

ANZSCTS Database Newsletter Issue # 6 August 2018



Welcome

Welcome to issue 6 of the Australian and New Zealand Society of Cardiothoracic Surgeons (ANZSCTS) Database Program Newsletter!

We want to make this an informative, relevant, and useful brief summary of activities by ANZSCTS Database. If you have any feedback or wish to see anything in the next Newsletter, please contact the ANZSCTS Database Team.

ANZSCTS and the GDPR

The European Union (EU) have recently introduced a General Data Protection Regulation (GDPR) policy that took effect as of the 25th of May 2018. The GDPR has extended its jurisdiction over previous privacy policies as it applies to all those processing personal data for participants residing in the EU, regardless of the managing institution's location. The GDPR relates to the protection of fundamental rights and freedoms of people within the EU, and the processing and movement of personal data of these people.

Monash University recognises GDPR as the new global standard in privacy legislation, with similar legislation expected to be adopted by



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IMPORTANT DATES

Data Deadlines

- Q2 Aug 17, 2018
- Q3 Nov 16, 2018
- Q4 February 15, 2018
- Q1 May 17, 2019

Research Committee Meetings

- June 11, 2018
- September 3, 2018
- December 3, 2018

the Australian government within the coming decade. The GDPR will impact the ANZSCTS Database Program as the policy will apply to located in the EU at the time of data collection (e.g. during follow up), including those just visiting the EU.

The policy has strengthened conditions for consent in the EU, whereby an opt-off method would no longer be appropriate. Participants would be required to give informed consent prior to their data being collected unless it passes a public interest test. Participants also maintain the right to access what personal data has been collected, and query how it will be processed and for what purpose. Finally if participants decide to withdraw consent they have the right to Data Erasure, whereby all personal data is deleted permanently.

Although at this stage we have not identified the direct impact the GDPR will have on the ANZSCTS Database program, we have acknowledged that some changes may need to be made in the near future in order to comply with the policy. The Monash legal team is currently formulating policies to ensure that all areas of Monash University are compliant.

March 11, 2019

Steering Committee Meetings

June 18, 2018
September 10, 2018
December 10, 2018
March 18, 2019

NEXT ISSUE
November 2018

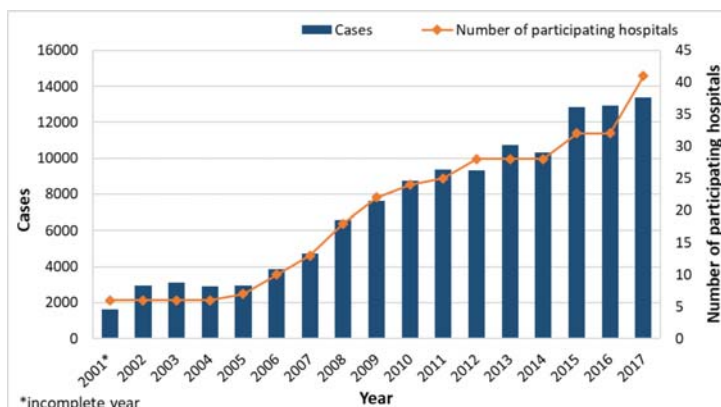
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Data Capture

To date, ANZSCTS Database holds information on over 123,000 patients, increasing at a rate of 12,000 cases per year.

We're glad to announce that the end of 2017 saw the addition of 7 new private hospitals contributing to the database. With each Unit's inclusion the quality of our bench-marking process improves.



Royal Hobart Hospital has also committed to contributing to the ANZSCTS Database in 2018. With their inclusion, this gives the ANZSCTS Database Program 100% coverage over Australian public Units.

[Email us to join!](#)

Data Collection Form Process

When it comes to collecting and entering data there are many ways to do it and there is no perfect method. We recognise that all Units are different and what may work at one Unit may not work at another. To ensure accountability and accuracy of data the ANZSCTS Database Steering Committee has established some guidelines that can help inform your Unit's data collection/entry process:

Preoperative data (sections 1-5): These sections should be entered by the surgeon (or resident), the main doctor with patient contact who would know pre-operative factors such as NYHA class or medications.

Intraoperative data (sections 6-10.3): Again this section should be entered by the surgeon. This information may be passed on to the anaesthetist during surgery for record taking.

Postoperative data (sections 11-13): the registrar, in conjunction with a Unit outcomes team and data manager to decide on complications based on the data definitions.

Finally all data should be checked and approved by the Unit data manager, and if any queries should arise they should be resolved by the responsible surgeon.

Please only use the above suggestion as a guide to find an optimum process for your Unit.

New Web System Functions

The web system has undergone some recent changes with a focus on simplifying data access and expanding our reporting systems. We are always looking to improve the system further and welcome any feedback.

