# TABLE OF CONTENTS

## Contents

- SA-PCCOC Vision ................................................................. 2
- Chairman's Report.............................................................. 3
- Research Update............................................................... 5
- The Database ........................................................................ 6
- Consumer Engagement ....................................................... 11
- Grants Received ................................................................. 12
- Publications ......................................................................... 15
- Looking Ahead ..................................................................... 17
- Committee Members .......................................................... 18
- Contact Information ............................................................ 19
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
Networking is the key word to describe SA-PCCOC in 2014 and as a result we increased our national and international profile, presence and footprint consistently throughout the year.

Our organisation is the South Australian arm of the Australian Prostate Cancer Clinical Registry (APCCR), having been instrumental along with the Department of Epidemiology of Monash University in developing this Australian database. As a consequence the Movember organisation established the Prostate Cancer Health Outcomes Research Unit (PCHORU), which is an affiliation of the University of South Australia, Monash University and the South Australian Health and Medical Research Institute (SAHMRI), and includes SA-PCCOC and the Victorian Prostate Cancer Registry, to report on demographics, treatment outcomes and patterns of treatment across both states. I continue our association with the International Consortium of Health Outcomes Measurement (ICHOM), which recently published their localized prostate cancer minimum data set in the journal, European Urology. We have strengthened our links with SAHMRI by participating in their Adelaide Registry Consortium Group. On the international scene, we have networked with the Michigan Urological Surgical Improvement Collaborative (MUSIC), CaPSURE in San Francisco and Memorial Sloan Kettering Cancer Centre. In 2015 we will engage in collaborations with these organisations.

SA-PCCOC has presented at all major national meetings, including USANZ, ANZUP and COSA, as well as internationally at the 2014 annual scientific conference of the European Society of Medical Oncologists (ESMO). Our presentation on prostate cancer in octogenarians, presented by Dr Sina Vatandoust, was awarded the prize for the best poster at the conference, which is an outstanding achievement given ESMO’s high profile and its’ 13,000 plus delegates.

During the year, we’ve seen major advances in our infrastructure research related to automated electronic data collection and have been able to commence filling gaps in our data fields. We have also made substantial progress in developing unique linkage tools, which will increase the efficiency of our data collection and decrease our costs in this area, so that those monies which would have otherwise been consumed, can be channelled in more productive directions. In this respect we received a grant from a Hospital Research Foundation affiliate, namely the Australian Prostate Cancer Research Society Ltd. The progress in these areas of infrastructure has, in the main, been due to the innovations of Scott Walsh along with Michael O’Callaghan and Tina Kopsaftis.
Unfortunately, we have not been able to propel our website (www.prostatehealth.org.au), the rebadged original “Lions Club Prostate Cancer” website for which we own all the intellectual property, as quickly as we had hoped. Hopefully next year, we’ll be able to secure a long term funding stream for the site.

The past twelve months has been a very good year for SA-PCCOC placing it on a firm launching platform for future national and more importantly, international collaborations. 2015 will hopefully be a more extraordinary 12 months, when a lot of threads will finally come together and sown seeds produce bounty. I would like to thank all of the team of members and individuals that have contributed to the success of SA-PCCOC in 2014. Congratulations, thank you and well done.

Associate Professor Kim Moretti
Chairman and Principal Investigator
MBBS FRACS (Urol)
March 2015

A/PROF KIM MORETTI
CHAIR, SA-PCCOC

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Research Update

PATIENT REPORTED OUTCOMES MEASURES
During 2014, Associate Professor Kim Moretti has continued participation in the International Consortium for Health Outcomes Measurement (ICHOM). ICHOM has reviewed instruments relating to prostate cancer health outcomes measures and published recommendations in the *European Urology*. Associate Professor Moretti presented a summary of this work at the 2014 World Cancer Congress. SA-PCCOC is currently using instruments recommended by this international panel and collecting the majority of data detailed in this report.

OLDER MEN
Medical oncologists Dr Sina Vatandoust and Dr Ganessan Kichenadasse have been investigating prostate cancer outcomes in a group of older men, particularly those aged over 80 years at the time of diagnosis. This work is particularly topical given Australia's aging population and the perception that men are most likely to 'die with prostate cancer, rather than from prostate cancer'. This adage has been challenged by the study results which have been presented at ANZUP, the SA/NT USANZ section meeting and the European Society of Medical Oncology meeting. At the later meeting, Dr Vatandoust was awarded ‘best poster’, an outstanding effort at a conference attracting over 13,000 delegates.

BONE HEALTH
In collaboration with Professor Bogda Koczwara and honours student Rachel Roberts, the bone health of prostate cancer patients treated with hormonal therapy at Flinders Medical Centre has been reviewed. The study found that no men receiving this treatment had DEXA scans to assess bone density, compared with 55% of women with breast cancer also receiving hormonal therapy. A survey of prostate cancer health care providers showed that lack of time and training were the most important barriers to taking a more active role in bone health management. Medical oncologists were identified as the most appropriate people to manage bone health in cancer survivors.

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 2014, the total number of patients recruited reached 9,362 (Figure 1.). Overall, the average age of men at the time of their diagnosis was 69 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 clinical follow-up.
Figure 2. SA-PCCOC database – patient age at diagnosis

Figure 3. Whole of SA-PCCOC database – patient treatment choices
2014 RECRUITMENT

During 2014, 915 patients were added to the SA-PCCOC database (Figure 4.). This represents 51% ascertainment of all prostate cancer cases diagnosed within South Australia, using data from the South Australia Cancer register (2009) as a denominator (Table 1.).

