

Patient Information Sheet

AUSTRALIAN AND NEW ZEALAND SOCIETY OF CARDIAC AND THORACIC SURGEONS' ADULT CARDIAC SURGERY DATABASE PROGRAM

Introduction

You are about to, or have recently undergone heart surgery. Generally, heart surgery is successful in improving the quality and length of the patient's life, with a small risk of death or major complications.

The Australian and New Zealand Society of Cardiac and Thoracic Surgeons (ANZSCTS) must ensure that the high standard of heart surgery in Australia is maintained, that is to ensure that the results of all surgeons and surgical units remain at a consistently high standard. Cardiac Surgeons always strive to improve the results of heart surgery. In order to achieve that, we need to know what factors increase a patient's risk of complications, and which surgical procedures and methods have the most successful outcomes. Therefore, the ANZSCTS has set up a Database to monitor the results of heart operations.

The Database aims to record information about <u>every</u> adult having a heart operation in Australia. Importantly, the effectiveness of the Database depends on having information about everyone who has heart surgery. Therefore, we ask you to participate in the Database, simply by allowing us to document information relevant to your operation.

You can see some of the information obtained from the Database by visiting the Victorian Department of Health website on: <u>www.health.vic.gov.au/surgicalperformance/cardiac.htm</u>. Additionally, you may wish to visit the ANZSCTS Database public facing website for an overview of the Database Program (<u>http://anzscts-database.org/</u>).

We will keep the information confidential

Your personal information is confidential and cannot be used outside the Database. Procedures, governed by Legal Statutes, are in place to protect your information and keep it confidential. The data is accessible only to authorised staff of the Database Program. A collective data analysis will be made available through the reporting system of ANZSCTS and publications in medical journals. You cannot be identified in any reports or publications produced by the Program. This study is conducted in accordance with the NHMRC National Statement on Ethical Conduct in Human Research (2007).

What information do we need?

The information we require is what you have already provided to the hospital. It includes your name, date of birth, Medicare Number, hospital identification number, the name of the hospital, the reason you are having heart surgery and other information directly related to your operation. The hospital will monitor your progress for 30 days from the day of the operation. You may have an outpatient visit, an appointment with your specialist or General Practitioner or receive a phone call during this time.

The long-term results of heart surgery are equally important, to allow us to evaluate the effectiveness of the various procedures. For that reason, the Database will retain your information for at least 15 years. We also plan to link patient information to hospital administrative and government databases to enable the assessment of longer term outcomes such as mortality. No identifiable information obtained from this would ever be published. Please note that any additional research involving ANZSCTS data will require approval by a Human Research Ethics Committee.

How we collect the information

The hospital staff will complete the forms required and the information will be entered onto a database computer.

Risk and Benefits – To You

Having your data entered into the database will not alter the care and treatment you receive.

However, the information obtained will enable us to continually assess and improve the standard of Cardiac surgical care.

You can choose not to be in the database

We understand that not everyone is comfortable about having details related to their cardiac condition documented in a Database. If you feel this way, and do not wish this information added to the Database, please contact the Project Coordinator on 1800 285 382. Once you have opted off the Database, all your personal identifiers will be removed however, your cardiac surgery procedure information will remain in the Database. Each time you undergo a new cardiac procedure you will need to opt-off.



A decision on whether or not you wish to be involved in the database does not affect your treatment in any way.

If you have any questions, concerns or require further information about the ANZSCTS Database, please do not hesitate to contact the Project Co-ordinator on 1800 285 382.