The ANZICS CORE: an evolution in registry activities for intensive care in Australia and New Zealand

Graeme K Hart, for the ANZICS Centre For Outcomes and Resources Evaluation (CORE) Management Committee

Since the first (unpublished) Australasian APACHE II study in the early 1990s, the Australian and New Zealand Intensive Care Society (ANZICS) has provided leadership in clinical registry and audit activities for intensive care outcomes, both adult and paediatric, and description of critical care resources. Initially supported by members’ efforts alone, these activities have now reached a complexity and scale that they require a sophisticated and well-resourced secretariat — the ANZICS Centre for Outcome and Resource Evaluation (CORE). External funding is essential, but comes with conditions. Jurisdictions responsible for health outcomes now insist on a governance and data access framework so that they can meet their own obligations to the electorate. The CORE Management Committee has established a framework that, we believe, will meet the expectations of members, hospitals, community and government, and will also be able to respond to the national guidelines for registry structure, function and governance currently being formulated.

ANZICS now receives data from more than 140 adult and 20 paediatric intensive care units, and the resources survey has described facilities from more than 93% of Australasian ICUs since 1998. Our computing and reporting infrastructure was upgraded this year to enable greater automation and efficiency and improved outcome reports, as well as standardised resource and process measures. Data quality, content and scope have all improved progressively over the years, and are now well documented, with significant resources expended on training, data quality audit, data exception checking and reporting to both individual unit contributors and governance organisations, at hospital, health service and state levels.

CORE data are increasingly used for research and planning, and the publication list has grown extensively over the past few years. ANZICS was able to provide critical information for New Zealand and Commonwealth Pandemic and Bio Security planning. The CORE is working closely with the ANZICS Clinical Trials Group and the Safety and Quality Committee to help formulate interventions and measure their impact. The science of what we do is being developed through workshops, conferences and collaboration, together with support for PhD students. We will explore the means to securely retrieve identified patient data that facilitate data linkage with other registries, such as trauma, cardiac surgery and death registries, under appropriate ethical and privacy conditions.

As always, CORE activities depend on, and are for the benefit of, the intensive care community at large. Without our data collectors, committee volunteers and collaborating researchers, we would not be so successful. The CORE staff have adopted the goals of ANZICS and support us with great enthusiasm and diligence. The continuing evolution of our registry is the prime motivation for changing our name from the ANZICS Databases to ANZICS CORE — to reflect what we do, rather than how we do it. The CORE will continue to be staffed by committed employees under the guidance and governance of the CORE Management Committee. In the near future, we hope to employ an epidemiologist to facilitate the high level of activities now occurring. Here, we review how we reached this point and how we plan to move forward in the coming years.

How did we get here?

It is 18 years since the first meeting held by ANZICS members to discuss comparing their ICU results using the APACHE II methodology of Knaus et al. Almost immediately, issues about data definition, collection software, comparison methods, reporting frameworks and other technical matters came to the fore. After this initial meeting, Rob Herkes and David McWilliam developed the ICON data collection software and the Adult Patient Database management centre at Royal Prince Alfred Hospital in Sydney. I set up the first Intensive Care Registry, which aimed to describe the resources, both physical and human, that sustained the provision of intensive care services — this Registry subsequently became known as the ANZIC Research Centre for Critical Care Resources. The Paediatric Intensive Care Study Group developed the ANZPIC Registry.

In 2000, it was clear that a sustainable, professionalised secretariat was needed to support all three ANZICS database registries, and that this would cost more than previously obtained. This culminated in the first triennial funding grant under the auspices of the Australian Health Ministers’ Advisory Council (AHMAC), 2002–2004 (A$1.02 million), and the second, 2005–2007 (A$1.8 million). As part of the negotiations around this funding, the ANZICS Database Management Committee (ADMC)
was expected to consolidate its activities, share resources between its three arms and be more accountable to both the intensive care constituency and funding agencies. To that end, the Adult Patient Database moved to ANZICS House in Melbourne in 2002.

In our third triennium, we have budgeted for $2.4 million. As part of the contractual obligation, a National Intensive Care Registry Steering Committee will be established to ensure a dialogue between the CORE and funding jurisdictions. Jurisdictional liaison committees will be established, if not already active, and an external review of CORE activities will be undertaken in the second half of the triennium.

Since the Bristol,2 King Edward3 and Bundaberg4 governance inquiries, politicians and health bureaucrats are intensely aware that they will be held accountable for governance problems in the future. In this context, health agencies are demanding greater access to information that has traditionally been seen by intensivists as “theirs”. In many cases, hospital authorities are not necessarily aware of all the information being collected by specialist groups and submitted to national peer group registries.

