



Our Ref: PW/AKB/FOI-07-439

17th July 2023

Stafford Education & Enterprise Park
Weston Road
Stafford
ST18 0BF

Telephone: 0300 123 1461

Sent by email

Dear

FOI-07-439

Your request for information under the Freedom of Information Act 2000

Thank you for your request for information received on the 5th July 2023. We can confirm that the Staffordshire and Stoke-on-Trent Integrated Care Board can provide the following information.

An anonymised copy of this response will be made publicly available on the ICB website.

Please see our responses in blue below:

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)?

Patients experiencing symptoms that result from any congenital cardiac abnormality will be referred by their GP to the local cardiologist for investigation and diagnosis. Under the NHS constitution patients do have the right to choose which NHS Trust they are referred to.

The ongoing care arrangements will depend on what the actual clinical need is. Many common congenital defects, such as septal repairs are relatively common and likely to be within the scope of competence of a local cardiac surgeon.

There are some teams dedicated to the care of patients suffering with the long-term symptoms resulting from congenital heart defects, but this isn't a need for all patients as surgical correction of the defect can be curative.

If the required procedure cannot be undertaken locally and the local consultant considers that a highly specialised service is required, then the consultant will arrange that referral (a so-called tertiary referral). Due to the highly specialised nature of such services, choice of hospital becomes more limited.

In all cases the local consultant will discuss the proposed treatment plan and the most appropriate option for where that care might be provided.

The majority of patients within Staffordshire and Stoke-on-Trent are primarily referred to:

- University Hospitals of North Midlands NHS Trust
- Royal Wolverhampton NHS Trust
- University Hospitals of Derby and Burton NHS Trust.

If surgery is not offered where would the patient be referred to?

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?

Please be advised that the Staffordshire and Stoke-on-Trent Integrated Care Board (ICB) is not an NHS Trust and does not hold details on how specific conditions are treated or managed. The ICB does not therefore hold the information requested.

Your request should be sent to the NHS Trusts that serve our population predominantly in terms of Elective Care, i.e. University Hospitals of North Midlands NHS Trust, Royal Wolverhampton NHS Trust and University Hospitals of Derby and Burton NHS Trust. Contact details below:

University Hospitals of North Midlands NHS Trust

<https://www.uhnm.nhs.uk/contact-us/>

Royal Wolverhampton NHS Trust

<https://www.royalwolverhampton.nhs.uk/about-us/freedom-of-information/>

University Hospitals of Derby and Burton NHS Trust

<https://www.uhdb.nhs.uk/freedom-of-information-foi/>

Right of Appeal

Should you require any further information or clarification regarding this response please do not hesitate to contact us. If you are dissatisfied with the response, you are entitled to request an internal review which should be formally requested in writing and must be within two calendar months from the date this response was issued.

To request an internal review

You can request an internal review by contacting the Staffordshire and Stoke-on-Trent Integrated Care Board FOI team by emailing the team at StaffsStokeFOI@staffsstoke.icb.nhs.uk or by post to the address at the top of this letter.

If you are not content with the outcome of your internal review, you may apply directly to the Information Commissioner's Office (ICO) for a decision. Generally, the ICO cannot make a decision unless you have exhausted the Staffordshire and Stoke-on-Trent Integrated Care Board's FOI complaints procedure.

The ICO can be contacted at:

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

Yours sincerely

Paul Winter
Associate Director of Corporate Governance