

Freedom of Information Act 2000 - Request Reference Fol/22/427

Surgery

Information Requested:

1. How many patients with any Ehlers Danlos Syndrome variant have any of your spinal or neurosurgeons operated on in the last five years?
2. How many of your neuro surgeons and how many of your spinal surgeons have operated on any patient with any Ehlers Danlos Syndrome variant in the last five years?
3. How many patients had cervical stabilisation surgeries has the health board performed in the last five years? How many of these were for patients with craniocervical and for patients with atlantoaxial instability (or both)? How many of these patients had any Ehlers Danlos Syndrome variant? Did any of the patients also have a documented PMP 22 deletion?

Response details:

Period: 01/04/2017 to 31/03/2022	
Number of Distinct Patients Ehlers Danlos Syndrome having a Procedure under Neurosurgery or Spinal	9
Cervical Stabilisation Surgeries (All Specialties)	625
Cervical Stabilisation Surgery + *	1
Ehlers Danlos Syndrome having Cervical Stabilisation Surgery	0

* **Please note:** patients who had Cervical Stabilisation Surgeries and were treated for Craniocervical or Atalntoxial Instability (or both) are coded the same.