South Australian
Prostate Cancer Clinical Outcome
Collaborative
(SA-PCCOC)

Annual Report 2011
Released: March 2012
### Prostate Cancer Clinical Outcomes Database

**Steering Committee**
- Kim Moretti, Chair
- Kym Horsell, Deputy Chair
- Carole Pinnock, Executive Officer
- Kerri Beckmann, Member
- Michael Chong, Member
- Darren Foreman, Member
- Jimmy Lam, Member
- Jeff Roberts, Member
- Peter Sutherland, Member
- Leigh Pretty, Member
- Martin Borg, Member
- Kim Pese, Member
- Tina Kopsaftis, Member
- Scott Walsh, Member
- David Roder, Member

**Research Committee**
- Martin Borg, Chair
- Carole Pinnock, Executive Officer
- Grant Buchanan, Member
- Kim Moretti, Member
- Kerri Beckmann, Member
- Michael Chong, Member
- Darren Foreman, Member
- Kym Horsell, Member
- Jason Lee, Member
- David Roder, Member

**Data Management**
- Carole Pinnock, Principal Research Scientist
- Tina Kopsaftis, Clinical Data Coordinator
- Shwu Fen Loh, Clinical Data Officer
- Elspeth Raymond, Clinical Data Officer
- Scott Walsh, Data Manager
Summary: activities 2011

Since its inception as a single consultant prostate cancer series in 1998, SA-PCCOC has grown into a multi-centre clinical registry collecting data with a recruitment of 6817 patients up to March 2012 (approximately 50% of men diagnosed with prostate cancer in South Australia). Our goal is to capture 80% of the population.

We have made significant advances towards our major reporting objectives: funding from the SA Cancer Collaborative has supported the development of a consultant case series report reporting risk adjusted outcomes, currently undergoing consultation; we have supported student, registrar and RMO research including 10 conference presentations; we opened up new research collaborations with Population and Research Outcomes at the University of Adelaide and the Flinders Centre for Epidemiology and Biostatistics, resulting in new and exciting research directions in areas of PSA kinetics and treatment decision-making for older men. In the meantime, our established research programs in risk adjustment and prognosis lead to a new publication in BJUint, and submission of a major publication on androgen receptor function by research committee member Grant Buchanan’s group in Cancer Research.

2011 also saw the initiation of data collection for patients from two large private practices. Additional infrastructure funding allowed us to undertake retrospective data collection, and development of a clinical reporting registry to reduce repetitive data management tasks such as consultant series reporting, generation of research datasets and annual statistics. We have also defined an information management road-map to address emerging issues with SA health’s move to EPAS, a new electronic patient record system. This affects our current collection systems and will require us to migrate to a new collection platform in 2012/3.

SA-PCCOC established a website in 2011, http://www.sa-pccoc.com/, with information about the collection, process of application to use data, a members section and a wiki with database documentation and processes. We have become formally affiliated with Flinders University through the Flinders Centre for Innovation in Cancer and the University of Adelaide and have web-pages on their sites. We have also become a supported project for the Hospital Research Foundation which provides an online portal for donations.

SA-PCCOC is part of a Movember-sponsored initiative to move towards a national prostate cancer registry which will develop in 2012-13. We have initiated a feasibility study for a prostate cancer registry in the Northern Territory. Dr Kym Horsell is leading this initiative.

The expanded capacity and achievements of the database in the past 12 months have been a result of the excellent work of the steering and research committee members and the leadership provided by chairs Dr Kim Moretti, Martin Borg, deputy chair Kym Horsell and Principal Research Scientist, Carole Pinnock; the multi-disciplinary nature of the committee, including consumer and nursing representation has been a major factor - also the outstanding work undertaken by the clinical data coordinator, Tina Kopsaftis and data manager, Scott Walsh. We have also welcomed Elspeth Raymond, Shwu Fen Loh in data acquisition and former data manager, David Tamblyn working in the NT project development role.
About the database: Current status

The following statistics summarise database growth to date December 2011. It shows continued growth in robotic surgical patients, although this may have peaked in 2010.

- Currently 6817 men on the database including 1399 private patients
- 815 new patients added to the database in the last 12 months (February 2011-February 2012).

