

**Reference Number:** FOI202223/360  
**From:** Commercial  
**Date:** 13 October 2022  
**Subject:** Use of defibrotide for the treatment of Hepatic Veno-occlusive Disease

- Q1 Please provide the number of patients with a diagnosis of Hepatic Veno Occlusive Disease (ICD-10 K765) and their age at the time of treatment in the following time periods
- Q2 How many Blueteq application forms were submitted (for reimbursement) for the use of defibrotide for the treatment of severe veno-occlusive disease (VOD) after stem cell transplant in the specified time periods below?
- Q3 Number of patients diagnosed with VOD split by age and by transplant type in the following time periods

A1-3 [Please see attached spreadsheet – FOI202223 360 Response](#)

The Trust is unable to respond to all or specific elements of your request where the response would indicate five or less individuals. The Trust is withholding this information under Section 40 (Personal Information) of the Freedom of Information Act (FOIA) 2000 to reduce the risk of any individuals being identified. The Trust is of the view that disclosure of such information would significantly increase the risk of individuals being identified and as such would constitute a breach of their personal data.

The Trust has applied exemption Section 40(2) of the FOIA and is therefore withholding the information as disclosure which may identify an individual would breach their rights under the Data Protection Act 2018. The grounds for application of this exemption include:

- Any data relating to patients or staff is third party data, furthermore health data is classified as sensitive personal data within the Data Protection Act 2018. As such, Section 40 (2) of the FOIA applies along with the Trusts duty of confidentiality. Therefore under s.2 (3) (f) (ii) of the FOIA, there is an absolute exemption from disclosure on the grounds that it would contravene the First Data Protection Principle.
- The Trust has a duty under the Data Protection Act 2018 and specifically the First Data Protection Principle to ensure personal data regarding staff and patients is processed fairly and lawfully. Disclosure of such data which may identify an individual, either through the data alone or other data in conjunction with that data which may identify an individual would therefore breach this principle.
- The Data Protection Act 2018 defines sensitive personal data to include data relating to the “physical or mental health or condition” of a person. Any such information about specific individuals falls within this category and disclosure of such data including statistical data, with any potential likelihood of identification would breach the Data Protection Act 2018.

Trust Name : Alder Hey Childrens Hospital

Please complete the following tables:

			NHS Year 2021-22											
			Apr-21	May-21	Jun-21	Jul-21	Aug-21	Sep-21	Oct-21	Nov-21	Dec-21	Jan-22	Feb-22	Mar-22
Question1	Number of patients with a diagnosis of Hepatic Venous Occlusive Disease (ICD-10 K765) and their age at the time of treatment in the following time periods	Adult (aged 18+)	Information not held - Alder Hey Children's NHS Foundation Trust is a specialist children's hospital and does not routinely treat adults											
		Child (aged 17 or under)	Information exempt under Section 40 - Personal Information											

			NHS Year 2021-22											
			Apr-21	May-21	Jun-21	Jul-21	Aug-21	Sep-21	Oct-21	Nov-21	Dec-21	Jan-22	Feb-22	Mar-22
Question 2	<i>How many Blueteq application forms were submitted (for reimbursement) for the use of defibrotide for the treatment of severe veno-occlusive disease (VOD) after stem cell transplant in the specified time periods below?</i>													
	Blueteq applications submitted for the use of defibrotide for the treatment of Hepatic Venous Occlusive Disease (VOD) after stem cell transplant	Adult (aged 18+)	Information not held - Alder Hey Children's NHS Foundation Trust is a specialist children's hospital and does not routinely treat adults											
		Child (aged 17 or under)	0	0	0	0	0	0	0	0	0	0	0	0

				NHS Year 2021-22											
				Apr-21	May-21	Jun-21	Jul-21	Aug-21	Sep-21	Oct-21	Nov-21	Dec-21	Jan-22	Feb-22	Mar-22
Question 3	Number of patients diagnosed with VOD split by age and by transplant type in the following time periods	Adult (aged 18+)	Autologous	Information not held - Alder Hey Children's NHS Foundation Trust is a specialist children's hospital and does not routinely treat adults											
		Adult (aged 18+)	Allogeneic												
		Child (aged 17 or under)	Autologous												
		Child (aged 17 or under)	Allogeneic	Information exempt under Section 40 - Personal Information											