

**Freedom of Information Request**

**Ref: 24-606**

6 August 2024

By Email

Dear Sir/Madam

Thank you for your request for information under the Freedom of Information Act 2000. The Trust's response is as follows:

- We can confirm that we hold some of the information you are requesting

**How many people including adults and children are diagnosed and known to the metabolic service/health board to be living with Glycogen Storage Disease (all types except type V - McArdles Disease) under this health board?**

12 (paediatrics)

The adults service is provided by North Bristol NHS Trust – please contact [foi@nbt.nhs.uk](mailto:foi@nbt.nhs.uk) for further information

**How many adults and children are diagnosed and known to be living with Glycogen storage Disease type V - aka McArdles Disease under this metabolic service/neurological department/health board?**

Zero

**How many specialist consultants with interest in Glycogen Storage Disease are there at your metabolic centre?**

Two

**\*Please note that Type V - aka Mcardle's Disease is normally looked after under the neurological department/specialist, however care may cross over with metabolic services, hence why this should be considered when gathering information and why I have asked for these separately.**

This concludes our response. We trust that you find this helpful, but please do not hesitate to contact us directly if we can be of any further assistance.

If, after that, you are dissatisfied with the handling of your request, you have the right to ask for an internal review. Internal review requests should be submitted within two months of the date of receipt of the response to your original letter and should be addressed to:

Data Protection Officer  
University Hospitals Bristol and Weston NHS Foundation Trust  
Trust Headquarters  
Marlborough Street  
Bristol  
BS1 3NU

Please remember to quote the reference number above in any future communications.

If you are not content with the outcome of the internal review, you have the right to apply directly to the Information Commissioner for a decision. The Information Commissioner can be contacted at: Information Commissioner's Office, Wycliffe House, Water Lane, Wilmslow, Cheshire, SK9 5AF

#### Publication

Please note that this letter and the information included/attached will be published on our website as part of the Trust's Freedom of Information Publication Log. This is because information disclosed in accordance with the Freedom of Information Act is disclosed to the public, not just to the individual making the request. We will remove any personal information (such as your name, email and so on) from any information we make public to protect your personal information.

To view the Freedom of Information Act in full please click [here](#).

Yours sincerely

**Freedom of Information Team**  
**University Hospitals Bristol and Weston NHS Foundation Trust**