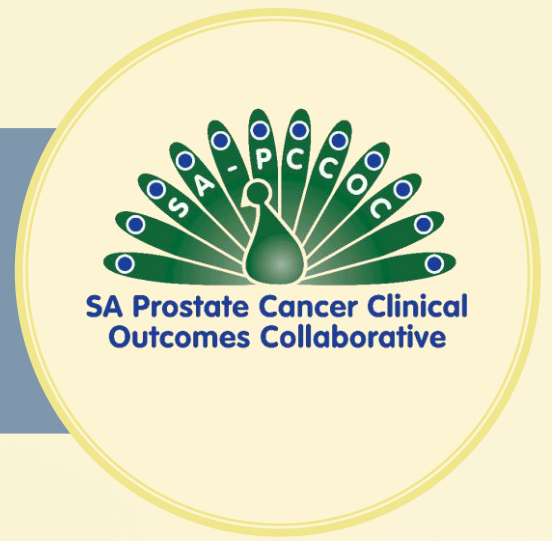


# SA-PCCOC ANNUAL REPORT



2013

*Towards a Population Based Registry*



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## SA-PCCOC Vision

### VISION

The South Australian Prostate Cancer Clinical Outcomes Collaborative (SA-PCCOC) is a multi-centre, multidisciplinary collaboration between men diagnosed with prostate cancer, clinicians involved in the treatment of prostate cancer and researchers.

We are committed to maintaining a comprehensive data collection of men diagnosed with prostate cancer and utilising evidence-based tools for assessing outcomes of treatment.

### AIMS

- To undertake clinical outcomes research in order to better understand progression of prostate cancer and ways of facilitating clinical decision-making
- To provide data to contributors relating to their clinical practice for audit and feedback purposes
- To facilitate clinical prostate cancer research for post-graduate students, surgical trainees, clinicians and researchers
- To collaborate closely with other prostate cancer registers in Australia and particularly in the Northern Territory
- To seek collaboration with other institutions and databases to validate the quality of data collection and contribute to multi-institutional research

## Chairman's Report

The year 2013 again proved challenging. Dr. Carole Pinnock, SA-PCCOC's Executive Officer, retired from her position in mid-2013, though continued in an active role on the steering committee as a research consultant and adviser. I am pleased to announce that Dr. Michael O'Callaghan PhD has been appointed in her place as Executive Officer of SA-PCCOC and Senior Researcher and Educator in the Urology Unit of the Repatriation General Hospital. He comes to us with a background in physiology, biochemistry, epidemiology and registry creation and management. He received several fellowships and awards whilst completing his PhD, including that for the best thesis in his discipline. He was instrumental in setting up the Australian cerebral palsy research study, and has consulted internationally in New Zealand and Singapore, advising on similar registries in those countries. Although he was new to the field of prostate cancer and urology when he first came on board, Michael has worked prodigiously to familiarise himself with these disciplines, and has contributed significantly to our research programme, publications, and has written and submitted many grant applications. Michael was selected from a very good short list of applicants, and the quality of those who applied for Carole's position speaks highly of the fact that SA-PCCOC is regarded both in SA and nationally as a significant organisation and research outcomes unit.

Clinical outcomes research continues to be the poor cousin of laboratory based endeavours; however there are immediate gains to be made in translational research by combining tissue bio-banks and clinical outcomes data and collaborating with similar groups. In this respect we have been successful in engaging with numerous other organisations throughout the year, including the Basil Hetzel Institute of the University of Adelaide, Population Research and Outcomes Studies (PROS) of the University of Adelaide, the Sansom Institute of the University of South Australia, Cancer Australia, Movember, the Nutritional Physiology Research Centre at the University of South Australia, and the Alan Walker Cancer Centre in Darwin.

For me, three highlights stand out in 2013. The first is that we have taken over responsibility for what was formerly known as the Lion's Australia Prostate Cancer website following that organisation's decision to no longer provide financial or physical support for its continuation. This is not new territory for us, as South Australian interests and personnel were largely responsible for the original construction and content of the website. The website has been rebranded as the SA-PCCOC Prostate Cancer Website and is currently in the process of undergoing a major upgrade, both in content and also functionality.

