SA-PCCOC 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
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Chairman’s Report

2018 will be our 20th anniversary of data collection from South Australia’s major teaching hospitals.

In preparation for that milestone it is probably appropriate to quickly reflect on what SA-PCCOC has accomplished since we began collection as a single surgeon and then a single hospital endeavour in 1998. We have published and presented over 260 times, with almost 1,500 citations and a h-index of 21 and an i10-index of 36. These achievements are remarkable given we are coming from a small population base compared to other jurisdictions. We continue to be the only non-mandated cancer registry that collects more than 90% of new prostate cancer diagnoses. This year we have had 11 publications and abstracts in peer review journals, as well as 18 presentations at state, national and international meetings. Dr Michael O’Callaghan had a podium presentation at the American Urological Association’s Annual Scientific Meeting in Boston and I was able to present in Thailand.

Our outcomes would not be possible without the continuing support of industry and also the Movember Foundation in particular, with whom we continue a close and beneficial collaboration.

2017 was a year not only of continuing evolution but in some respects, one of revolution as well. Our in house team developed a new contemporary logo, and completely redesigned the website, so that it now caters for researchers and health care professionals, men and families affected by prostate cancer, as well as our collaborators and partners. The new website (www.prostatehealth.org.au) is very contemporary and interactive. The information available to men and their families in particular has received positive feedback.

For the third year we again ran a successful research symposium in collaboration with the University of Adelaide’s Freemasons Foundation Centre for Men’s Health, The South Australian Health and Medical Research Institute (SAHMRI), the University of South Australia’s Sansom Institute for Health Research, and Flinders University’s Centre for Innovation in Cancer. Associate Professor Anthony Lowe, the CEO of the Prostate Cancer Foundation of Australia, was the guest speaker, and opened the symposium. Once again we are indebted to the sponsors of the event – Ferring, Ipsen, AstraZeneca, Tolmar and Abbvie pharmaceutical companies.

Our national and international reputation and collaborations continue to grow. This year we received requests for collaboration from interstate, UK universities, the Prostate Cancer Foundation of Australia, and through our association with the University of South Australia, an EORTC quality of life cancer survivorship project.

Once again my thanks to all those involved in SA-PCCOC, and in particular to our sponsors and patients who contribute to the database.

PROF KIM MORETTI
CHAIR, SA-PCCOC
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2017 Research Committee report

The Research Committee of SA-PCCOC met six times in 2017.

The committee comprises members representing the relative professions involved in the care of men with prostate cancer, including myself as chair representing Radiation Oncology, Professor Kim Moretti, Associate Professor Nick Brooks and Dr Darren Foreman representing the urological community, Dr Ganessan Kichenadasse representing the medical oncology specialty, Dr Andrew Vincent as statistician, Tina Kopsaftis and Scott Walsh from the data management team and Dr Michael O’Callaghan as epidemiologist and executive officer.

The SA-PCCOC Research Committee oversees around 30 projects each year, 20% of which are published during the year. Several of the projects were presented at both local and international urological and oncological meetings. These involve cooperation within a wide variety of specialties and centres both locally and interstate.

At each meeting, potential research ideas are formally presented for review. Approved investigators are able to access data from the registry and expertise of the various members of SA-PCCOC. The committee looks forward to developing and promoting further research studies.

A/PROF MARTIN BORG
CHAIR, RESEARCH COMMITTEE
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The Registry
20 years in the making

- 1998: Single surgeon series commences at the Repatriation General Hospital/Flinders Medical Centre
- 2002: 1,000th participant recruited
- 2005-7: Expansion to include private practices
- 2012: Additional public hospitals in the Adelaide metropolitan area recruited
- 2014: Commencement of PCOR-ANZ – national registry
- 2015: 10,000th participant recruited
- 2016: Population coverage reached
- 2017: SA-PCCOC offices re-locate to FMC with the closure of RGH
- 2018: 20 years of SA-PCCOC
- 2019: Expansion to include all cases at Repatriation General Hospital/Flinders Medical Centre
- 2020: Governance processes implemented with formal steering and research committees
- 2022: Registry database updates to state of the art web-based software
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 2017, the total number of patients recruited reached 13,132 (Figure 1.). Overall, the average age of men at the time of their diagnosis was 68 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.
2017 Recruitment

During 2017, 1,300 patients were added to the SA-PCCOC database (Figure 4.). This represents 93% ascertainment of all prostate cancer cases diagnosed within South Australia, using the most recent incidence data published by the South Australian Cancer Registry (2014) as a denominator.

Of patients recruited in 2017, 33% were from public hospitals with the remaining 67% from private practices. Average age at the time of diagnosis was 67 years with most treatments being with radical prostatectomy (71%) or radiation therapy (18%).