Figure 1: Database Growth

Figure 2: Distribution of Treatment Choices
Governance

Steering committee

The committee has had a productive year and achieved the following in 2011/12

- Established guidelines for data access for potential researchers
- Oversighted development of a website (see below): [http://www.sa-pccoc.com/](http://www.sa-pccoc.com/) with public and secure access. The secure area includes additional information for collaborators and a wiki to support data management.
- Finished the design of a patient summary report, accessible at the point of care within the SA-Health domain (see below)
- Improved the completeness of the radiation oncology data collection (with participation of Dr M. Borg)
- Established an affiliation with Flinders University, membership of the Flinders Centre for Cancer Prevention and control, and a presence on the Flinders Cancer Centre’s website [www.flinders.edu.au/cancer/sa-pccoc.cfm](http://www.flinders.edu.au/cancer/sa-pccoc.cfm)
- Establishment of a research committee (TOR) chaired by Dr Martin Borg, Radiation Oncologist.

- The steering committee, and subsequently the research committee (established 1.4.2011) have supported with feedback and discussion, all the research abstracts and papers submitted for publication.

**Research committee**

The research committee met in July 2011, and has since reviewed papers and presentation prepared for conferences and submission to journals, developed a list of projects and potential projects, and advised on funding proposals. Its work is evident in the large list of presentations and publications (below). We are grateful to Dr Martin Borg for his leadership of that committee.

We have established a new partnership with Dr Zumin Shi, an epidemiologist and biostatistician at the Population Research and Outcome Studies Unit of the University of Adelaide. Dr Shi examined PSA patterns post EBRT and radical prostatectomy in SA_PCCOC patients and presented his findings to the committee. A paper has been prepared together with Dr Stephen Kinsey-Trotman reporting interesting findings regarding PSA velocity post EBRT.

**Data management and Governance**

SA-PCCOC has seen significant progress in areas of data management and data governance in the last year, with a number of important issues addressed:

**An integrated clinical reporting registry (CaPStudies)**

The SA-PCCOC data management framework has evolved over time to be comprised of several inter-connected databases. Routine reporting and extraction of datasets for research analyses require database snapshots at a point in time, and implementation of a number of standard extraction procedures to link data from several different sources. We have developed a new clinical reporting registry (CapStudies) that links data from several databases, with scripts that can be run on demand to automate many of data extraction tasks.

The registry produces a snapshot of patient cancer diagnosis, investigations and treatments, and patient reported symptom questionnaire data. It also generates derived variables (such as biochemical recurrence) that are calculated each time a new snapshot is initiated. This, has greatly increased the efficiency of using the data,
improved consistency, reduced the time required to produce research datasets, and enabled us to progress our development of Consultant’s risk-adjusted outcome reports.

Data completion project

With the addition of private practices to the collection, we have a significant backlog of data entry. This has been addressed by collaborating with private pathology providers and the addition of two part time data acquisition staff (0.15 FTE each). Such staff are highly qualified (RN and pharmacy graduate), but in addition require significant investment in training, undertaken by the data coordinator. This has proven very successful, evidenced by a rapid growth rate in the database.

Data quality checks

We have developed an extended system of reports to improve our monitoring of data quality. This assists in locating missing data ad performing data integrity and range checking.

Consultant surgical series report

One of the major objectives for the registry is to produce routine reports for data contributors that will help them monitor their outcomes over time. This requires both appropriate risk adjustment and a comparison group for a ‘current practice’ control. We have produced the first version of such a report and are currently engaged in consultation about improvements. A sample is shown. For radical prostatectomy patients, a useful tool is CAPRA-S, developed and validated by the CAPSURE team. This incorporates diagnostic PSA, pathology Gleason, surgical margin status, lymph node status and seminal vesicle invasion into a single score which can be categorized into low, moderate and high risk of recurrence. The CAPRA score has been validated in our population [1] and found to be excellent discriminator of risk of recurrence.

Patient summary report

Another benefit of the clinical registry is its capacity to present data from multiple systems in a summary form to provide a single page view of each patient’s diagnosis and treatment. The Patient Summary Report was developed to use this capacity to provide a single page summary of a patient’s diagnosis and treatment over time, including a graphical representation of treatments against PSA. The report is now available at the point-of-care with the SA-HEALTH domain to all data contributors.
Promoting the work of the collaborative - Website

The SA-PCCOC steering committee commissioned a website in 2011 to establish an online presence for communicating for promoting the database to potential collaborators and sponsors, promote publications and disseminate reports a unique domain name at http://www.sa-pccoc.com/. This website provides information about the database, our partnerships, funding, output, news and achievements. In addition it hosts a members section where we can post working documents, and a wiki, as described below with database documentation and logs.