## CHAIRMAN'S REPORT

The second major highlight is the establishment of the Australian Prostate Cancer Clinical Registry (APCCR) which is funded by Movember, and hopes to capture 90% of all new prostate cancer diagnoses in Australia by the end of 2016. It will be unique in the world, in that it will capture not only clinical and pathological data, but also extensive patient reported outcome measures (PROMS), the latter not being featured prominently in most other prostate cancer registries. SA-PCCOC has been contracted to collect and contribute the South Australian data to the national registry. David Roder (Professor of Cancer Epidemiology at the University of South Australia), who is a member of our Steering and Research committees, was selected as the inaugural chairman of the Steering Committee for the APCCR, and Kim Moretti (Chairman & Principal Investigator of SA-PCCOC), was invited onto the Steering Committee as the SA representative. Our organisation is thus centrally placed to make a substantial contribution and influence to this Australian initiative.

Lastly, I mention the commissioning of a new, flexible data platform - *The Cloud Factory* - to replace our aging legacy systems. We worked in close association with that company to configure their product for our purposes, and since going live, the new platform has proved to be an outstanding success with excellent functionality. We plan to continue our association with *The Cloud Factory* in developing electronic tools and collection methods to facilitate data collection.

**Associate Professor Kim Moretti**  
Chairman and Principal Investigator  
MBBS FRACS (Urol)  
June 10<sup>th</sup> 2014

A/PROF KIM MORETTI  
CHAIR, SA-PCCOC



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# RESEARCH UPDATE

## Research Update

### TRANSLATIONAL RESEARCH

During 2013 the successful collaboration with the Cancer Biology Group at the Basil Hetzel Institute for Translational Research continued. Dr. Andrew Trotta was lead author on a publication in the *International Journal of Cancer* describing how androgen receptor gene expression is regulated to modify prostate cancer tumour growth. This work was possible using patient data drawn from the SA-PCCOC database, together with tumour samples available for the same group of men. This unique combination of clinical data, together with samples available for molecular analysis provides exciting opportunities for collaborative prostate cancer research.

### PREDICTING CANCER OUTCOMES

An important aspect of SA-PCCOC's research objective is to develop robust tools to aide decision making. 2013 saw the publication of a prediction tool using Prostate Specific Antigen (PSA) Velocity to predict if prostate cancer will lead to death in patients treated by radiation therapy. This work was led by collaborating biostatistician Dr. Zumin Shi from PROS at the University of Adelaide. The work was published in the journal *Radiotherapy and Oncology* and also presented at the 2013 Clinical Oncology Society of Australia Annual Scientific Meeting. This work continues in 2014 with further work presented at the Urological Society of Australia and New Zealand Annual Scientific Meeting in March 2014.

### CLINICAL EPIDEMIOLOGY

Accurate biopsy results determining the Gleason score of prostate cancer is an important step in patient treatment. Based on the results obtained, patients with their clinicians decide which treatment path to take, a decision which will influence cancer outcomes and also quality of life.

When patients elect to be treated by radical prostatectomy, there is opportunity to see how accurate the original biopsy test was. This year, SA-PCCOC studied the accuracy of biopsy tests are in South Australian patients. Supporting other studies around the world, biopsies were consistent in up to 66% of patients with up to 27% of tumours found to be more aggressive at the time of surgery than when the biopsy was taken. Differences in tumour grading between biopsy and surgery were influenced by the age of the patient and also the time between taking a biopsy and performing surgery.

A/PROF  
MARTIN BORG  
CHAIR,  
RESEARCH COMMITTEE



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## The Database

### DATA COLLECTED

SA-PCCOC collects data relating to men's prostate cancer diagnosis, treatment, pathology and surgical outcomes. Patients are also asked about the outcomes they experience such as incontinence and impotence. As at December 2013, the total number of patients recruited reached 8,432 (Figure 1.). Overall, the average age of men at the time of their diagnosis was 66 years (Figure 2.). The database continues to recruit men receiving a spectrum of treatment options (Figure 3.) providing a valuable cohort for tracking the outcomes of each type of treatment over time. As the database continues to grow, it remains a challenge to maintain data collection rates.