<table>
<thead>
<tr>
<th>Therapy</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Surgery</td>
<td>57.1%</td>
</tr>
<tr>
<td>Radiation</td>
<td>22.4%</td>
</tr>
<tr>
<td>Hormones</td>
<td>10.6%</td>
</tr>
<tr>
<td>Observation</td>
<td>9.5%</td>
</tr>
<tr>
<td>Chemotherapy</td>
<td>0.4%</td>
</tr>
</tbody>
</table>

Figure 1. SA-PCCOC database - growth 2007-2017

DR. MICHAEL O’CALLAGHAN
EXECUTIVE OFFICER
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2017 SA-PCCOC Snapshot

Number recruited: 1,300

Population coverage: 93%
(using last published SA CR incidence, 2014)

Treatment Choices:
- Surgery: 57.1%
- Radiation: 22.4%
- Hormones: 10.6%
- Observation: 9.5%
- Chemotherapy: 0.4%

Treatment facility:
- Public: 33%
- Private: 67%

Participating Urologists: 71%

Active Research Projects: 30

Publications: 11

Abstracts: 18

Population coverage: 93%
(using last published SA CR incidence, 2014)
Prostate Cancer in South Australia - 2017

**Incidence**
- Prostate Cancer is the most common cancer of males in SA
- The SA Cancer Registry projected 1,132 new cases in 2017
- Incidence is estimated to have dropped 19% since 2014

**Mortality**
- Estimated 248 deaths from prostate cancer in SA in 2017
- Estimated drop of 5% since 2014
- Second most common cause of cancer death in SA

**PSA testing**
- PSA screening in SA
  - Compared with other states in Australia, SA used 30% more PSA screening tests per 100,000 population (MBS data)
- PSA monitoring in SA
  - Compared with other states in Australia, SA used the same number PSA monitoring tests per 100,000 population (MBS data)

**Outcomes**
- 88% - 5 year observed survival after diagnosis
- How do we score 12 months after treatment?
  - Urinary incontinence at 12 months: 74
  - Urinary obstruction at 12 months: 89
  - Sexual score at 12 months: 32
  - Bowel score at 12 months: 79
  - Hormonal at 12 months: 87

Scores are on a scale 0-100, where 0 represents poor health and 100 represents perfect health. Data relates to patients recruited in 2016 who returned questionnaires.

**Support groups**
- 21 prostate cancer support groups in SA

**Specialist nurse**
- 1 prostate cancer specialist nurse for the state (2nd appointed in 2018)
Consumer Engagement

The fastidious recording process of prostate cancer case information which SA-PCCOC staff have evolved for all South Australian prostate cancer afflicted men has ensured a most significant database of cases diagnosed in the state since 1998.

This unique collection of data provides information of inestimable value to researchers and clinicians. The professionally respected team working on the SA-PCCOC Registry deserve our support, recognition and congratulations.

Many South Australians afflicted by prostate cancer are not aware of the significance or scope of the Data Base and would benefit and appreciate education on the importance of maintaining accurate responses to the regular surveys.

The privilege of the invitation to join the Steering Committee as a Consumer Representative challenges me. Principally I strive to pursue a mechanism for enhancing knowledge of the database among my colleagues, contacts and friends in the prostate cancer afflicted community. In addition to supporting the SA-PCCOC perhaps financially, more emphasis to support questionnaires accurately, and the opportunity to attend Symposia on the subject open to the public, I see such awareness as providing the means for many men to be better informed about their disease and to have the confidence to seek answers to the many questions which present to post treatment men.

In my role as a PCFA Ambassador Speaker to men’s groups and my contact with Prostate Cancer Support Groups of the Prostate Cancer Foundation of Australia (PCFA), I am aware of the need for answers to clinically based questions from concerned men with a limited understanding of their health situation. I believe wide promotion of a tailored Symposium in April 2018 would provide a valuable platform for men in the community. Further, this meeting would present SA-PCCOC in the public light it deserves.

MR. DAVID MERRY
SA-PCCOC CONSUMER REPRESENTATIVE
SA Prostate Cancer Symposium

The third South Australian Prostate Cancer Symposium was convened by SA-PCCOC on Friday 20th September in Adelaide. Associate Professor Anthony Lowe (CEO, Prostate Cancer Foundation of Australia) was the invited guest and opened the meeting. There were 100 registrants.

The aim of the symposium is to draw together prostate cancer researchers and clinicians from around the state and provide a snapshot of research underway as well as clinical updates. The forum also provides an opportunity for informal networking which is proving invaluable.

This year we invited a number of "collaborating partners" to participate, included the Sansom Institute for Health Research, University of South Australia; Flinders University Centre for Innovation in Cancer; the Freemasons Foundation Centre for Men’s Health, University of Adelaide, and the South Australian Health and Medical Research institute (SAHMRI). The symposium was sponsored by Ferring, IPSEN, Astra Zeneca, Tomar and Abbvie pharmaceutical companies.

The program included the latest prostate cancer research undertaken in this State, and also discussed on line support for South Australian prostate cancer survivors, the benefits of exercise medicine in prostate malignancy, and the epidemiology and burden of prostate cancer in the western world. The complete program can be found here and the 2017 Symposium flyer Professor Lowe’s talk on “Advancing prostate cancer survivorship research in Australia” was very topical, and for interest one of his slides is reproduced below.

