

The Central Cardiac Audit Database (CCAD)

This leaflet explains more about the Central Cardiac Audit Database (CCAD). If you have any further questions, please speak to a cardiac (heart) doctor or nurse caring for you.

What is CCAD?

CCAD is a national audit database that monitors the outcomes of children or adults with congenital heart disease who undergo either a surgical or a catheter (minimally invasive) procedure in all specialist centres in the UK. We are required to submit information to CCAD by the Care Quality Commission (CQC) who oversee all NHS hospitals. This ensures our services are of the highest quality.

CCAD is independent of the NHS and their work is overseen by the following organisations:

- Royal College of Surgeons
- British Congenital Cardiac Association
- Care Quality Commission
- Department of Health

What are the aims of CCAD?

The CCAD aims to improve the quality of care children and adults with congenital heart disease are given and shows us a detailed picture of how it is treated around the country. It also helps us help our patients by:

- allowing us to examine the management of patients with heart disease and use findings to identify and maintain improvements
- providing the public with access to data related to the outcomes of specific procedures
- allowing us to analyse the information to ensure that individual hospitals and doctors' performances are compared
- offering the potential to improve the quality of life and survival outcomes for patients.

You can read more about the audit at **www.ccad.org.uk/congenital**

This website also has a useful 'Information for patients' section.

What information is shared with CCAD?

Information is only shared with CCAD if you have a cardiac operation, catheter procedure or if there is an infection in your heart or blood vessels. The information will include your name, NHS number, date of birth and postcode so that immediate and long-term outcomes can be monitored. Information regarding your diagnosis, the procedure performed and who performed it is also submitted.

Is my information secure?

Yes. Your information is encrypted and transmitted electronically by a secure internet connection so that it is kept confidential. Your information is stored and transmitted in a way that is approved by the Data Protection Act (1998). No one other than our clinical lead for CCAD (a doctor) within the hospital and a small number of staff at CCAD can see individual patient data once it has been sent. This is so any queries raised by the clinical team can be reviewed and corrected. When the data is published all patient names and personal details are removed so that your privacy is protected.

Is the information shared with any other organisations?

We do not share your information with anybody other than CCAD. To allow for long-term monitoring of outcomes, CCAD links with the Office of National Statistics. You or your child's NHS number is all that is used for this purpose.

Sometimes CCAD receives requests for information about congenital heart disease from doctors or other groups. These are considered on an individual basis by the clinical lead of CCAD. When information is shared it is completely anonymous so you cannot be identified.

Can I refuse to have my information on the database?

Yes. We will not put your details on the database without your consent (permission).

Does anyone check that the information is correct?

Yes. Representatives of CCAD visit every hospital that sends information to CCAD. This visit is undertaken every year to check that the information that is being sent to CCAD is correct. The people checking the information are an audit nurse from CCAD and a doctor or surgeon who cares for patients with congenital heart disease.

How do they check that the information is correct?

CCAD sends us a list of case notes they would like to check. These are selected at random from all the patients whose information has been sent to CCAD for the year being checked. The team from CCAD and a member of our team then check through the case notes to make sure the information is correct.

We need your permission for the people from CCAD to look at case notes. The team looking after you will ask you to complete a form stating whether or not you consent to your case notes to be reviewed. This will stay in your case notes and you have the right to change your mind at any time.

Can I refuse to give my permission for my notes to be reviewed?

Yes, you can refuse to allow your notes to be reviewed when the team from CCAD come to look at the case notes.

If you decide to refuse consent for your case notes to be reviewed, this will in no way affect the care you will receive.

Contact us

If you would like further information relating to any of the information in this leaflet, please do not hesitate to discuss this with the heart (cardiac) doctors or nurses looking after you, or contact:

- the Nurse Case Manager for Structural Heart Disease on 020 7188 1093 (Monday to Friday, 9am to 5pm)
- the clinical lead for CCAD within our department on 020 7188 4554 (Monday to Friday, 9am to 5pm).

For more information leaflets on conditions, procedures, treatments and services offered at our hospitals, please visit www.guysandstthomas.nhs.uk/leaflets

Pharmacy Medicines Helpline

If you have any questions or concerns about your medicines, please speak to the staff caring for you or call our helpline.

t: 020 7188 8748 9am to 5pm, Monday to Friday

Patient Advice and Liaison Service (PALS)

To make comments or raise concerns about the Trust's services, please contact PALS. Ask a member of staff to direct you to the PALS office or:

e: 020 7188 8801 at St Thomas' **t:** 020 7188 8803 at Guy's **e:** pals@gstt.nhs.uk

Knowledge & Information Centre (KIC)

For more information about health conditions, support groups and local services, or to search the internet and send emails, please visit the KIC on the Ground Floor, North Wing, St Thomas' Hospital.

t: 020 7188 3416

Language support services

If you need an interpreter or information about your care in a different language or format, please get in touch using the following contact details.

t: 020 7188 8815 **fax:** 020 7188 5953

NHS Choices

Provides online information and guidance on all aspects of health and healthcare, to help you make choices about your health.

w: www.nhs.uk

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