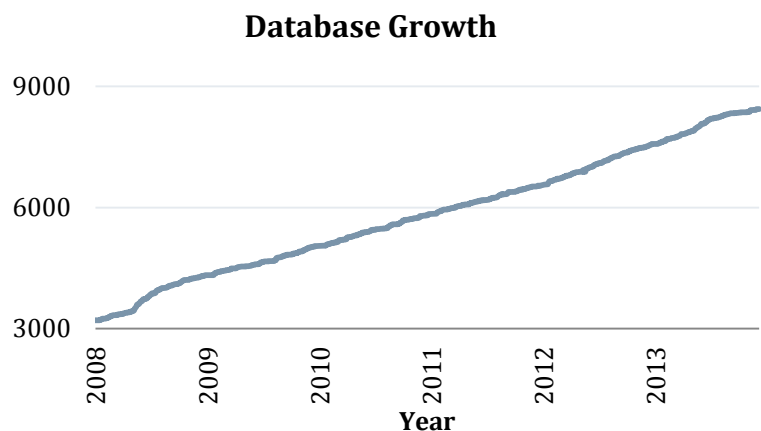


Figure 1. SA-PCCOC database - growth 2008-2013

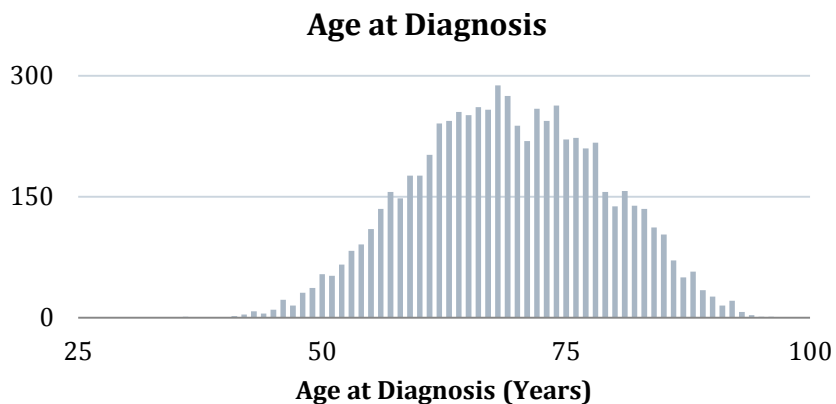


Figure 2. SA-PCCOC database – patient age at diagnosis

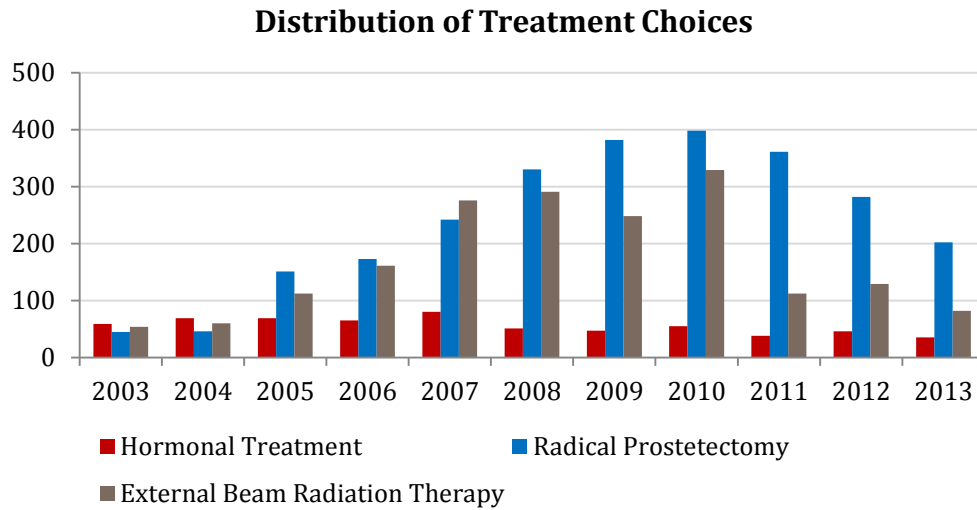


Figure 3. Whole of SA-PCCOC database – patient treatment choices

## 2013 RECRUITMENT

During 2013, 862 patients were added to the SA-PCCOC database (Figure 4.). This represents 53% ascertainment of all prostate cancer cases diagnosed within South Australia, using projections provided by the Australian Institute of Health and Welfare as a denominator (Table 1.).