As a consequence of developing stronger collaborations with the universities, we also have pages on others sites as follows: Flinders University www.flinders.edu.au/cancer/sa-pccoc.cfm, University of Adelaide http://health.adelaide.edu.au/surgery/sapccoc/ and The Hospital Research Foundation http://www.hospitalresearch.com.au/research/diseases-illnesses/prostate-cancer/
A Knowledge Base for collaborators and data management:

Documentation of decisions regarding data collection, data definitions and logging relevant events such as a change in IMVS PSA assays and introduction of new staging or grading versions is a constant task for data repositories. Consistent with a move away from paper-based records, the data management team has established a wiki.
Linked to our website, this knowledge base provides a version repository for the data management team on the following:

- Data collection business rules
- Data dictionaries and variable descriptions
- Routine data management and data collection tasks
- A summary of each research study and information about how data is compiled.

This information is very helpful when research datasets need to be revisited, and as a record of the developing data collection system.

**Movember**

SA-PCCOC was contacted by and joined an initiative by prostate cancer fund-raising organisation Movember to establish a national prostate cancer database. This is a national initiative and joins together a number of organisations which have collected prostate cancer data in different contexts, such as patterns of care studies (NSW, Queensland), and a population–based prostate cancer registry at Monash. Movember are prepared to fund “A ‘federated’ Australian registry that builds on existing initiatives currently undertaken at a state registry level, to a model that, with the fullness of time, would be able to provide valid nation-wide comparisons of important outcomes for men living with prostate cancer in order the guide system improvement at all levels.”

Movember has established a web forum for discussion and intend holding an initial meeting of the steering committee for the initiative in early April. SA-PCCOC members Dr Kim Moretti and Carole Pinnock have been appointed to the steering committee, as has SA’s Professor David Roder, author of Cancer Australia’s ‘National Cancer Data Strategy for Australia’ and a leader in the field of cancer epidemiology.

**Challenges and the Future**

**A new platform**

SA Health has embarked on an ambitious project to replace a number of disparate and legacy systems with a single patient electronic health record system called EPAS. The transition will occur over several years; however, as a consequence, support for existing systems has significantly diminished and will ultimately render one of SA-PCCOC’s data linkage systems (eProstate) unusable.

Together with emerging data requirements and an aging collection system, we have accelerated our timetable for moving to a new platform. An important step in this was to develop an architectural roadmap for consolidating SA-PCCOC systems. A business requirements specification has also been developed as the basis for assessing suitable replacement systems. The document is attached. Potential platforms include a locally developed one, that used by Monash University for their prostate cancer registry, CAISIS, a
US-developed open source software package and the CAPSURE application. These enquiries are progressing.

**Feasibility of a NT expansion**

SA-PCCOC Urologists Kym Horsell frequently visits the Northern Territory and is one of several Urological Consultants providing the only specialised Urology Service at the Royal Darwin Hospital. Although there are not many prostate cancer diagnoses in the Northern Territory (population 230,000, about one eighth the population of SA), there is a suspicion that many of the 50 new diagnoses per year are late diagnoses with poor prognoses. We have taken advantage of former SA-PCCOC data manager David Tamblyn’s visit to Darwin to explore the feasibility of a similar prostate cancer registry in that city. Discussions with radiation Oncologist Dr Siddhartha (Sid) Baxi, Health Gains (Epidemiology) Unit in the NT government, Steven Guthridge and Director of the NT Department of Health and Families, Kristine Luke, suggest that it is feasible and would be supported by local clinicians. David Tamblyn is preparing a strategy document which includes suggestions for the siting and staffing of the project.

Sid Baxi is warmly supportive, and has been appointed as NT representative on the Movember national database steering committee. We think that with funding from Movember, the prospects for go-ahead look good.
Publications submitted/accepted

- **Loss of stromal androgen receptor depletes the protective microenvironment and leads to poor outcome in prostate cancer** Damien A. Leach, Eleanor F. Need, Samarth Chopra, David J. Tamblyn Tina Kopsaftis Georgina M. England Carole B. Pinnock Gail P. Risbridger, Lee Peng, Renea A. Taylor, Grant Buchanan Submitted to Cancer Research, 16.3.2012

- **Comparative analysis of three risk assessment tools in Australian prostate cancer patients** David J. Tamblyn, Samarth Chopra, Changhong Yu, Michael W. Kattan, Carole Pinnock, Tina Kopsaftis s. BJUI (108 supp 2), November 2011, p 51-57.