![Annual Recruits](image)

Figure 4. SA-PCCOC database – patients recruited annually

Of patients recruited in 2014, 42% were from public hospitals with the remaining 58% from private practices. Average age at the time of diagnosis was 67 years with most treatments being with radical prostatectomy (79%) or radiation therapy (13%).
The South Australian Prostate Cancer Clinical Outcomes Collaborative

SA-PCCOC Snapshot

2014

Men recruited 915

Population coverage 51%

Treatment Choices

- Surgery 80%
- Radiation Therapy 13%
- Hormone Treatment 7%

Public 42% Private 58%

Average age at diagnosis 67
GOVERNANCE CHANGES
In 2014, governance structures for SA-PCCOC were reviewed. The steering and research committees continue to manage the collaboration, albeit with a reduced number of members. A Clinical Contributors group has been introduced to recognise all clinicians who invite patients to participate and to ensure they remain aware of the activities of the collaboration. A Collaborating Researcher group was also introduced to facilitate communication with any researchers who may wish to access SA-PCCOC data.

STUDENT PROJECTS
SA-PCCOC has hosted two summer research students from the University of Adelaide who have won scholarships from the Freemasons Foundation for Men's Health.

Mann Ang (6th year medicine) investigated the outcomes of men who have a very high PSA (over 100) at the time of diagnosis.

Michelle Forgione (1st year science) investigated satisfaction with care in men receiving treatment for their prostate cancer.

DR. MICHAEL O’CALLAGHAN, EXECUTIVE OFFICER
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Consumer Engagement

I have been a consumer representative on SA-PCCOC Steering Committee for the past five years and strongly believe it is important to have representation from support and awareness groups on the committee.

For the past sixteen years I have been active in promoting prostate cancer awareness, often with events involving Prostate Cancer Foundation of Australia (PCFA) – the key organisation for prostate cancer in Australia. Currently there are more than 170 Support Groups affiliated with PCFA.

During my time on the Steering Committee I have learnt a great deal of the activities of SA-PCCOC, Australia's largest numbered prostate cancer patient database, and greatly admire the fantastic achievements of both the Steering and Research Committee's.

MR. JEFF ROBERTS
SA-PCCOC
Consumer Representative

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Grants Received

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

Title: SA-PCCOC Database Sponsorship

Period of Funding: 2014-2016

REBECCA L COOPER MEDICAL RESEARCH FOUNDATION LTD.

Title: ePROSTATE: Custom Software for Prostate Cancer Research

Investigators: O’Callaghan ME, Moretti KL, Walsh S, Kopsaftis T

Period of Funding: 2014

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
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: Prostate Cancer and Co-Morbidities

Investigators: O’Callaghan ME, Moretti KL, Sarfati D, Koczwara, Walsh S, Kopsaftis T, Shi Z

Period of Funding: 2014

FERRING PHARMACEUTICALS

Title: SA-PCCOC Database Sponsorship

Period of Funding: 2014-2016
Lions Australia

Title: SA-PCCOC Database Sponsorship

Period of Funding: 2014
Publications

A full list of SA-PCCOC publications and abstracts can be found on Google Scholar.

2014 JOURNAL ARTICLES


2014 PRESENTATION ABSTRACTS


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 50% of all diagnosed prostate cancer cases in the state. By the end of 2015 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 PSA test results, vital status updates through the Births Deaths and Marriages Register and Radiation therapy treatment.

EXPANDING RESEARCH STUDENT COHORT
SA-PCCOC collaborates with all three universities in South Australia together with the South Australian Health and Medical Research Institute (SAHMRI). 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 will continue to seek partners for the consumer website prostatehealth.org and sponsorship 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 2015. 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

STEERING COMMITTEE

- Kim Moretti: Chairman & Principal Investigator
- Kym Horsell: Deputy Chairman
- Michael O’Callaghan: Executive Officer
- Carole Pinnock: Research Consultant and Advisor
- Martin Borg
- Kerri Beckmann
- Caroline Miller
- Tina Kopsaftis
- Scott Walsh
- David Roder
- Leigh Pretty
- Jeff Roberts

CLINICAL CONTRIBUTORS

- John Bolt
- Nick Brook
- Michael Chong
- David Elder
- Darren Foreman
- Andrew Fuller
- Kym Horsell
- Jimmy Lam
- Jason Lee
- John Miller
- Kim Moretti
- Kim Pese
- Adrian Porter
- Alan Stapleton
- Denby Steele
- Peter Sutherland
- Richard Wells

RESEARCH COMMITTEE

- Martin Borg: Chairman
- Kerri Beckmann: Deputy chair
- Tina Kopsaftis
- Ganessan Kichenadasse
- Scott Walsh
- Michael O’Callaghan
- Kim Moretti
- Caroline Miller

DATA MANAGEMENT TEAM

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

COLLABORATING RESEARCHERS

- Michael Chong
- Darren Foreman
- Kym Horsell
- David Roder
- Grant Buchanan
- Jimmy Lam
- Daniel Spernat
- Jason Lee
- Sina Vatandoust
- Ned Kinnear

- Sally Sara
- Andrew Shepherd
- Nick Brook
- Branimir Rajcic
- Ivan Hoh
- Lovelace Osei-Tutu
- Jonathan Cho
- Peter Penkoff
- Sophie Plagakis
- Bogda Koczwara
Contact Information

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Signed May 2015:

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