- **New data download functionality**

Data Managers are now able to download all data complete to baseline. Simply click the 'Include cases complete up to baseline' to include all data with or without the mortality/readmission page completed.

Surgeons now have a data download function available to them. If a

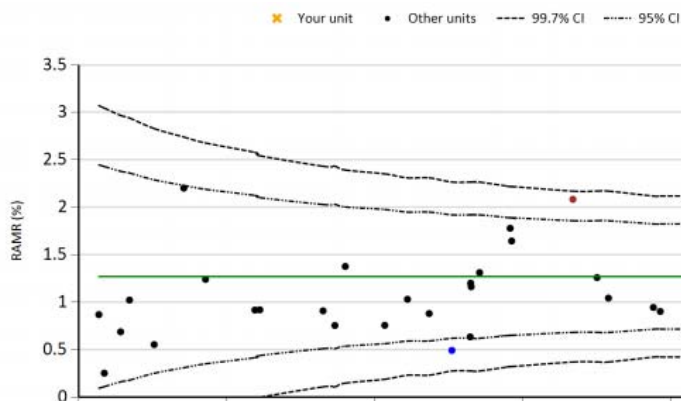
surgeon logs in, they are able to download all their cases for all the Units they operate at.

- **New web reports**

To complement the summary report there are brand new site and surgeon comparative reports. These new reports compare individual surgeon or Unit performance to all other surgeons or Units for multiple key outcomes across different procedure types.

Below is an example of a Unit comparison for one key outcome.

Note that when an individual runs a report they will be highlighted in yellow.



Data Security

Please be reminded of the sensitive nature of the data stored in the database. As a data manager or surgeon you have access to download identifiable information. Once it has been removed from the database you are responsible for the handling of this data. You should ensure that you comply with the Privacy Act (1988), the Health Records Act (2010) and your own hospital's information dissemination policy.

Additionally, under no circumstances should a Data Manager or Surgeon's username and password be shared. Doing so compromises data quality and security. If you are sharing a single username and password let us know so we can organise separate logins and training in system use if required.

If there is ever any doubt about who should have access to your Unit's data or who should have access to the system or what level of access they should have please contact the ANZSCTS Database Team ASAP and we can give clear guidance on the matter.

Dissemination of PIS

All patients must be given the Patient Information Sheet (PIS) as a condition of the project's HREC approval. This document provides information on the ANZSCTS Database Program, data security and use, and options for patient opt –out. Please ensure the patient receives the PIS prior to discharge.

In the unfortunate event that a patient passes away prior to receiving the PIS, the Next of Kin PIS must be provided to the patient's next of kin.

Electronic copies of PIS and NOKPIS are available by contacting ANZSCTS Database staff at anzscts.sphpm@monash.edu.

Suggested dissemination of PIS:

Elective patients:

- Pre-admission pack

Urgent, emergency and salvage patients:

- Discharge pack
- On the ward either pre- or post- surgery

Avoid:

- Verbal explanations of the PIS
- Mailing the PIS after the patient has been discharged

Unit Personnel Change or Leave

If you know of any personnel changes and/or leave within your Unit, whether it be the HOD or Data Manager, please inform ANZSCTS Database staff by email anzscts.sphpm@monash.edu, as soon as possible. This allows us time to foster good relationships with new staff, train them in the use of the Database, and provide a smooth transition to avoid any gaps in data collection.

ANZSCTS Database Team

Farewell to staff

Over the past couple of months we have been saying farewell to our program manager Lavinia Tran, one of our research officers Nicole Marrow and our research assistant Kathy Fotis. They will all be taking maternity leave and will return in the new year.

We wish them the best of luck in this new and exciting chapter.

New staff members!

Dr Jenni Williams-Spence completed her PhD in Clinical Research at Victoria University of Wellington, which focused on a novel intervention for cardiac surgery patients. Since then, she has worked on public health projects and in the Victorian Cancer Registry, but is excited to get back to her academic and cardiac research roots in her new role as the ANZSCTS Program Manager. In her spare time, Jenni enjoys baking and following her husband to sporting events.

Ms Jenna McLaren completed her Bachelor of Biomedical Science (Honours), from RMIT in 2012. She has been a research assistant at Monash University in early phase drug discovery for 5 years with expertise in metabolic stability and metabolite identification. Jenna joined the ANZSCTS Database team as a Research Officer in May, 2018. She is an avid footy fan (Go Bombers!) and enjoys reading, live music and craft beer.

Mr Mark Lucus

Mark Lucas has 21 years technical experience working with Data, Databases and applications in a number of organisations such as Nursing Australia and The Department of Human services (Vic). While at Monash, Mark has been working on the Cancer 2015 project for 6 years assisting investigators by providing data extractions and assisting them with the mechanics of data analysis. He maintains the CORE registry database and application for the project and provided support to the clinical nurses and pathologist that use the system as well as importing data and providing linkages to other data sets as the project requires.



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