This potential conflict over data ownership and governance can only be resolved by open dialogue between state committees of intensivists and health bureaucrats. Such a model has been developed and is operating successfully in Victoria through the Data Review Committee, which sits as a subcommittee of the Victorian Intensive Care Advisory Committee. This committee commenced as a result of the first AHMAC funding agreement after a special general meeting of intensive care directors agreed to allow the data submitted to ANZICS to be reviewed in concert with Department of Human Services officials. Over time, trust has developed, which has now resulted in an annual report.5 This report consolidates the ANZICS-derived and hospital administrative data. In the most recent edition, standardised mortality ratios and other information are reported in a manner that identifies hospitals and ICUs. Other states, including New South Wales and Queensland, are currently developing and implementing such models. In both these states, recent high-profile media events have made “trust” difficult to achieve, yet more important than ever.

These liaison committees will become increasingly important as the CORE releases reports such as funnel plots and resetting adjusted sequential probability (RASPRT) data, which provide more sensitive indications of potential drift from outcomes predicted by the standardisation model (eg, APACHE 3-J). The use and reporting of these outcome data mandates an effective governance structure that works through an agreed internal process and outlier review model.

**Where are we going?**

Over the past 3 years, the ADMC saw its role expand in support of the activities of the ANZICS Clinical Trials Group, ANZIC Research Centre and the ANZICS Safety and Quality Committee. The ADMC sponsored a PhD student scholarship in Brisbane with the University of Queensland and commenced a collaboration with a PhD student from the Monash University Department of Epidemiology and Preventive Medicine in 2008. Increasingly, the information held by CORE is seen as high value and high quality; it therefore should be used effectively to demonstrate and improve the high level of care provided by Australasian ICUs. Development of appropriate intermediate indicators, validated for Australian conditions, is now a high priority, and this is increasingly being undertaken in conjunction with the Clinical Trials Group and the Safety and Quality Committee. The ADMC sponsored the Key Performance Indicator Development Workshop in 2005, and in 2007 conducted the First International Conference on Safety, Quality, Audit and Intensive Care Outcomes in Queenstown, New Zealand.7 This conference was designed as “working meetings”, similar to the Clinical Trials Group meetings held in Noosa, Queensland. The aim is to bridge the gap between the high level of rigour attached to research and the perceived lesser rigour attached to safety and quality activities. In addition, the complexity and breadth of Registry activities require a dedicated forum for discussion and presentation. The first meeting was highly successful, and a second will be held in Christchurch, New Zealand, on 28–29 August 2008,8 to be repeated annually thereafter.

The research outputs of the ADMC have grown rapidly in the past 2–3 years, often in conjunction with collaborators from the Clinical Trials Group, the ANZIC Research Centre and other individuals.9 Publications and reports are listed in the Appendix.

Specialty and disease or therapy-based registries have a long history of dedicated (often voluntary) service, transcend jurisdictional boundaries and political cycles, and provide in-depth knowledge of the clinical domain by which to understand the strengths and weaknesses of the data and provide considered interpretation. Such analysis is most beneficial when provided in a defined governance framework in consultation with jurisdictional authorities, as interventions based on the data can then be more expeditiously implemented.

Traditionally, the Adult and Paediatric Patient Databases have provided periodic analysis of standardised mortality, length of ICU and hospital stay, and age- and case-mix-based utilisation figures. The ANZPIC Registry has been reporting control charts for some time, and the Adult Patient Database is now also moving to continuous process control charts (CUSUM and RASPRT), with more frequent
and timely cycles. Contributor access to standard reports and on-line data exploration tools are now provided via a secure SAS web portal.10

Is this enough?
The knowledge embedded in such large data repositories must be unleashed, and to this end appropriate access for third-party users of the data is critical. The data can be used in several key areas:

- Cumulative reporting of utilisation statistics with trend analysis over time;11
- First-pass reality-checking of reporting of research findings, such as glucose12 and sepsis13 data;
- Determination of disease incidence (such as asthma14), frequency and outcomes (long-term outcomes) by researchers “scoping” major prospective research projects; and
- Research into outcome methodology and statistical process.

Perhaps even more important is the capacity to prioritise, shape and initiate research into issues identified, but not explained by, the database. Comparison can be made to the four phases of prospective research.

Phase 1. Hypothesis generation and scoping — identification of questions from the data repository:

- Increased mortality associated with after-hours ICU discharge;15
- Increased mortality and ICU resource use after interhospital transfer;16

Phase 2a. Small-scale pilot study to explore key issues:

- Pilot study of factors associated with after-hours ICU discharge presented to the Clinical Trials Group meeting (J Santamaria. Pilot analysis of ICU discharge data. Noosa, QLD; March 2007).