Abstracts Presented

- **Poorly differentiated low PSA prostate cancer: Evaluation of survival and treatment outcomes** Alexander Jay, Carole Pinnock, Tina Kopsaftis, David Tamblyn and Kim Moretti
  *Poster presented in Darwin April 2012 at USANZ national meeting*

- **Comparison of TRUS Biopsy and Subsequent Radical Prostatectomy Histology to Assess Rate of Upgrading in Gleason 3+4 Prostate Cancer** Lee J, Plagakis S  
  *Abstract presented at the SA section USANZ meeting October 2011 and USANZ National meeting in Darwin March 2012*

- **SA Prostate Cancer Clinical Outcomes Database: 2011 Update** Kim Moretti on behalf of SA Prostate Cancer Outcomes Database Steering Committee and Management Team.
  *Abstract presented at the SA Section Urological Society of Australia and New Zealand (USANZ) meeting October 21, 2011*

- **Is Robot Assisted Radical Prostatectomy an effective treatment for pT3 Prostate Cancer?** Samarth Chopra, Scott Walsh, Tina Kopsaftis, Carole Pinnock, Peter D Sutherland.
  *Abstract submitted for presentation at the AUA 2011.*

- **Stromal but not epithelial androgen receptor level is associated with prostate cancer related death.** Samarth Chopra, Damien Leach, Eleanor F Need, Villis R. Marshall, Tina Kopsaftis, David Tamblyn, Carole Pinnock, Tony Thomas, Grant Buchanan.  
  *Abstract accepted as a moderated poster presentation at the AUA, May 2011, Washington DC, USA*

- **SA Prostate Cancer Clinical Outcomes Database: 2010 Update** Carole Pinnock on behalf of SA Prostate Cancer Outcomes Database Steering Committee and Management Team.  
  *Abstract presented at the local USANZ meeting 11&12 September 2010*

- **Clinical Profile of Veterans and Non-Veterans diagnosed with Prostate Cancer in the South Australian Prostate Cancer Outcomes Database.** HARBISON, S. CHOPRA, C.PINNOCK, T. KOPSAFTIS, S. WALSH.  
  *Abstract presented at the local USANZ meeting September 2010*

- **Poorly differentiated low PSA prostate cancer – how do these men perform?** A JAY, C PINNOCK, D TAMBLYN, T KOPSAFTIS.  
  *Abstract presented at, SA section USANZ meeting September 2010 (won St. Paul’s ball Prize for Best Trainee Paper).*  
  *Abstract submitted for presentation at the AUA 2011.*
- Comparative analysis of predictive accuracy of risk assessment tools in Australian Prostate Cancer patients S CHOPRA, D TAMBLYN, Y CHANGHONG, C PINNOCK, T KOPSAFTIS, M KATTAN. Abstract presented at the, SA section USANZ meeting September 2010 (won prize for Best Paper) and submitted for presentation at the AUA 2011.

- Active Surveillance – can we reduce the rate of failure? S CHOPRA, M CHONG, D TAMBLYN, T KOPSAFTIS, C PINNOCK. Abstract accepted as a moderated poster presentation at the AUA, May 2011, Washington DC, USA

Grants/Funding received 2011/12

- Flinders Centre for Innovation in Cancer. Delays in care of older men diagnosed with prostate cancer: $18,052. Dr Carole Pinnock, A/Prof Richard Woodman


- SA Health and Medical Research Institute (SAHMRI) Data Manager support program., $29,750


- Urological Society of Australia and New Zealand – SA Section $25,000 SA-Prostate Cancer Clinical Outcomes Collaborative – infrastructure support.

- Ferring Pharmaceuticals database sponsorship $15,000

- Ipsen Pty Ltd, $5000

- Hospira Pharma research grant for one year

Projects going forward

- Prostate-Specific Antigen (PSA) rate of decline post external beam radiotherapy may predict prostate cancer death. Analysis of PSA kinetics in the first two years post external beam radiotherapy for localised prostate cancer. Publication in preparation. Dr Zumin Shi, Dr Stephen Kinsey-Trotman, Dr Carole Pinnock, Dr Martin Borg, Dr Kim Moretti.

- Development of risk adjusted clinical outcomes for Consultant’s Case series. Steering Committee, SA-PCCOC, Data management team.


- Prostate Cancer Clinical Outcomes Collection in the Northern Territory. Kym Horsell, D.Tamblyn, steering committee. Strategic plan in preparation

- Movember: Plan to progress a national prostate cancer outcomes database. Our representatives on national steering committee- K. Moretti, C.Pinnock. Also on committee from SA: Prof David Roder

- Migration to a new database platform: Documentation of requirements and process.
Conclusion

2011/12 has been an exciting year for the database with new opportunities opening up and a consolidation of existing achievements.

Signed:

Chair: Kim Moretti MBBS, FRACS (Urol)

Executive Officer: Carole Pinnock AM, PhD

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