**Patient Information Sheet**

### AUSTRALIAN and NEW ZEALAND SOCIETY of CARDIAC AND THORACIC SURGERY (ANZSCTS) CARDIAC SURGERY DATABASE and AUSTRALIAN AND NEW ZEALAND COLLABORATIVE PERFUSION REGISTRY (ANZCPR)

**Introduction**

You are about to undergo, 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. However, in certain people the surgery is less successful. This may be due to some people having characteristics that increase their risk of complications, or it may be due to the type of operation done and the circumstances in which it is performed.

Quality Assurance is a vital component of your hospital stay. That is, to ensure that the results of all surgeons and surgical units remain at a consistently high standard. In order to improve the success of heart surgery, we need to know what factors increase a patient's risk of complications, and which surgical procedures have the most successful outcome. To achieve this, the Australian and New Zealand Society of Cardiac and Thoracic Surgeons (ANZSCTS) Cardiac Surgery Database and the Australian and New Zealand Collaborative Perfusion Registry (ANZCPR) have been set up to monitor the results of cardiac operations.

*These registries aim to record information on every adult having* a *heart operation. The success of these registries depends on the amount of data we collect. We are asking you to participate in these Cardiac Surgery registries, by allowing us to document information relevant to your operation.*

These projects will be conducted in accordance with the NHRMC National Statement on Ethical Conduct in Human Research, 2007 (updated May 2015).

**What Information Do We Need?**

The information we require includes your name, date of birth, Medicare Number, hospital identification number, the name of the hospital, the reason you are having cardiac surgery and other information directly related to your operation. The hospital will also undertake follow up of you at 30 days to collect any relevant health or medical information since your procedure.

The long-term results of heart surgery are equally important to us since it allows us to evaluate the real effectiveness of the various procedures. For that reason, the registries 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.

**We Will Keep Your Information Confidential**

Your personal information is confidential and cannot be used outside the registries. Procedures are in place to protect your information and keep it confidential. Registry data is only accessible by authorised staff of the Cardiac Surgery Database and ANZCPR projects. A collective data analysis will be made available through the reporting system of ANZSCTS and ANZCPR and through publications in medical journals. You cannot be identified in any reports produced by these registries.

**How We Collected 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**

Your information is protected and legally, we are not allowed to identify you. The registries will produce general reports and medical publications on the outcomes of surgery, which we anticipate will improve the quality of cardiac surgery in the future. *Having your data entered into the registries will not alter the care and treatment you receive.*

**You Can Choose Not to Be in these Registries**

We understand that not everyone is comfortable about having details related to their cardiac condition documented in a registry. If you feel this way, and do not want this information included, please contact the ANZCPR project co-ordinator on 08 8204 5382, who in turn will contact the ANZSCTS Project Co-ordinator on 1800 285 382. Once you have opted off these registries, all your personal identifiers will be removed however, your cardiac surgery procedure information will remain.

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

**If you have any questions, concerns or require further information about either Cardiac Surgery Registry, please do not hesitate to contact the ANZCPR Project Co-ordinator on 08 8204 5382, or the ANZSCTS Cardiac Surgery Database Project Co-ordinator on 1800 285 382.**

This study has been reviewed by the Southern Adelaide Clinical Human Research Ethics Committee (SAC HREC). Should you wish to discuss the project with someone not directly involved, in particular in relation to matters concerning policies, your rights as a participant, or should you wish to make a confidential complaint, you may contact the Executive Officer of the SAC HREC on 08 8204 6453.