Phase 2b. Large-scale multicentre exploration of issues in greater depth, to test generalisability of the ideas developed:

- Proposal presented to the Clinical Trials Group meeting (J Santamaria. Multicentre study proposal to assess out of hours discharges and readmissions to ICU. Noosa, QLD; March 2008).

Phase 3. Interventions targeting systematic issues as a result of those findings and determination of effectiveness of the intervention.

Phase 4. Post-implementation and post-publication surveillance. Assessment of uptake, effectiveness and observation for unexpected outcomes of widespread use of the intervention (eg, impact of medical emergency teams on ICU admission rate following cardiac arrest17).

The ability to conduct such comprehensive programs is not widespread. Critical requirements include adequate and sustained resourcing of the basic reporting infrastructure, high-level penetration of the program across all areas of interest, strong commitment from contributors, and a collegial framework for collaboration.

ANZICS provides such a framework through its subcommittees CORE, the Safety and Quality Committee, and the Clinical Trials Group, together with the ANZIC Research Centre (the last funded by the National Health and Medical Research Council [NHMRC]). These concepts have evolved further over the past few years as a result of a coordinated funding framework through AHMAC and the Australian and New Zealand Health Departments, and strong relationships with related organisations, such as the Joint Faculty of Intensive Care Medicine, state acute health and quality staff, and national quality organisations.

As the sophistication of our reporting infrastructure increases, and the science of statistical control charting and multidimensional information displays improves, the CORE Management Committee hopes to provide contributors and funding agencies with increasingly important, validated and contemporary information, thereby enhancing its usefulness, effectiveness and quality for intensive care providers, governments and the community.

Critically, none of this would happen without the willing cooperation and strong quality orientation of ANZICS members. Many ICUs still do not have funded data collectors and rely on medical staff for primary data collection, which inevitably competes for time with patient care and administration duties. This is a fragile and interim arrangement, as the time required for data collection, entry and checking is significant. Periodic changes to the data collected, in response to new quality or research imperatives, require a stable group of people knowledgeable about data definitions and data quality. The more important the conclusions reached about unit-based outcome performance, the more critical the quality of the data becomes. A stable base of trained data collectors becomes ever more important. ANZICS CORE has developed a strong training base through workshops and Internet activities, and has now audited the data of more than 20 ICUs. Reports on this data audit will be published shortly.18

In conclusion

From humble but enthusiastic beginnings in the early 1990s, the ADMC has evolved to become a standards-setting registry that is widely recognised locally and increasingly overseas. To reflect the more ambitious objectives that we have now set for ourselves, and to better describe our role, the ADMC has resolved, and the ANZICS Board has endorsed, a change in name from the ANZICS...
Databases to the ANZICS Centre for Outcomes and Resources Evaluation — the ANZICS CORE.

This milestone has prompted an examination of the most effective human-resources structure for the future, and we propose to appoint an epidemiologist to assist our future development. The initial objectives of the CORE will be to finalise negotiations for the next 3 years of funding, to update the server architecture and reporting software to increase efficiency and timeliness of data uploads and reporting, and to improve the audit reporting styles and information available to users. In addition, we will continue to turn information into practice in conjunction with the ANZICS Safety and Quality Committee and the Clinical Trials Group, through both collaborative research and the continuation of the scientific meetings in Queenstown.

The ANZICS CORE Management Committee thanks our staff and all contributors, past and present, and invites the input and collaboration of the intensive care community to develop the audit and research outputs that are meaningful and useful to us all.

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References

Appendix. Publications of the Australian and New Zealand Intensive Care Society Centre for Outcome and Resource Evaluation (ANZICS CORE)

The following is a list of all articles published by ANZICS CORE, using CORE resources or in association with CORE staff.

2008

Peer-reviewed journals


2007

Peer-reviewed journals


2006

Peer-reviewed journals

George C, Higlett T, Norton L. The Australian and New Zealand Intensive Care Database. ICU Management 2006; Spring.


Reports


Book chapter


Conference presentations


2005

Reports


Conference presentations


Appendix continued

2005 continued


2003

Peer-reviewed journals


Reports


Conference presentations

Bishop N, Moran J, George C, Higlett T, Bellomo R. Customising APACHE II to improve calibration and discrimination for the Australian and New Zealand context. Presented at the 29th Australian and New Zealand Intensive Care Society Annual Scientific Meeting on Intensive Care; 7-10 Oct 2004; Melbourne, VIC.

