

Freedom of Information Request**Ref: UHB 17-392**

Date 15 August 2017



Thank you for your request for information under the Freedom of Information Act 2000. The Trusts response is as follows:

- 1. Please provide information on the total number of unplanned admissions to your Trust for patients with the following conditions broken down by hospital (where appropriate) and by calendar year since 2011 including data for 2017 to date. If you hold data by financial year then that is acceptable also:**
 - a. Neuromuscular conditions**
 - b. Muscular dystrophies**
 - c. Duchenne muscular dystrophy**

We do not hold this information as our clinical coding system does not currently record this data in this way.

- 2. Please provide a breakdown of the reasons for the unplanned admissions e.g. Accident, breathing problems, etc. – this should be broken down by the relevant data sets that you hold, broken down by hospital (where appropriate) and by calendar year since 2011 including data for 2017 to date. If you hold data by financial year then that is acceptable also.**

This information is not currently held in a format which we can easily obtain and quantify. To obtain this information would require a manual trawl through the notes of each admission which would significantly exceed the 18 hours limit set down by the FOI as the reasonable limit. Section 12 of the FOIA provides that we are not obliged to spend in excess of 18 hours in any sixty day period locating, retrieving and identifying information in order to deal with a request for information and therefore we are withholding this information at this time

3. Please provide the following outcomes broken down by the same hospitals (as appropriate), calendar (or financial) years for each condition as detailed above:

a. Discharged from A&E

We do not hold this information as our clinical coding system does not currently record this data in this way

b. Admitted to hospital and subsequently discharged

There were 52 patients with neuromuscular conditions admitted to an inpatient setting. Please see breakdown by site and year in the table below:

Please note we are unable to provide a greater level of detail than neuromuscular conditions as our coding system does not record this information.

Year	Bristol Royal Hospital for Children	Bristol Royal Infirmary
2012	**	0
2013	5	**
2014	9	5
2015	**	5
2016	8	**
2017 (Q1)	**	**

Where the figures are less than 5, this has been denoted by **. Where numbers are low we have considered that there is the potential for the individuals to be identified from the information provided, when considered with other information that may also be in the public domain. In our view disclosure of these low figures would breach one of the Data Protection Principles set out in Schedule 1 of the Data Protection Act, namely Principle 1. There therefore find that the Section 40(2) exemption contained within the Freedom of information Act 2000 is engaged. Section 40 is the exemption for personal information

c. Died

We do not hold this information as our clinical coding system does not currently record this data in this way. However, we are able to confirm that out of the 52 patients admitted, two passed away while admitted.

- 4. Please provide a breakdown of unexpected deaths of patients in your Trust broken down by the above conditions and by the same hospitals (as appropriate), and by calendar (or financial) years.**

The Trust does not hold the data in a format that would enable us to fully respond to your request to the level of detail required and a manual trawl for this information would significantly exceed the 18 hours limit set down by the FOI as the reasonable limit. Section 12 of the FOIA provides that we are not obliged to spend in excess of 18 hours in any sixty day period locating, retrieving and identifying information in order to deal with a request for information and therefore we are withholding this information at this time

- 5. Please provide details of any changes that your Trust has made to care and other policies as a result of unexpected deaths of patients with the referenced conditions in the time period stated.**

The Trust does not hold the data in a format that would enable us to fully respond to your request to the level of detail required and a manual trawl for this information would significantly exceed the 18 hours limit set down by the FOI as the reasonable limit. Section 12 of the FOIA provides that we are not obliged to spend in excess of 18 hours in any sixty day period locating, retrieving and identifying information in order to deal with a request for information and therefore we are withholding this information at this time

- 6. Please provide a copy of the protocols to be followed by all paramedic, ambulance and A&E staff dealing with an unplanned admission of a patient with one of the specified conditions.**

We do not hold any information on the ambulance service as we are an Acute Trust therefore we are unable to answer at this time. If you require further information, please redirect this question as an FOI to Information.Governance@swast.nhs.uk.

- 7. Please provide details of adaptations provided by hospitals in your trust for persons with neuromuscular (and other) conditions who may not be ambulant, or who may be unable to lift items such as cutlery, press buttons etc. For example, provision of hoists, wash/dry toilets, adapted call buttons; intercom systems; modified cutlery; provision of staff to feed a patient who is unable to do so him or herself due to muscle wasting.**

Any patient who is not ambulant regardless of the underlying condition which cause the loss of full independent function, has a complete holistic assessment, that is contributed to by the full multi professional team. This includes a full of review of how each patient manages their daily activities of living prior to their hospital stay in addition to an assessment of any changes in their functional abilities.

Full adjustments are then made to support the patient. In specific response to the query:

- Every bed space has nurse call bells, if a patient is unable to use these, due to functioning, a discussion is held on how they call for help.
- There are a number of bed spaces in the organisation that overhead bed hoisting, in addition, to each clinical area has access to a t least mobile hoist and a range of further hoists are available to suit patient's needs.
- Further, all clinical areas have a full disabled bathroom with many having en suites with this arrangement.
- In relation to provision of cutlery, every patient is assessed as to their ability to eat independently and support given for those who are not fully independent, this can include adapted cutlery but also nursing staff and trained volunteers to support the patient eat.
- Seating and beds are also selected based on a patient's needs, to support them as required.

8. Please provide details of the procedures hospitals in your trust follow if a physiotherapist is required at night for persons who have a neuromuscular condition, especially if physiotherapists are not normally on duty in the night.

We do not provide an out-of-hours physiotherapy service for patients with neuromuscular conditions. We do provide an out-of-hours on-call respiratory physiotherapy service covering the main BRI site for in-patients – 24/7. This service is for patients experiencing an acute respiratory event and is provided to prevent further deterioration/ optimise patient's ventilation and airway clearance abilities. This is for all in-patients which may include patients with a neuromuscular condition but it is not specifically for any particular disease or condition.

This concludes our response. We trust that you find this helpful, but please do not hesitate to contact us directly if we can be of any further assistance.

If, after that, you are dissatisfied with the handling of your request, you have the right to ask for an internal review. Internal review requests should be submitted within two months of the date of receipt of the response to your original letter and should be addressed to:

Trust Secretary
University Hospitals Bristol NHS Foundation Trust
Trust Headquarters
Marlborough Street
Bristol
BS1 3NU

Please remember to quote the reference number above in any future communications.

If you are not content with the outcome of the internal review, you have the right to apply directly to the Information Commissioner for a decision. The Information Commissioner can be contacted at: Information Commissioner's Office, Wycliffe House, Water Lane, Wilmslow, Cheshire, SK9 5AF

To view the Freedom of Information Act in full please click [here](#).

Yours sincerely,

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