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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 decisionmaking
- 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
- To seek collaboration with other institutions and databases to validate the quality of data collection and contribute to multi-institutional research

# Chairman's Report

Our history goes back 18 years, commencing in 1998. Prior to 2000 the database was a single hospital endeavor. From this date we will have been collecting data from the major public teaching hospitals in South Australia for more than 15 years, so 2015 is an appropriate time to reflect on our achievements over the past decade and a half.

During this time SA-PCCOC's influence and reputation has grown, in that we are now recognised both nationally and internationally as a substantial prostate cancer registry and resource. We were the first prospective prostate cancer disease specific registry in Australia and the Southern Hemisphere, commencing in 1998. From inception we have been third party collected, independent of treating physicians and hence able to minimise collection, reporting and physician biases. As a result the quality of our data is unsurpassed.

We are also one of the few prostate cancer registries worldwide which, again since inception, has routinely collected patient reported outcomes (PROMS) and unlike many other registries we capture baseline pretreatment data which is vitally important in assessing the effects of therapy on quality of life.

With time our data dictionary has expanded as has our ability to innovate and collect information electronically direct from their sources such as individual laboratories, administrative data, and hospital records. As a consequence we have a near complete historical record of all patient PSAs before and after diagnosis, which is an extremely powerful collection given that PSA is the most commonly reported de facto end point to reflect disease progression and treatment response.

SA-PCCOC has published in all areas of prostate cancer interest including: urology, medical oncology, radiation oncology, epidemiology and physiotherapy.

Since 1998 the collaboration has published and presented over 180 times and received over 1,000 citations (Google Scholar). 40% of this activity has occurred in the last 5 years. In 2015 we presented at 24 conferences and symposia, of which 14 were national or international meetings. In 2015 we were active in 26 research projects.

The number of patients we collect each year has increased (see page 10). In 2015 we passed the 10,000 mark for the number patients included in the database At the beginning of the year we were collecting 74% of all new prostate cancer diagnoses in this state, and at the end of the year 91%, which will allow us to claim the mantel of a population based registry, a truly remarkable achievement and a world first for a non-mandated cancer registry.

In 2015, SA-PCCOC brought together prostate cancer researchers, clinicians, support workers and patients for networking and an update on research in South Australia on 7th August at the National Wine Centre. His Excellence the Honourable Hieu Van Le, AO, Governor of South Australia, as patron of the Repat Foundation and the Prostate Cancer Foundation of Australia (South Australian Chapter) opened the symposium. Presenters from the Flinders Centre for Innovation in Cancer, the University of South Australia, SAHMRI, The University of Adelaide (Freemason's Foundation Centre for Men's Health) and SA Health contributed to the day. Topics spanned population health, laboratory and animal work and survivorship aspects of prostate cancer. The diversity of speakers and topics reflects the multidisciplinary and collaborative work of SA-PCCOC. The event was a sell-out success and there is strong interest in making this an annual event.

#### Chairman's Report

Throughout the year SA-PCCOC has again continued to play a major role in the *Prostate Cancer Outcomes Registry – Australia and New Zealand* and provide leadership in the *Prostate Cancer Health Outcomes Research Unit*, both of which are initiatives of the Movember Organization.

The achievements since 1998 would never have occurred without the dedicated and hardworking staff, team and committee members who have given their time and expertise, nor without our clinical collaborators and patients who contribute to the database. To all who have made SA-PCCOC the powerful registry it is today, I say thank you, and trust you're looking forward to the next fifteen years!



#### The Movember Foundation Prostate Cancer Health Outcomes Research Unit

In 2015/2016, SA-PCCOC has enthusiastically supported the Prostate Cancer Health Outcomes Research Unit (PCHORU) in undertaking its research. The PCHORU is a collaborative partnership between The University of South Australia, the South Australian Health and Medical Research Institute and Monash University, which was established and supported by the Movember Foundation. Over the past 18 months PCHORU has been actively engaged in analysis of registry data, researching risk stratification tools, reporting on patient reported outcomes, investigating the needs of men and their family members around support as well as the role of general practitioners in caring for men with prostate cancer. The provision of high quality clinical and outcomes data from SA-PCCOC has underpinned much of this work. SA-PCCOC has also supported psychosocial research projects through assisting researchers to recruit participants for surveys and interviews to better understand men's experience, beyond what clinical data can provide.

