University Hospitals of North Midlands NHS Trust

Royal Stoke University Hospital
Quality, Safety and Compliance Department
Newcastle Road
Stoke-on-Trent
Staffordshire
ST4 6QG

Email foi@uhnm.nhs.uk

Ref: FOIA Reference 2019/20-141

Date: 4th July 2019

Dear

I am writing in response to your email dated 12th June 2019 requesting information under the Freedom of Information Act (2000) regarding MM and other Cancers.

I can neither confirm nor deny whether some of the information you have requested is held by the Trust in its entirety. This is because the information requested in question 3 is not held centrally, but may be recorded in individual health records. In order to confirm whether this information is held we would therefore have to individually access all health records within the Trust and extract the information where it is present. We therefore estimate that complying with your request is exempt under section 12 of the FOI Act: *cost of compliance is excessive*. The section 12 exemption applies when it is estimated a request will take in excess of 18 hours to complete. We estimate that accessing and reviewing all health records and then extracting relevant information would take longer than the 18 hours allowed for.

In addition to the section 12 exemption the Trust is also applying section 14 (1) exemption: *oppressive burden on the authority.*

Under section 16 of the FOI Act we are required to provide requestors with advice and assistance where possible. We would therefore like to advise you that your request is shortened to just questions the we are able to comply within the 18 hour time frame. In order to avoid delay to your response we have provided this below.

As of 1st November 2014 University Hospitals of North Midlands NHS Trust (UHNM) manages two hospital sites – Royal Stoke University Hospital, and County Hospital (Stafford). Therefore the response below is for the two sites combined from that date where appropriate.

Q1 **I am writing to you today to request the following information regarding Cancer Treatments at your organisation.**

Does your Trust treat adult multiple myeloma [MM]? - If you refer your multiple myeloma patients to another centre, please state which.

A1 UHNM does treat myeloma patients at both Hospital sites. Numbers quoted for question 2 contain both patients on standard treatment and within clinical trials.

Q2 **If yes, then how many MM patients, have been treated in the past 6 months with the following;**

- **Bortezomib [Velcade]**

- **Carfilzomib [Kyprolis]**
- **Ixazomib [Ninlaro]**
- **Lenalidomide [Revlimid]**
- **Daratumumab [Darzalex]**
- **Melphalan, prednisolone and thalidomide (known as MPT)**
- **Cyclophosphamide, thalidomide and dexamethasone (known as CTD)**
- **Pomalidomide [Imnovid]**

A2 Please see below: please note figures contain both patients on standard treatment and within clinical trials;

Bortezomib [Velcade]	69
Carfilzomib [Kyprolis]	0
Ixazomib [Ninlaro]	15
Lenalidomide [Revlimid]	64
Daratumumab [Darzalex]	23
Melphalan, prednisolone and thalidomide (known as MPT)	0
Cyclophosphamide, thalidomide and dexamethasone (known as CTD)	14
Pomalidomide [Imnovid]	13

Q3 If you are able to split by therapy line for question 2, please indicate the number of patients above being treated, 1st line and 2nd line.

A3 Sections 12 and 14 exemptions as detailed above:

Q4 Does your Trust treat adult/paediatric primary immune thrombocytopenia patients [ITP]? - If you refer your adult/paediatric primary immune thrombocytopenia patients to another centre, please state which.

A4 Both adult and paediatric ITP patients are being treated at UHNM.

Q5 If yes, then of the treated adult/paediatric primary immune thrombocytopenia patients, how many are on the following;

- **Eltrombopag [Revolade]**
- **Romiplostim [Nplate]**

A5 Please see below:

- Eltrombopag [Revolade] = 11
- Romiplostim [Nplate] = 12

Q6 At what line of treatment would you currently use a Thrombopoietin Receptor Agonist [TPO] (Eltrombopag [Revolade], Romiplostim [Nplate]) in an immune thrombocytopenia purpura [ITP] patient?

- **1st**
- **2nd**
- **3rd**
- **4th**
- **Unknown**

A6 In general they are mostly used at 2nd or 3rd line; this is depending on the prescriber.

Q7 Do you treat patients with a Thrombopoietin Receptor Agonist TPO for the following diseases?

