

24 December 2024

## **Combined Diastematomyelia & Hemivertebra and Spina Bifida**

- 1. Patients diagnosed both in the UK and Northern Ireland with Combined Diastematomyelia and Hemivertebra since 1970.**

The Trust's database goes back 32 years to 1992. The information held on that database is not recorded in a way that would allow us to respond to this question.

Note: We are not able to provide information on behalf of the UK.

- 2. What surgeries and treatment these patients received in the UK and Northern Ireland and what were the surgical outcomes.**

Unable to provide this information for the reasons outlined at Question 1

- 3. Of these patients how many had a leg length discrepancy and how was this surgically treated?**

Unable to provide this information for the reasons outlined at Question 1.

- 4. A full history of leg lengthening surgery in the UK and Northern Ireland between 1980 and 2023. I would like dates of the first surgery for leg lengthening in both the UK and Northern Ireland, surgical methods, the surgical outcomes, the conditions treated with the surgery, how many surgeries were carried out in this time period. I would also like to know the ages of the patients.**

Note: We are not able to provide information on behalf of the UK.

***I would like dates of the first surgery for leg lengthening in both the UK and Northern Ireland,***

The first surgery recorded is March 1993.

We cannot give the exact date, as this has the potential to make patients personally identifiable. The date is therefore exempt under Section 40(2) of the Freedom of Information Act, which relates to personal information relating to a third party. Disclosure would constitute a breach of the principles of the General Data Protection Regulation 2018.

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***Surgical methods***

We are unable to provide surgical methods, as this would require a manual chart review, which would take in excess of 18 hours.

We estimate that compliance with this request for information would exceed the appropriate costs limit. Under Section 12 of the Freedom of Information Act 2000, the limit has been specified as £450 and represents the estimated cost of one or more persons spending 18 hours in determining whether we hold the information, locating, retrieving and extracting this information.

***Surgical outcomes***

We are unable to provide surgical outcomes, as this would require a manual chart review, which would take in excess of 18 hours.

Again, we estimate that compliance with this request for information would exceed the appropriate costs limit under Section 12 of the Freedom of Information Act 2000.

***Conditions treated with the surgery***

Limb length discrepancy  
Limb length deformity / recurvatum deformity  
Left DDH / Leg length discrepancy  
Limb length to be altered  
Limb length inequality due to old perthes disease  
Limb length inequality due to osteomyelitis  
Limb length inequality  
Limb length required  
Limb length inequality following basal fracture right proximal femur  
Limb length deformity

***How many surgeries were carried out in this time period?***

From 1992 onwards, a total of 72 surgeries were carried out.

***Ages of the patients***

From 1992 onwards, the surgeries carried out covered an age range of six to 63.

**5. The number of cases in the UK and Northern Ireland, which included both epiphysiodesis and leg lengthening surgery from 1980 to 2024.**

A total of 25 surgeries were carried out from 1992 to date.

Note: We are not able to provide information on behalf of the UK.

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**6. Full history and dates of vertebrae resection surgery in the UK and Northern Ireland for patients with hemi vertebrae between the dates of 1980 and 1990.**

Belfast Trust is unable to provide this information for the following reasons:

- The Trust's database only goes back to 1992 (32 years).
- Historical records are not fully completed or in line with today's data standards.
- Diagnosis often sits within a free text field. Historical records are not as complete.
- Primary conditions recorded are not necessarily the genetic condition of the patient.

**7. Full history of treatment and surgeries, the number of patient surgeries for UK and northern patients who had spina bifida between 1970 and 2024**

A total of 259 surgeries were carried out from 1992 to date.

We are unable to provide a full history of treatment as this would require a manual chart review, which would take in excess of 18 hours.

We estimate that compliance with this request for information would exceed the appropriate costs limit under Section 12 of the Freedom of Information Act 2000.