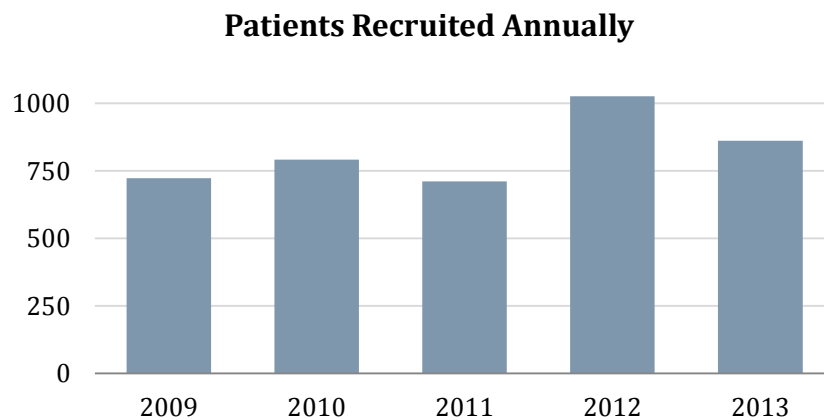


Figure 4. SA-PCCOC database – patients recruited annually



# THE DATABASE

Of patients recruited in 2013, 68% were from public hospitals with the remaining 32% from private practices. Average age at the time of diagnosis was 69 years with most treatments being with radical prostatectomy (63%) or radiation therapy (26%, Table 1.).

SA-PCCOC 2013 cohort	
<b>Number of Patients Recruited</b>	862
<b>Population coverage</b>	53%
<b>Mean Age at Diagnosis</b>	69
<b>Public patients</b>	68%
<b>Radical Prostatectomies</b>	63%
<b>Radiation Therapy</b>	26%
<b>Hormone Treatment</b>	11%

Table 1. 2013 recruitment summary – patient characteristics

## ETHICS FRAMEWORK

The SA-PCCOC database has had active ethics approval from all contributing hospitals since its inception in 1998. Historically, the database had operated under a waiver of consent model for public hospitals and a consenting model in private practices. In 2013 these policies were reviewed and approval granted for an opt-out model to operate across the state. Under this model, patients diagnosed with prostate cancer are provided with an information sheet about the database prior to their initial treatment. Patients are included in the database unless the data management team is contacted. This change in policy is consistent with international guidelines for clinical registries and provides a consistent framework for all recruitment. Recruitment rates will be monitored closely in 2014 to assess the impact of this policy change.

## EXPANSION OF PRIVATE PRACTICE RECRUITMENT

Recruitment in private practices continues at South Terrace Urology, Urological Solutions and from consultants Dr. Jimmy Lam and Dr. Alan Stapleton.

## THE DATABASE

St Andrew's Hospital has also commenced recruiting patients and this is particularly important with the relocation of the da Vinci robot in October 2013 from the Royal Adelaide Hospital to St Andrew's Private Hospital. Public patients will have access to the machine under an agreement with SA Health, and SA-PCCOC will continue to collect data on all robotic prostatectomy patients.

### THE CLOUD FACTORY PLATFORM

During 2013, SA-PCCOC implemented a new customized web-based application to store data and manage patient recruitment. This system was provided by *The Cloud Factory* and supported by infrastructure funding provided by the South Australian Health and Medical Research Institute (SAHMRI). The new system allows secure data entry from multiple sites and replaces a dated system that was no longer compatible with the hardware within SA Health. With the pending roll out of electronic health care records across South Australia, this new system will position SA-PCCOC well for efficient and secure data collection and storage into the future. The system will also incorporate data linkage and tailored diagnostics and reporting.