Specific projects undertaken by the PCHORU which have utilised the SA-PCCOC database include:

- 1. Combining SA clinical registry data with similar data from the Victorian prostate cancer registry to provide a broad picture of patterns of care and outcomes for Australian men with prostate cancer. Results of this work are available in Movember's *Prostate Cancer Outcomes Annual Report 2016*
- 2. Comparison of prostate cancer survival between men who were referred with prostate or urinary symptoms and men referred with elevated PSA.
- 3. Comparison of outcomes for men living in rural South Australia compared with their metropolitan counterparts
- 4. Assessment of how well the proposed new International Society of Urological Pathologists five (i.e. the South Australian experience)
- 5. Validation of several risk prediction tools which assist clinical decision making for men with prostate cancer undergoing different treatments in the Australian setting
- 6. Gaining a deeper understanding of the psychosocial needs of men following diagnosis and treatment for prostate cancer.

Results of these studies have been presented at state, national and international urology or prostate cancer conferences (listed on page 14) and will be published in peer reviewed journals in the near future. The comprehensive nature of the data items collected, along with long term follow-up of treatment and outcomes, has established the South Australia registry as a valuable resource for understanding and improving care for men with prostate cancer in Australia. This is evident through the work of the PCHORU and other research projects that the SA-PCCOC database has supported. SA-PCCOC's data collection is being further strengthened through involvement with the research activities of PCHORU and support from the Movember Foundation, which is gratefully acknowledged.



# Research Update

The SA-PCCOC database continues to support a wide variety of research projects and continues to receive expressions of interest from all specialties involved in the care of prostate cancer.

The Research Committee meets bi-monthly to discuss new expressions of interest together with the progress of research studies underway. The Research Committee includes expertise in radiation oncology, urology, epidemiology, data management, nursing, medical oncology and most recently pathology. This allows each project proposal to receive input from many areas and improve the quality of research conducted.

In 2015, seven peer reviewed publications and an additional 24 peer reviewed presentations were made. 2015 also saw the completion of two, (and the commencement of a third), summer research scholars supported by the Freemasons Foundation Centre for Men's Health together with commencement of two MD students undertaking research electives through Flinders University.

Highlights from the research publications include:

- Citation of SA-PCCOC within a review of leading prostate cancer registries globally published in European Urology the top urology journal in the world
- Contribution to the debate on PSA screening (in "Annals of Internal Medicine") and cancer risk (in "Science")
- Presentations at: the Urological Society of Australia and New Zealand national and state meetings, the World Prostate Cancer Congress, the American Society of Clinical Oncology Annual Meeting, the Genitourinary Cancer Symposium and the 35th Congress of the Société Internationale d'Urologie

A/PROF
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# The Registry

## 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 2015, the total number of patients recruited reached 10,635 (Figure 1.). Overall, the average age of men at the time of their diagnosis was 67 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 therapy over time. As the database continues to grow, it remains a challenge to maintain clinical follow-up.

