**Information Sheet for next of kin**

### AUSTRALIAN AND NEW ZEALAND COLLABORATIVE PERFUSION REGISTRY (ANZCPR)

**Introduction**

# In the usual course of events this information sheet is provided to heart surgery patients to notify them of a program being conducted that involves the use of information related to their surgery. As we are unable to provide this information sheet to the patient, we are providing it to you as their next of kin.

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 the program. 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 Collaborative Perfusion Registry (ANZCPR) has been set up to monitor the results of cardiac operations.

*This registry aims to record information on every adult having a heart operation. The success of this registry depends on the amount of data we collect. We ask for your permission to include data related to your relative in this registry by allowing us to document information relevant to their operation.*

This project will be conducted in accordance with the NHMRC National Statement on Ethical Conduct in Human Research (2007, updated May 2015).

**What Information Do We Need?**

The information we require include name, date of birth, Medicare Number, hospital identification number, the name of the hospital, the reason for having cardiac surgery and other information directly related to the operation.

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 registry will retain 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**

Personal information is confidential and cannot be used outside the registry. Procedures are in place to protect information and keep it confidential. Registry data is only accessible by authorised staff of the ANZCPR project. A collective data analysis will be made available through the reporting system of ANZCPR and publications in medical journals. Your relative cannot be identified in any reports produced by this registry.

**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**

Your relative’s information is protected and legally we are not allowed to identify individuals. The registry 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.

 **You Can Choose for Your Relative’s Information to Not be in this Registry**

We understand that you may not be comfortable with having details related to your relative’s cardiac condition documented in a registry. If you believe that your relative would feel this way, and you do not want this information included, please contact the ANZCPR project co-ordinator on 08 8204 5382. Once you have opted off this registry, all your personal identifiers will be removed however your cardiac surgery procedure information will remain.

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

**If you have any questions, concerns or require further information about the ANZCPR, please do not hesitate to contact the ANZCPR Project Co-ordinator on 08 8204 5382.**

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.