



Patient information Sheet for next of kin

Introduction

In the usual course of events this information sheet is provided to heart surgery patients to notify them of a Program that involves the use of information related to their surgery. Sadly some heart surgery patients do not survive or are otherwise unable to consent for themselves. As we are unable to provide this information sheet to the patient, we are providing it to you as their next of kin.

Your relative has been included in the ANZSCTS Cardiac Surgery Database Program as they are about to undergo, or have recently undergone, heart surgery.

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. 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 established a Database to monitor the results of heart operations.

The Database aims to record information about every adult having a heart operation in Australia. Importantly, the effectiveness of the Database depends on having information about everyone who has heart surgery, particularly those patients who had an unfavourable outcome. Therefore, we ask for your permission to include information related to your relative in the Database, simply by allowing us to document information relevant to their operation.

You may visit the ANZSCTS Database website (<https://anzscts.org/database/>) for an overview of the Database Program. A Privacy Policy can also be accessed here.

Your relative has been included in this Database, but registration is voluntary. If you don't wish your relative to be in the database, they don't have to be.

What information do we need?

The information we require is what you have already provided to the hospital. It includes personal information, such as name, date of birth, Medicare number, hospital identification number, the name of the hospital, the reason for having heart surgery, and other information directly related to the operation. The hospital will monitor your relative's progress for 30 days from the day of the operation. They may have an outpatient visit, an appointment with your specialist or General Practitioner or receive a phone call during this time. Their health status at 30 days will be included in the Database.

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 indefinitely.

How we collect the information

Hospital staff will complete the forms required and the information will be entered into the Database. You and your relative will not be contacted by the Database staff, and are not required to do anything.

We will keep your information confidential

Your relative's 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. It is stored securely within Monash University using advanced encryption software. A collective data analysis will be made available through the reporting system of ANZSCTS, and publications in medical



Patient information Sheet for next of kin

journals. Your relative 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).

How will the information be used?

We will produce general reports on heart surgery outcomes for public, government, clinical and academic audiences. We anticipate that these publications will help to inform the public and clinical community about common trends and/or needs that may exist in service provision. No publication or report will ever contain any identifying information about your relative.

Researchers may use unidentified, group data for future research projects. Any further research undertaken using ANZSCTS data will require approval by a Human Research Ethics Committee. Please be aware that by consenting to having your relative's information stored in the Registry, you agree that the information collected may be used for further research relating to the standard of care provided to patients undergoing cardiac surgery in Australia. Linkages to hospital administrative and government databases including the Australian Institute of Health and Welfare's (AIHW) National Death Index (NDI) may be conducted to help determine long-term outcomes and mortality. To protect your relative's privacy, all linkage activities are bound by privacy legislation and must meet specific privacy and security conditions before ethical approval is granted.

Risk and Benefits – To you and your relative

Your relative's information is protected and legally, we are not allowed to identify individuals. The information obtained will enable us to continually assess and improve the standard of Cardiac surgical care.

Your relative's information will be securely protected.

You can choose for your relative's information not to be included in the Database

We understand that you may not be comfortable about having details related to your relative's heart condition documented in a Database.

If you decide to allow your relative's information to be recorded in the Database but later change your mind, you are free to withdraw your consent at any stage by contacting the ANZSCTS Database directly.

If you believe that your relative would feel this way, and do not want this information added to the Database, please contact the Project Co-ordinator on 1800 285 382

Once you have opted off the Database, all your relative's personal identifiers will be removed; however their cardiac surgery procedure information will remain in the Database. Each time your relative undergoes a new cardiac procedure you will need to call and opt-off.

A decision on whether or not you wish your relative's information to be involved in the Database does not affect their 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.