DR. MICHAEL O'CALLAGHAN,  
EXECUTIVE OFFICER



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# CONSUMER ENGAGEMENT

## Consumer Engagement

SA-PCCOC maintains close links with the community and prostate cancer patients. The collaboration is privileged to have input from Mr. Jeff Roberts as a member of the steering committee.

Mr. Roberts was diagnosed with prostate cancer in 1999. For treatment he elected to have a radical prostatectomy which resulted in a very successful outcome. Following treatment Mr. Roberts has been extensively involved with the Prostate Cancer Foundation of Australia (PCFA) by way of support, awareness and advocacy groups. Currently, Mr. Roberts is a Support Group Representative on the PCFA SA Board.

Mr. Roberts advocates strongly for increased prostate cancer specialist services and patient support together with accessible education material for newly diagnosed men.

MR. JEFF  
ROBERTS  
SA-PCCOC  
Consumer  
Representative



[thebanjeff@bigpond.com](mailto:thebanjeff@bigpond.com)

# GRANTS RECEIVED

## Grants Received

### SA & NT SECTION OF THE UROLOGICAL SOCIETY OF AUSTRALIA AND NEW ZEALAND

Title: SA-PCCOC Database Sponsorship

Period of Funding: 2012-2013



**UROLOGICAL SOCIETY  
OF AUSTRALIA  
AND NEW ZEALAND**

### CANCER AUSTRALIA

Title: Piloting of a Prostate Cancer Data Set Specification

Investigators: Brook N, Pinnock C

Period of Funding: 2013



**Australian Government  
Cancer Australia**

### MOVEMBER

Title: The Australian Prostate Cancer Clinical Cancer Registry

Investigators: Moretti KL, Pinnock C, Walsh S, Kopsaftis T, O'Callaghan ME

Period of Funding: 2014-2016



# GRANTS RECEIVED

## SOUTH AUSTRALIAN HEALTH AND MEDICAL RESEARCH INSTITUTE

Title: Beat Cancer Project – Data Manager Funding

Investigators: Moretti KL

Period of Funding: 2014-2015



## THE REPAT FOUNDATION

Title: Optimising Hormone Treatment for Prostate Cancer Patients

Investigators: O'Callaghan ME, Moretti KL, Kichenadasse G, Walsh S, Kopsaftis T

Period of Funding: 2014



## FERRING PHARMACEUTICALS

Title: SA-PCCOC Database Sponsorship

Period of Funding: 2011-2013



## Publications

### PEER REVIEWED JOURNAL ARTICLES

1. **Knockdown of the cochaperone SGTA results in the suppression of androgen and PI3K/Akt signaling and inhibition of prostate cancer cell proliferation.**

Trotta AP, Need EF, Selth LA, Chopra S, Pinnock CB, Leach DA, Coetzee GA, Butler LM, Tilley WD, Buchanan G.

International Journal of Cancer. 2013 Dec 15;133(12):2812-23.

2. **Upgrading of standard and Transperineal Transrectal Ultrasound Guided Prostate Biopsies on Subsequent Radical Prostatectomy: A Population Based Study.**

Osei-Tutu L, S Plagakis S, Lee J, Pinnock C, Moretti KL.

The Internet Journal of Urology, 2013 Volume 11 No.1

3. **Prostate-specific antigen (PSA) rate of decline post external beam radiotherapy predicts prostate cancer death.**

Shi Z, Pinnock CB, Kinsey-Trotman S, Borg M, Moretti KL, Walsh S, Kopsaftis T.

Radiotherapy and Oncology. 2013 May;107(2):129-33.