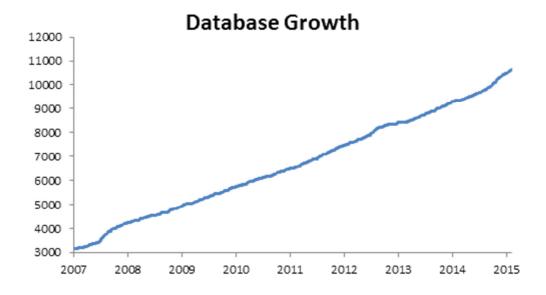


Figure 1. SA-PCCOC database - growth 2007-2015

# **Age at Diagnosis**

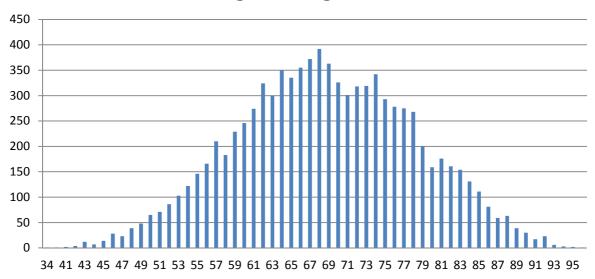


Figure 2. SA-PCCOC database – patient age at diagnosis

# **Distribution of Treatment Choices**

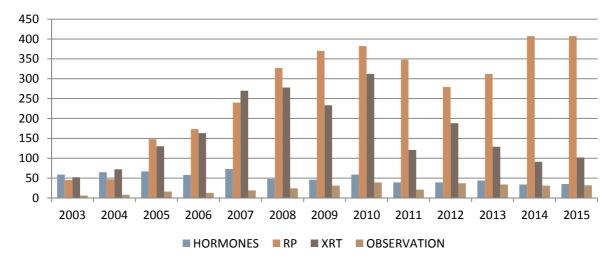


Figure 3. SA-PCCOC database – patient treatment choices

## 2015 Recruitment

During 2015, 1,302 patients were added to the SA-PCCOC database (Figure 4.). This represents 91% ascertainment of all prostate cancer cases diagnosed within South Australia, using data projections from the South Australia Cancer register as a denominator.

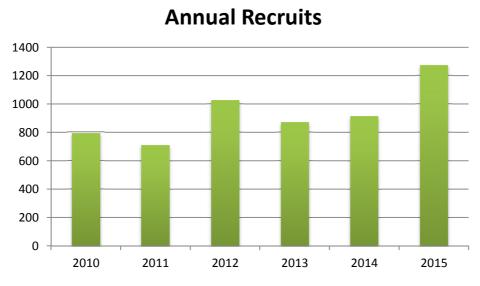


Figure 4. SA-PCCOC database recruits by year

Of patients recruited in 2015, 58% were from public hospitals with the remaining 42% 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%).

SA-PCCOC continues to invest in tools to improve data collection efficiencies. This year, electronic collection of PSA test results and new cancer notifications have helped to achieve our recruitment goals. Plans for additional tools include further links to private pathology providers to access PSA test results and giving men the option to complete symptom questionnaire electronically.



The South Australian Prostate Cancer Clinical Outcomes Collaborative

## **SA-PCCOC SNAPSHOT**

Men recruited:

1,302

Population coverage:



#### **Treatment choices**



Radiation Therapy Observation



Public 58%

Private 42%



6%

18%





Average age at Diagnosis:



**Participating urologists** 



Active research projects



**Publications** in 2015





**Abstracts** in 2015

#### Men returning questionnaires...

...sent to them before treatment commenced:

...sent to them 5 years after treatment:

75%

58%

**Total Registry Size** (as at 31/12/2015)

10,635

# Consumer Engagement

I am most privileged at being invited by the SA-PCCOC Steering Committee to join the organisation as a consumer representative following the retirement of Mr Jeff Roberts.

I am a survivor of prostate cancer, and am regularly in contact with men touched by the disease. I am a former member of the Prostate Cancer Chapter Council SA / NT of the Prostate Cancer Foundation of Australia (PCFA), an Ambassador speaker for men's health, and an active member of the PC Action Group (SA). I am passionate about promoting awareness of the disease.

In the community there is limited knowledge of the remarkable achievements of the SA-PCCOC over the past 18 years since the database was inaugurated. The documentation of the clinical histories of over 10,000 South Australian men exposed to the disease reflects a most conscientious effort by the database staff, co-operating clinicians, hospitals, laboratories and the patients themselves. This world recognised repository providing unique material to researchers and clinicians is well respected in scientific and clinical circles but also deserves wider recognition in the community.

I accept the commitment of assisting to educate the prostate cancer community of South Australia and the community at large to recognise this highly respected resource.

