

Freedom of Information Act 2000 – Request Reference FoI/24/185
Ehlers Danlos Syndrome

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 trust 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:

The below information reflects the period 1 January 2019 to 1 April 2024.

1. 11 patients (determined by ICD code Q796).
2. Nine spinal orthopaedic consultants.
3. 428 surgeries (cervical stabilisation surgery determined by OPC codes V402, V221, or V294). None of these patients underwent cervical stabilisation with Ehlers-Danlos syndrome, or underwent cranio-cervical stabilisation (i.e. V402, V221, or V294 in conjunction with diagnosis code M5321).