Next year will mark the 20th anniversary of the commencement of SA-PCCOC’s data collection from the major teaching hospitals with another (bigger) symposium planned.
Grants Received

1. SA & NT Section of the Urological Society of Australia and New Zealand  
   Title: SA-PCCOC Database Sponsorship  
   Period of Funding: 2017-2018

2. Movember  
   Title: The Prostate Cancer Outcome Registry of Australia and New Zealand  
   Investigators: Moretti KL, Pinnock C, Walsh S, Kopsaftis T, O’Callaghan ME  
   Period of Funding: 2017

3. The Hospital Research Foundation  
   Title: Infrastructure Grant  
   Period of Funding: 2017

4. Ferring Pharmaceuticals  
   Title: SA-PCCOC Database Sponsorship  
   Period of Funding: 2016-2018

5. Tolmar Australia  
   Title: SA-PCCOC Database Sponsorship  
   Period of Funding: 2017-2019

6. Ipsen  
   Title: SA-PCCOC Database Sponsorship  
   Period of Funding: 2017

7. AstraZeneca  
   Title: SA-PCCOC Database Sponsorship  
   Period of Funding: 2017

8. Abbvie  
   Title: SA-PCCOC Database Sponsorship  
   Period of Funding: 2017

Patient Donations

We gratefully acknowledge patient donations received during 2017 which contribute enormously to helping advance the important research of SA-PCCOC.
Partner groups

1. SA Health
2. Flinders Uni
3. Flinders Centre for Innovation in Cancer
4. Flinders Foundation
5. Adelaide Uni
6. Freemasons Foundation Centre for Men’s Health
7. UniSA
8. Sansom Institute
9. SAHMRI
Publications

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

2017 Journal articles


2017 Presentation Abstracts

1. D Lin, ME O’Callaghan, P Neumann, A Fuller, R Wells, P Sutherland, D Foreman. Does urethral length affect continence outcomes following robot assisted laparoscopic radical prostatectomy (RALP)? SA-NT USANZ Section Meeting, 21st October 2017, Adelaide, South Australia. Winner of the 2017 St Paul’s Ball Award


5. ME O’Callaghan, E Raymond, J Campbell, AD Vincent, K Beckmann, D Roder, S Evans, J McNeil, J Millar, J Zalberg, M Borg and K Moretti. Predicting Patient Reported Outcomes after Radical Prostatectomy: A Systematic Review. Flinders Health Research Week, 4-8 September 2017, Flinders Medical Centre, Adelaide, South Australia

6. A Kahokehr, R Hoffmann, C Logan, D Foreman, K D’Onise, M O’Callaghan. Urological Cancers across South Australia. Flinders Health Research Week, 4-8 September 2017, Flinders Medical Centre, Adelaide, South Australia


11. K Das, F Ordones, A Fuller, M O’Callaghan and N Brook. Comparison of oncological and functional outcomes following radical prostatectomy in clinical T2 and clinical T3 prostate cancers: findings from the SA-PCOCC database. Urological Society of Australia and New Zealand Annual Scientific Meeting, Canberra 24-27 February 2017. Published in BJUI 119, Supplement 2 pg 64.


14. D Lin, S Plagakis, M O’Callaghan, P Neumann, A Fuller, R Wells, P Sutherland and D Foreman. Does age, BMI or prostate volume affect continence outcomes following robot assisted laparoscopic radical prostatectomy (RALP)? Urological Society of Australia and New Zealand Annual Scientific Meeting, Canberra 24-27 February 2017. Published in BJUI 119, Supplement 2 pg 28.


18. Kim L Moretti Co-morbidity assessment in localized prostate cancer
Committee Members

Steering Committee
- Kim Moretti: Chairman & Principal Investigator
- Kym Horsell: Deputy Chairman
- Michael O’Callaghan: Executive Officer
- Martin Borg
- Tina Kopsaftis
- Scott Walsh
- David Merry
- Sally Sara
- Ganessan Kichenadasse
- Braden Higgs

Clinical Contributors
- John Bolt
- Nick Brook
- Michael Chong
- David Elder
- Darren Foreman
- Andrew Fuller
- Kym Horsell
- Alex Jay
- 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
- Tina Kopsaftis
- Ganessan Kichenadasse
- Scott Walsh
- Michael O’Callaghan
- Kim Moretti
- Sally Sara
- Andrew Vincent
- Nick Brook

Data Management Team
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- Karen Hall
- Elspeth Raymond
- Helen Claridge
- Lisa Leopardi

Collaborating Researchers
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- Darren Foreman
- Kym Horsell
- David Roder
- Jimmy Lam
- Jason Lee
- Sina Vatandoust
- Ned Kinnear
- Mann Ang
- Trish Neumann
- Lisa Butler
- Caroline Miller
- Kerry Ettridge
- Krishanu Das
- Flavio Orones
- Sue Evans
- Rasa Ruesckate
- Richard Hoffmann
- Danny Sung
- Alex Jay
- Kate Kennedy
- Kevin O’Shannuesy
- Marion Eckert
- Wendy Winall
- Andrew Shepherd
- Nick Brook
- Sophie Plagakis
- Kerri Beckmann
- Ganessan Kichenadasse
- Alwin Soo
- Stephen-Kinsey Trotman
- Andrew Vincent
- Michelle Forgione
- Adel Aref