Both the Steering and Research committees of SA-PCCOC and the staff of the database deserve congratulations on their achievements.



"Many thanks for giving me the opportunity to share my progress following the medical procedure"

"Happy to be in the database"

"Very happy to keep in contact with prostate cancer outcome [research] I see it as

"Glad to give some feedback"

**Consumer Feedback** 

2015

"Happy to fill in questionnaire sheets as required"

"Thanks and please include me in any more surveys or whatever, I'm only too happy to help"

"I am only too happy to help with your research or other sufferers"

# **Grants Received**

## Movember

#### Title:

The Australian Prostate Cancer Clinical Cancer Registry – SA Node

## Investigators:

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

## Period of Funding:

2014-2016

#### Title:

Prostate Cancer Health Outcomes Research Unit

#### Investigators:

D Roder, K Beckmann, C Miller, R Ruseckaite, J Millar, J McNeil, S Evans, J Zalcberg, K Moretti, M O'Callaghan

## Period of Funding:

2015-2016





# SA & NT Section of the Urological Society of Australia and New Zealand

Title:

SA-PCCOC Database Sponsorship



# 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 Hospital Research Foundation

Title:

Infrastructure Grant

Period of Funding:

2015





## Tolmar Australia

Title:

SA-PCCOC Database Sponsorship

Period of Funding:

2014-2016



Title:

Prostate Cancer Symposium

Period of Funding:

2015



# Rotary Club Coromandel Valley

Title:

Project Contribution

Period of Funding:

2015



## **Patient Donations**

We gratefully acknowledge patient donations received during 2015 which contribute enormously to helping advance the important research of SA-PCCOC.

# **Collaborating Partners**





















## **Publications**

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

## 2015 Journal Articles

- 1. Leach DA, Need EF, Toivanen R, Trotta AP, Palethorpe HM, Tamblyn DJ, Kopsaftis T, England GM, Smith E, Drew PA, Pinnock CB. Erratum: Stromal androgen receptor regulates the composition of the microenvironment to influence prostate cancer outcome. Oncotarget. 2015 Nov 3;6(34):36923.
- 2. Gandaglia G, Bray F, Cooperberg MR, Karnes RJ, Leveridge MJ, Moretti K, Murphy DG, Penson DF, Miller DC. Reply from Authors re: Julia Verne, Luke Hounsome, Roger Kockelbergh, Jem Rashbass. Improving Outcomes from Prostate Cancer: Unlocking the Treasure Trove of Information in Cancer Registries. Eur Urol. In press. http://dx. doi. org/10.1016/j. eururo. 2015.07. 022. European urology. 2015 Oct 9.
- 3. Leach DA, Need EF, Toivanen R, Trotta AP, Palenthorpe HM, Tamblyn DJ, Kopsaftis T, England GM, Smith E, Drew PA, Pinnock CB. Stromal androgen receptor regulates the composition of the microenvironment to influence prostate cancer outcome. Oncotarget. 2015 Jun 30;6(18):16135.
- 4. Gandaglia G, Bray F, Cooperberg MR, Karnes RJ, Leveridge MJ, Moretti K, Murphy DG, Penson DF, Miller DC. Prostate Cancer Registries: current status and future directions. European urology. 2015 Jun 6.
- 5. O'Callaghan ME, Kichenadasse G, Vatandoust S, Moretti K. Informed decision making about prostate cancer screening. Annals of internal medicine. 2015 Mar 17;162(6):457.
- 6. O'Callaghan M. Cancer risk: accuracy of literature. Science. 2015 Feb 13;347(6223):729.
- 7. Raymond E, Moretti K, Vincent A, Beckmann K, O'Callaghan ME. An appraisal of analytical tools, used in predicting clinical and patient reported outcomes following treatment of men with prostate cancer: a systematic review. PROSPERO International prospective register of systematic reviews. 2015.