7a. Chronic hepatitis C virus (HCV) infection for the treatment of thrombocytopenia, where the degree of thrombocytopenia is the main factor preventing the initiation or limiting the ability to maintain optimal interferon-based therapy

- **Eltrombopag [Revolade]**
- **Romiplostim [Nplate]**

7b.Acquired severe aplastic anaemia (SAA) who were either refractory to prior immunosuppressive therapy or heavily pre-treated and are unsuitable for haematopoietic stem cell transplantation

- **Eltrombopag [Revolade]**
- **Romiplostim [Nplate]**

7c. Chemotherapy induced thrombocytopenia (CIT)

- **Eltrombopag [Revolade]**
- **Romiplostim [Nplate]**

- **7d myelodysplastic syndromes (MDS)**
- **Eltrombopag [Revolade]**
- **Romiplostim [Nplate]**

A7 These drugs are not used in any of the indications listed in Q7,they are only used for Immune thrombocytopenia (ITP).

Q8 Over the past 6 months [latest possible], how many chronic lymphocytic leukaemia (CLL) patients have you treated?

A8 In the past 6 months there has been forty five (45) chronic lymphocytic leukaemia (CLL) patients treated.

Q9 If possible how many CLL patients treated were new to therapy in the past 3 months?

A9 We are unable to provide the information you require in the requested format as to release this data could lead to the identification of the person(s) involved due to the low numbers involved, and would breach the Trusts obligations under Data Protection Act 2018. Accordingly, this aspect of your request is exempt from disclosure under the terms of Section 40(2) of the FOI Act. Personal information. However as the Trust is committed to openness and transparency we can band the numbers as being less than five.

Q10 How many chronic lymphocytic leukaemia patients, have been treated in the past 6 months with the following;

- **Fludarabine (Fludara), cyclophosphamide (Cytoxan), and rituximab (known as FCR)**
- **Bendamustine and rituximab (known as BR)**
- **Ibrutinib [Imbruvica]**
- **Chlorambucil**
- **Venetoclax**

- **Obinutuzumab**
- **Idelalisib**
- **Fludarabine and rituximab (known as FR)**
- **High-dose prednisone and rituximab**
- **Pentostatin (Nipent), cyclophosphamide, and rituximab (known as PCR)**
- **Alemtuzumab (Campath) with rituximab**

A10 We are unable to provide the information you require in the requested format as to release this data could lead to the identification of the person(s) involved due to the low numbers involved, and would breach the Trusts obligations under Data Protection Act 2018. Accordingly, this aspect of your request is exempt from disclosure under the terms of Section 40(2) of the FOI Act. Personal information. However as the Trust is committed to openness and transparency we can band the numbers, please see below:

Fludarabine (Fludara), cyclophosphamide (Cytoxan), and rituximab (known as FCR)	0
Bendamustine and rituximab (known as BR)	Less than 5
Ibrutinib [Imbruvica]	23
Chlorambucil	Less than 5
Venetoclax	8
Obinutuzumab	0
Idelalisib	Less than 5
Fludarabine and rituximab (known as FR)	0
High-dose prednisone and rituximab	0
Pentostatin (Nipent), cyclophosphamide, and rituximab (known as PCR)	0
Alemtuzumab (Campath) with rituximab	0

*Please note that any individuals identified do not give consent for their personal data to be processed for the purposes of direct marketing.

UHNM NHS Trust is a public sector body and governed by EU law. FOI requestors should note that any new Trust requirements over the EU threshold will be subject to these regulations and will be advertised for open competition accordingly.

An anonymised copy of this request can be found on the Trust's disclosure log, please note that all requests can be found at the following link: http://www.uhnm.nhs.uk/aboutus/Statutory-Policies-and-Procedures/Pages/Freedom-of-Information-Disclosure-Log.aspx

This letter confirms the completion of this request. A log of this request and a copy of this letter will be held by the Trust.

If you have any queries related to the response provided please in the first instance contact my office.

University Hospitals of North Midlands NHS Trust

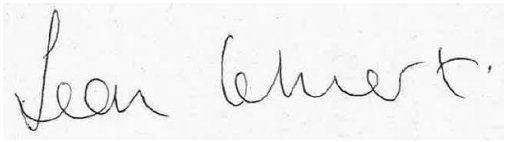
Should you have a complaint about the response or the handling of your request, please also contact my office to request a review of this. If having exhausted the Trust's FOIA complaints process you are still not satisfied, you are entitled to approach the Information Commissioner's Office (ICO) and request an assessment of the manner in which the Trust has managed your request.

The Information Commissioner may be contacted at:

Information Commissioner's Office, Wycliffe House, Water Lane, Wilmslow, Cheshire SK9 5AF or via www.ico.org.uk.

If following review of the responses I can be of any further assistance please contact my secretary on 01782 676474.

Yours,



Jean Lehnert
Information Governance Manager