



GIG
CYMRU
NHS
WALES

Bwrdd Iechyd Prifysgol
Bae Abertawe
Swansea Bay University
Health Board

Cadeirydd/Chair: **Emma Woollett**
Prif Weithredwr/Chief Executive: **Mark Hackett**

gofalu am ein gilydd, cydweithio, gwella bob amser
caring for each other, working together, always improving

Rydym yn croesawu gohebiaeth yn y Gymraeg neu'r Saesneg. Atebir gohebiaeth Gymraeg yn y Gymraeg, ac ni fydd hyn yn arwain at oedi.
We welcome correspondence in Welsh or English. Welsh language correspondence will be replied to in Welsh, and this will not lead to a delay.

Cais Rhyddid Gwybodaeth / Freedom of Information request **Ein Cyf / Our Ref: 22-I-013**

You asked:

Question	Response
I. How many adult patients (aged 18 or over) are currently under the care of your Trust/Service with C3 Glomerulopathy?	6 patients
II. How many paediatric patients (aged 18 or under) are currently under the care of your Trust/Service with C3 Glomerulopathy?	Nil
III. How many patients are currently under the care of your Trust/Service whose C3 Glomerulopathy has recurred following a kidney transplantation?	This information is not held centrally, therefore to obtain this information would involve a manual trawl and search of records which we have estimated would significantly exceed the 18 hours limit set down by the FOI Act as the reasonable limit. This is due to us needing to source multiple sets of patient notes from multiple health boards, reading through those notes to extract this information, checking GP records and also liaising with the renal registry. Section 12 of the FOI Act and The Freedom of Information and Data Protection (Appropriate Limit and Fees) Regulation 2004 provides that we are not obliged to spend in excess of 18 hours in



Pencadlys BIP Bae Abertawe, Un Porthfa Talbot, Port Talbot, SA12 7BR / Swansea Bay UHB Headquarters, One Talbot Gateway, Port Talbot, SA12 7BR

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Swansea Bay University Health Board is the operational name of Swansea Bay University Local Health Board

	any sixty day period locating, retrieving and identifying information in order to deal with a request for information and therefore we are withholding this information at this time.
IV. How many of the total patients currently under the care of your Trust/Service with C3 Glomerulopathy have had a biopsy confirmation of disease?	6 patients
V. 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?	This information is not held centrally, therefore to obtain this information would involve a manual trawl and search of records which we have estimated would significantly exceed the 18 hours limit set down by the FOI Act as the reasonable limit. This is due to us needing to source multiple sets of patient notes from multiple health boards, reading through those notes to extract this information, checking GP records and also liaising with the renal registry. Section 12 of the FOI Act and The Freedom of Information and Data Protection (Appropriate Limit and Fees) Regulation 2004 provides that we are not obliged to spend in excess of 18 hours in any sixty day period locating, retrieving and identifying information in order to deal with a request for information and therefore we are withholding this information at this time.
VI. 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?	Less than 5 patients, we are unable to provide you with the exact number of patients as due to the low numbers, there is a potential risk of identifying individuals if this was disclosed. We are therefore withholding this detail under Section 40(2) of the Freedom of Information Act 2000. This information is protected by the General Data Protection Regulation (GDPR) and



	<p>Data Protection Act 2018 and its disclosure would be contrary to the data protection principles and constitute as unfair and unlawful processing in regard to Articles 5, 6, and 9 of GDPR. This exemption is absolute and therefore there is no requirement to apply the public interest test.</p>
<p>VII. 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?</p>	<p>This information is not held centrally, therefore to obtain this information would involve a manual trawl and search of records which we have estimated would significantly exceed the 18 hours limit set down by the FOI Act as the reasonable limit. This is due to us needing to source multiple sets of patient notes from multiple health boards, reading through those notes to extract this information, checking GP records and also liaising with the renal registry. Section 12 of the FOI Act and The Freedom of Information and Data Protection (Appropriate Limit and Fees) Regulation 2004 provides that we are not obliged to spend in excess of 18 hours in any sixty day period locating, retrieving and identifying information in order to deal with a request for information and therefore we are withholding this information at this time.</p>
<p>VIII. How many of the total patients currently under the care of your Trust/Service with C3 Glomerulopathy have eGFR =30 mL/min/1.73 m2?</p>	<p>This information is not held centrally, therefore to obtain this information would involve a manual trawl and search of records which we have estimated would significantly exceed the 18 hours limit set down by the FOI Act as the reasonable limit. This is due to us needing to source multiple sets of patient notes from multiple health boards, reading through those notes to extract this information,</p>



	<p>checking GP records and also liaising with the renal registry. Section 12 of the FOI Act and The Freedom of Information and Data Protection (Appropriate Limit and Fees) Regulation 2004 provides that we are not obliged to spend in excess of 18 hours in any sixty day period locating, retrieving and identifying information in order to deal with a request for information and therefore we are withholding this information at this time.</p>
<p>IX. 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)?</p>	<p>This information is not held centrally, therefore to obtain this information would involve a manual trawl and search of records which we have estimated would significantly exceed the 18 hours limit set down by the FOI Act as the reasonable limit. This is due to us needing to source multiple sets of patient notes from multiple health boards, reading through those notes to extract this information, checking GP records and also liaising with the renal registry. Section 12 of the FOI Act and The Freedom of Information and Data Protection (Appropriate Limit and Fees) Regulation 2004 provides that we are not obliged to spend in excess of 18 hours in any sixty day period locating, retrieving and identifying information in order to deal with a request for information and therefore we are withholding this information at this time.</p>

