

Ref: FOI/00474/CMICB
21 July 2023

Dear,

**Re: Freedom of Information Act 2000
Patient Treatment Options for Inherited Cardiac Conditions**

Thank you for your information request indicated in bold below, which has now been considered under the Freedom of Information Act 2000 by NHS Cheshire & Merseyside Integrated Care Board (ICB). I am able to provide you with the following information and responses.

Please note from 01 July 2022, Clinical Commissioning Groups (CCGs) were disestablished, and their statutory functions and responsibilities inherited by NHS Cheshire and Merseyside ICB.

Your Request:

As a patient with an inherited cardiac condition (hypertrophic cardiomyopathy) I would like to establish what centres within the ICS would I be under the care of? I.e., what hospitals have a dedicated inherited cardiac conditions team.? If they do not have a dedicated team or would not treat the condition where would patients be referred to?

Specifically, would a local hospital manage drug treatment up until the stage of surgery (septal ablation or surgical myectomy)? If surgery is not offered where would the patient be referred to?

Our Response:

NHS Cheshire & Merseyside ICB is unable to provide information in relation to your specific individual clinical needs and treatment as a patient under the Freedom of Information Act. However, most general cardiologists with the necessary expertise in the NHS district general hospitals that operate within Cheshire & Merseyside would be able to adequately assess and treat patients with hypertrophic cardiomyopathy with appropriate medication.

Should the general Cardiologist in an NHS district general hospital feel they do not have the necessary expertise in relation to treatment of a patient's condition, they can refer the patient to a Cardiac Surgical Centre for investigation and general management. Within NHS Cheshire & Merseyside ICB's area that would be Liverpool Heart and Chest Hospital NHS Foundation Trust (LHCH) for investigation and general management. Additionally, dependent on a patient's location, they may also be referred to Cardiac Surgical Centres in neighboring ICB areas such as South Manchester and Staffordshire.

Any patient/family can be referred to the dedicated Inherited Cardiac Conditions ICC Clinic which is operated by LHCH. The ICC Clinic provides counselling and access to genetic testing for family screening, as well as advanced diagnostics such as Cardiac Magnetic Resonance (CMR) scans and can provide medical treatment as required or advice back to the referring local district general hospital Cardiologist.

LHCH also has services for invasive treatment, including alcohol septal ablation and surgical myectomy. LHCH also has services for invasive treatment including alcohol septal ablation and surgical myectomy.

Should you require any further information or clarification regarding this response or do not feel that your request has been answered as you would expect, please contact us to discuss.

We also wish to take this opportunity to inform you that, where you are not satisfied with the response to your request for information, a formal complaints and internal review process is available.

This can be formally requested by emailing foi@cheshireandmerseyside.nhs.uk and must be done within a reasonable time period (3 calendar months) from the date this response was issued.

Where you remain dissatisfied with our review under the Freedom of Information Act or the Environmental Information Regulations, you may apply directly to the Information Commissioners Office (ICO) for a review of your appeal decision. Generally, the ICO cannot make a decision unless you have exhausted our complaints procedure. The ICO can be contacted at;

The Information Commissioner's Office
Wycliffe House
Water Lane
Wilmslow
Cheshire
SK9 5AF
www.ico.gov.uk

Should you need any further clarification or assistance, please do not hesitate to contact us quoting the above FOI reference.