?**
- 6.1 Acalabrutinib (Calquence)**
 - 6.2 Ibrutinib (Imbruvica)**
 - 6.3 Pirtobrutinib (Jaypirca)**
 - 6.4 Venetoclax (Venclyxto)**
 - 6.5 Zanubrutinib (Brukinsa)**
- Q7. How many patients with Chronic Lymphocytic Leukaemia OR Small B-Cell Lymphoma – ICD10 codes = C911, C91.1 OR C830, C83.0 - were treated with the following medicines in the 3 months between the start of July 2024 and end of September 2024, or latest 3-month period available?**
- 7.1 Acalabrutinib (Calquence)**
 - 7.2 Ibrutinib (Imbruvica)**
 - 7.3 Pirtobrutinib (Jaypirca)**
 - 7.4 Venetoclax (Venclyxto)**
 - 7.5 Zanubrutinib (Brukinsa)**
 - 7.6 Obinutuzumab (Gazyvaro)**
 - 7.7 Rituximab**
 - 7.8 Bendamustine**
 - 7.9 Chlorambucil**
 - 7.10 Fludarabine**
 - 7.11 Idelalisib**
- Q8. How many patients with Chronic Lymphocytic Leukaemia OR Small B-Cell Lymphoma were treated with the following medicines as monotherapy, or in combination, in the 3 months between the start of July 2024 and end of September 2024, or latest 3-month period available?**
- 8.1 Ibrutinib + venetoclax**
 - 8.2 Obinutuzumab + venetoclax**
 - 8.3 Zanubrutinib monotherapy / maintenance**
 - 8.4 Ibrutinib monotherapy / maintenance**
 - 8.5 Venetoclax monotherapy**
 - 8.6 Venetoclax + rituximab**
 - 8.7 Acalabrutinib + obinutuzumab**

A1–8. The information that you have requested is not centrally held in a way which is easily extracted. To obtain this information would require a manual review of records.

This would exceed the 'Appropriate Limit' as defined by the Freedom of Information Act 2000. The Trust therefore exempts the release of this information under Section 12(1).

12.-(1) Section 1(1) does not oblige a public authority to comply with a request for information if the authority estimates that the cost of complying with the request would exceed the appropriate limit.

In accordance with the Freedom of Information Act 2000 this statement acts as a Refusal Notice.