

Freedom of Information request 335-17

Request

Please provide the following information which I outline below. If you do not hold the information please advise if it is held elsewhere. If only partial information is held then please provide that.

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

Clarification:

The specific condition I am looking at is Duchenne 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 Health Board 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

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.

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

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

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

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.

7. Please provide details of adaptations provided by hospitals in your Health Board 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.

8. Please provide details of the procedures hospitals in your Health Board 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.

Response

Please note there are no patients diagnosed with Duchenne Muscular Dystrophy within the NHS Borders area.

1-3 Please find below the data as per request for questions 1-3:

Emergency Inpatients Discharged with a Diagnosis Of Primary Disorders Of Muscles: Calendar Years 2011 to 2016 and 2017 to date

Diagnosis Code	Diagnosis Description	Emergency Discharge						
		2011	2012	2013	2014	2015	2016	2017
G710	Muscular Dystrophy	<5	5	<5	<5	5	<5	<5
G711	Myotonic Disorders	<5	<5		<5	8	<5	<5
G713	Mitochondrial Myopathy, Not Elsewhere Classified		<5					
Total		6	9	<5	7	13	<5	<5

Patient Died

2011	2012	2013	2014	2015	2016	2017
	<5					
0	<5*	0	0	0	0	0

*Please Note: The cause of death was not the main diagnosis

Notes:

Diagnosis Code G71 used to extract the data in any position

All BGH episodes of care.

Source: SMR1

ED Attendances	2011	2012	2013	2015	2016	2017
Main Diagnosis						
G718 Other Primary Disorders Of Muscles					<5	
G719 Primary Disorder Of Muscle, Unspecified	<5	<5	<5	<5	<5	
Total	<5	<5	<5	<5	<5	0
Presenting Complaint						
It leg injury	<5					
Other primary disorders of muscles					<5	
Primary disorder of muscle		<5				
Primary disorder of muscle unspecified			<5	<5	<5	
Total	<5	<5	<5	<5	<5	0
Outcome						
Discharged from ED	<5	<5	<5	<5	<5	
Admitted to Hospital and then Discharged		<5		<5		
Total	<5	<5	<5	<5	<5	0

Notes:

Diagnosis Code G71 used to extract the data, only the main diagnosis is recorded in the ED stats.

Source: A&E2

4. We do not record whether these were unexpected deaths, therefore under Section 17 of the FOI(S)A 2002 this data is not held.
5. Not applicable.
6. NHS Borders do not hold specific 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. Therefore under Section 17 of the FOI(S)A 2002 this data is not held.
7. The nursing staff and relevant AHPs assess the patient on ward and it is noted what, if any aids, are required to assist with eg moving/handling and/or to promote independence. It is the aim that required equipment will be provided and in some instances where it has not been available, NHS Borders have arranged an equipment hire.
8. Please see attached service guidance. Physiotherapy service would respond to person with neuromuscular condition if requires respiratory intervention to prevent deterioration out with working hours.



Physio On-Call
Service.pdf

If you are not satisfied with the way your request has been handled or the decision given, you may ask NHS Borders to review its actions and the decision. If you would like to request a review please apply in writing to, Freedom of Information Review, NHS Borders, Room 2EC3, Education Centre, Borders General Hospital, Melrose, TD6 9BS or foi.enquiries@borders.scot.nhs.uk.

The request for a review should include your name and address for correspondence, the request for information to which the request relates and the issue which you wish to be reviewed. Please state the reference number **335-17** on this request. Your request should be made within 40 working days from receipt of this letter.

If following this review, you remain dissatisfied with the outcome, you may appeal to the Scottish Information Commissioner and request an investigation of your complaint. Your request to the Scottish Information Commissioner should be in writing (or other permanent form), stating your name and an address for correspondence. You should provide the details of the request and your reasons for dissatisfaction with both the original response by NHS Borders and your reasons for dissatisfaction with the outcome of the internal review. Your application for an investigation by the Scottish Information Commissioner must be made within six months of your receipt of the response with which you are dissatisfied. The address for the Office of the Scottish Information Commissioner is, Office of the Scottish Information Commissioner, Kinburn Castle, Doubledykes Road, St Andrews, Fife.