### PRESENTATION ABSTRACTS

1. **Analysis of Quality of Life survey response rates from the South Australian Prostate Cancer Clinical Outcomes Collaborative.** Lovelace Osei-Tutu, Jason Lee. Abstract presented at the 66<sup>th</sup> USANZ National Meeting in Melbourne in 2013, BJUI Supp 1, 2013,111 p59

2. **Prostate-Specific Antigen (PSA) rate of decline post external beam radiotherapy may predict prostate cancer death:** Stephen Kinsey-Trotman, Zumin Shi, Carole Pinnock, Martin Borg, Kim Moretti, Scott Walsh, Tina Kopsaftis. BJUI Supp 1, 2013,111 p93;

3. **Radical Prostatectomy: do positive surgical margins at the apex matter?** P.Penkoff, Carole Pinnock, Kym Horsell, Kim Moretti, Scott Walsh, Tina Kopsaftis, and the SA-Prostate Cancer Clinical Outcomes Collaborative. Abstract presented at the 66<sup>th</sup> USANZ National Meeting Melbourne in 2013. BJUI Supp 1, 2013,111 p58

4. **Analysis of transperineal biopsy and subsequent radical prostatectomy, utilising the SA-PCCOC database:** Lovelace Osei-Tutu, Scott Walsh, Tina Kopsaftis, Jason Lee. Abstract presented at the 66<sup>th</sup> USANZ National Meeting in Melbourne in 2013. BJUI Supp 1, 2013,111 p98

## Looking Ahead

SA-PCCOC is committed to building a population based register of men with prostate cancer in South Australia. The organisation has a number of key objectives to help meet this goal:

### EXPANDING RECRUITMENT AND CONTRIBUTING TO THE AUSTRALIAN PROSTATE CANCER CLINICAL REGISTER

SA-PCCOC currently recruits approximately 55% of all diagnosed prostate cancer cases in the state. By the end of 2014 we will have data linkage tools in place to provide us with 90% of all histological prostate cancer notifications in South Australia and to contribute data to the newly formed Australian Prostate Cancer Clinical Register.

### EXPANDING DATA LINKAGE CAPACITY

With expanded population coverage and limited data collection resources, SA-PCCOC will seek to implement data linkage solutions to automate collection of important treatment data. This objective will include data linkage to all PSA test results for men currently recruited and seeking further opportunities as electronic healthcare records are rolled out across the state.

### EXPANDING RESEARCH STUDENT COHORT

SA-PCCOC collaborates with all three universities in South Australia together with the newly formed South Australian Health and Medical Research Institute. SA-PCCOC will expand the number of projects available for research student engagement at all levels of postgraduate study and for surgical trainees.

### EXPANDING CONSUMER ENGAGEMENT

SA-PCCOC is committed to further building its consumer engagement in the future, particularly through prostatehealth.org. Rebranding of this website is currently underway and we seek to re-activate a key element – online clinical support to men and families with prostate health questions.

Successful achievement of these goals will transform SA-PCCOC by the end of 2014. The organisation's historic aims and objectives will be maintained along with previous levels of performance and excellence. SA-PCCOC will provide a significant, pre-eminent and data rich prostate cancer registry into the future, and be well positioned to contribute in the wider area of registry informatics.

# COMMITTEE MEMBERS

## Committee Members

### STEERING COMMITTEE

- Kim Moretti: Chairman & Principal Investigator
- Kym Horsell: Deputy Chairman
- Michael O'Callaghan: Executive Officer
- Carole Pinnock: Research Consultant and Advisor
- Martin Borg
- Kym Pese
- Peter Sutherland
- Kerri Beckmann
- Michael Chong
- Darren Foreman
- Caroline Miller
- Tina Kopsaftis
- Scott Walsh
- David Roder
- Jimmy Lam
- Jason Lee
- Leigh Pretty
- Jeff Roberts

### RESEARCH COMMITTEE

- Martin Borg: Chairman
- Grant Buchanan
- Kim Moretti
- Kerri Beckmann
- Michael Chong
- Darren Foreman
- Kym Horsell
- David Roder
- Tina Kopsaftis
- Scott Walsh
- Jimmy Lam
- Daniel Spernat
- Ganessan Kichenadasse
- Jason Lee
- Michael O'Callaghan

### DATA MANAGEMENT TEAM

- Michael O'Callaghan
- Scott Walsh
- Tina Kopsaftis
- Karen Hall
- Elspeth Raymond



# CONTACT INFORMATION

## Contact Information

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Signed 12<sup>th</sup> June 2014:



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Chairman and Principal Investigator  
MBBS FRACS (Urol)



**Dr. Michael O'Callaghan**  
Executive Officer  
BSc (Hons) PhD