

Date: 26/07/2017

FREEDOM OF INFORMATION REQUEST FOI/013545 - Muscular dystrophy

In this request I will make reference to neuromuscular conditions, muscular dystrophy, and Duchene muscular dystrophy.

For the purposes of this request:

- Neuromuscular conditions refer to any such conditions, including all types of Muscular dystrophy;
- Muscular dystrophy refers to all such conditions including Duchenne muscular dystrophy; and
- Duchenne muscular dystrophy refers only to that specific condition

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 are not able to split the data by the above conditions – the ICD10 code used is G71.0. The date range used is 01/04/2012 to 30/06/2017

Non-elective admissions with ICD10 G71.0 by financial year

	2012/13	2013/14	2014/15	2015/16	2016/17	2017/18	Grand Total
Total	15	11	11	12	10	4	63

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.

The reason for the admission is not recorded against the admission.

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
- b. Admitted to hospital and subsequently discharged
- c. Died

If the patient was discharged from A&E they wouldn't have been recorded as an admission

Discharge_Method	2012/13	2013/14	2014/15	2015/16	2016/17	2017/18	Grand Total
Clinical Discharge	15	10	11	10	9	4	59
Self Discharge					1		1
Died		1		2			3
Grand Total	15	11	11	12	10	4	63

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.

As per the answer to Q1, we cannot split the data by the conditions

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.

There have been no changes that the Trust has made to care and other policies as a result of unexpected deaths of patients with the referenced conditions.

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.

There are no protocols specific to these conditions.

For information on Paramedics and Ambulance staff please contact the service direct

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.

With regard to cutlery a patient with neuromuscular, they would be assessed by therapy staff and adapted cutlery required would be provided.

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.

There is a physiotherapy service on call every night from 4 pm to 8 am for patients with acute respiratory conditions.

If a patient with a neuromuscular condition also has an acute respiratory condition and they meet the criteria for the service then a request for the physiotherapist to attend can be made. This is the only reason that a physiotherapist would attend overnight