#### 2015 Presentation Abstracts

- Plagakis S, O'Callaghan M, Kopsaftis T, Walsh S, Lee J, Foreman D. Surgical pathology outcomes for discontinued active surveillance in South Australian men with prostate cancer. In BJU INTERNATIONAL 2015 Apr 1 (Vol. 115, pp. 7-7). 111 RIVER ST, HOBOKEN 07030-5774, NJ USA: WILEY-BLACKWELL.
- 2. Osei-Tutu L, O'Callaghan M, Walsh S, Lee J. CT scans for prostate cancer staging-prevalence of incidentalomas and the effect on management. In BJU INTERNATIONAL 2015 Apr 1 (Vol. 115, pp. 29-29). 111 RIVER ST, HOBOKEN 07030-5774, NJ USA: WILEY-BLACKWELL.
- 3. Shepherd A, O'Callaghan M. Eligibility for active surveillance of prostate cancer and functional outcomes after prostatectomy. In BJU INTERNATIONAL 2015 Apr 1 (Vol. 115, pp. 33-33). 111 RIVER ST, HOBOKEN 07030-5774, NJ USA: WILEY-BLACKWELL.

- 4. Vatandoust S, Kichenadasse G, O'Callaghan ME, Kopsaftis T, Walsh S, Borg M, Karapetis CS, Moretti KL. Antiandrogen withdrawal (AAWD) in patients (pts) with prostate cancer (PCa): Retrospective analysis of data from the South Australian Prostate Cancer Clinical Outcome Collaborative (SA-PCCOC). In ASCO Annual Meeting Proceedings 2015 Mar 1 (Vol. 33, No. 7 suppl, p. 240).
- 5. Shepherd A, O'Callaghan ME. Eligibility for Active Surveillance of Prostate Cancer and Functional Outcomes after Prostatectomy. 35th Congress of the Société Internationale d'Urologie, Melbourne 33 (1), 40 2015
- 6. Plagakis S, O'Callaghan M, Moretti K, Foreman D. Surgical Outcomes of South Australian Patients Who Have Discontinued Active Surveillance. 35th Congress of the Société Internationale d'Urologie, Melbourne 33 (1), 28 2015
- 7. Cho J, Foreman D, Fuller A, O'Callaghan M. How Predictive of Prostate Cancer Are PIRADS 4 or 5 Lesions on MRI? 35th Congress of the Société Internationale d'Urologie, Melbourne 33 (1), 13 2015
- 8. Prostate Cancer outcomes amongst men who present with symptoms. KR Beckmann, N Kinnear, ME O'Callaghan, T Kopsaftis, S Walsh, et al SA-NT USANZ meeting 9-10th October 2015, SAHMRI 2015
- 9. Radical prostatectomy vs External beam radiotherapy for high risk prostate cancer: an observational study of mortality outcomes. H Cruickshanks-Boyd, C Logan, J Johnston, J Lee, MEO'Callaghan, et al SA-NT USANZ meeting 9-10th October 2015, SAHMRI 2015
- 10. Delays in prostate cancer treatment following diagnosis. M O'Callaghan, Z Shi, S Walsh, T Kopsaftis, K and Moretti SA-NT USANZ meeting 9-10th October 2015, SAHMRI 2015
- 11. Clinical outcomes for rural patients with prostate cancer in South Australia. A Shepherd, KR Beckmann, ME O'Callaghan SA-NT USANZ meeting 9-10th October 2015, SAHMRI 2015
- 12. Satisfaction with care in men with prostate cancer. M Forgione, S Sara, A Vincent, K Moretti, M O'Callaghan. SA-NT USANZ meeting 9-10th October 2015, SAHMRI 2015
- 13. Men presenting with prostate specific antigen (PSA) levels over100 ng/mL at the time of diagnosis. M Ang, B Rajic, DFMO Callaghan. SA-NT USANZ meeting 9-10th October 2015, SAHMRI 2015
- 14. A retrospective analysis of South Australian and Victorian clinical registries for prostate cancer. R Ruseckaite, K Beckmann, MO Callaghan, D Roder, K Moretti, J Millar, et al SA-NT USANZ meeting 9-10th October 2015, SAHMRI 2015
- 15. The changing profile of prostate cancer in South Australia. K Beckmann, MO Callaghan, R Ruseckaite, K Moretti, S Evans, J Millar, et al SA-NT USANZ meeting 9-10th October 2015, SAHMRI 2015
- A review of the incidence, management and prognosis of ductal subtype of prostate cancer. N
   Mathur, KR Beckmann, K Moretti, T Kopsaftis, K D'Onise, et al SA-NT USANZ meeting 9-10th
   October 2015, SAHMRI 2015
- 17. Active Surveillance protocols and the surgical outcomes of South Australian Patients who have discontinued active surveillance for prostate cancer. S Plagakis, MEO Callaghan, K Moretti, D Foreman. SA-NT USANZ meeting 9-10th October 2015, SAHMRI 2015
- 18. A retrospective analysis of South Australian and Victorian clinical registries for prostate cancer. R Ruseckaite, K Beckmann, ME O'Callaghan, D Roder, K Moretti, J Millar, et al The Prostate Cancer World Congress 116 (Supplement 1), 17 2015

