

**Freedom of Information Act 2000 - Request Reference FoI/22/501**

**C3 Glomerulopathy**

**Information Requested:**

1. How many adult patients (aged 18 or over) are currently under the care of your Trust/Service with C3 Glomerulopathy?
2. How many paediatric patients (aged 18 or under) are currently under the care of your Trust/Service with C3 Glomerulopathy?
3. How many patients are currently under the care of your Trust/Service whose C3 Glomerulopathy has recurred following a kidney transplantation?
4. How many of the total patients currently under the care of your Trust/Service with C3 Glomerulopathy have had a biopsy confirmation of disease?
5. In the last 3 years, how many of the total patients currently under the care of your Trust/Service with C3 Glomerulopathy have been diagnosed with support from another Trust/service/pathologist for biopsy interpretation, but otherwise not been referred for their care?
6. In the last 3 years, how many of the total patients with C3 Glomerulopathy have been referred from your Trust/Service to another Trust or Service and therefore are no longer within your care?
7. How many of the total patients currently under the care of your Trust/Service with C3 Glomerulopathy have proteinuria of >1g/day despite use of an ACE inhibitor or ARB?
8. How many of the total patients currently under the care of your Trust/Service with C3 Glomerulopathy have eGFR =30 mL/min/1.73 m<sup>2</sup>?
9. How many of the total patients currently under the care of your Trust/Service with C3 Glomerulopathy have been entered into The National Registry of Rare Kidney Diseases (RaDaR)?

**Response details:**

In completing a search for the information requested, Cardiff and Vale University Health Board (the UHB) has confirmed that this information is not centrally recorded or collated. To retrieve the information requested would require a manual search through individual records and the UHB considers that this would exceed the limit set within regulations for responding to a request. The UHB has therefore relied upon the Section 12 exemption ('Exemption where cost of compliance exceeds appropriate limit') of the Freedom of Information Act 2000 and is refusing your request.

The UHB has estimated that to complete the work needed to respond to this request would exceed the time limit as set within regulations to respond to a Freedom of Information Act request. Under the Act there is an allowance of two and a half days, or 18 hours, to comply with a request and the cost limit set

within the fees' regulations for this amount of work (18 hours) is £450 for the UHB. The fees regulations specify that the cost of complying with a request must be calculated at the rate of £25 per hour.