- 19. The changing profile of prostate cancer in South Australia. K Beckmann, M O'Callaghan, R Ruseckaite, K Moretti, S Evans, J Millar, et al The Prostate Cancer World Congress 116 (Supplement 1), 20 2015
- 20. Satisfaction with care in men with prostate cancer M Forgione, S Sara, A Vincent, K Moretti, M O'Callaghan The Prostate Cancer World Congress 116 (Supplement 1), 22 2015
- 21. Men presenting with prostate specific antigen (PSA) levels over 100 ng/mL at the time of diagnosis M Ang, B Rajic, D Foreman, M O'Callaghan The Prostate Cancer World Congress 116 (Supplement 1), 23 2015
- 22. Delays in prostate cancer treatment following diagnosis M O'Callaghan, Z Shi, S Walsh, T Kopsaftis, K Moretti The Prostate Cancer World Congress 116 (Supplement 1), 21-22 2015
- 23. Prostate cancer in men aged less than 50 years at diagnosis N Kinnear, G Kichenadasse, S Plagakis, M O'Callaghan, T Kopsaftis, et al 68th Annual Scientific Meeting of the Urological-Society-of-Australia-and NZ 2015
- 24. Antiandrogen withdrawal (AAWD) in patients (pts) with prostate cancer (PCa): Retrospective analysis of data from the South Australian Prostate Cancer Clinical Outcome Collaborative (SA-PCCOC). Sina Vatandoust, Ganessan Kichenadasse, Michael O'Callaghan, Tina Kopsaftis et al Genitourinary Cancers Symposium, Feb 26-28 2015, Orlando, Florida. 2015

## Committee Members

# **Steering Committee**

- Kim Moretti: Chairman & Principal Investigator
- Kym Horsell: Deputy Chairman
- Michael O'Callaghan: Executive Officer
- Martin Borg
- Kerri Beckmann
- Tina Kopsaftis
- Scott Walsh
- David Merry
- Sally Sara
- Braden Higgs (2016)

## **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
- Raj Singh-Rai
- 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
- Sally Sara
- Penelope Cohen (2016)

## Data Management Team

- Michael O'Callaghan
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# **Collaborating Researchers**

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- Michael Chong
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- Kerry Ettridge
- Sue Evans
- Darren Foreman
- Chris Hocking
- Ivan Hoh
- Kym Horsell
- Ned Kinnear
- Bogda Koczwara
- Jimmy Lam
- Jason Lee
- Diwei Lin

- Callum Logan
- Namit Mathur
- John McNeil
- Jeremy Millar
- Caroline Miller
- Patricia Neumann
- Lovelace Osei-Tutu
- Peter Penkoff
- Sophie Plagakis
- Rasa Ruseckaite
- Branimir Rajcic
- David Roder
- Andrew Shepherd
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Signed September 2016:

Associate Professor Kim Moretti

Chairman and Principal Investigator

MBBS FRACS (Urol)

lin Mouth

Dr. Michael O'Callaghan

Executive Officer

BSc (Hons) PhD

