

Prostate Summit Newsletter

Quality of life in prostate cancer



March 2017

From the clinical working party co-chaired by Jeremy Millar and Damien Bolton

Recap

[The Prostate Cancer Summit](#) was a call for collective action for better outcomes in prostate cancer in three areas: access to data, quality of life and early diagnosis. In this newsletter we share insights from our inquiry into models of care addressing quality of life in prostate cancer.



- 90% (48) respondents agreed that the developing an integrated model of care should be a priority for their health service.
- 22% (12) respondents thought that their health care service offered an integrated model of care and did not need any improvement.
- 51% (27) reported their model of care is integrated but improvements were needed.
- 9% (5) respondents reported no access to services to support men with prostate cancer such as a specialist nurse, social worker or other allied health professionals.

Missed out?

Missed out on attending the summit?

Read the [Summary Report](#).

Why is quality of life important?



4585

On average 4585 men are diagnosed with prostate cancer every year in Victoria.¹ Socio-economic disparities, disease presentation and access to care contribute to men experiencing long term physical and psychosexual effects of prostate cancer treatment.²

Support for men who identify emotional, physical, practical or informational issues is inadequate and not fulfilling their needs.³ Addressing the unmet needs is critical for men who survive and outlive their prostate cancer.

Defining integrated models of care

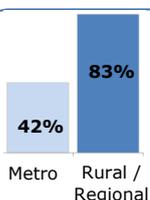
A model of care broadly defines the way health services are delivered and an integrated model of care addresses both patient's medical and quality of life needs.

A model of care outlines best practice patient care delivery, through the application of a set of service principles across identified clinical streams and patient flow continuums.⁴

Integrated care involves the provision of seamless, effective and efficient care that reflects the whole of a person's health needs.⁵

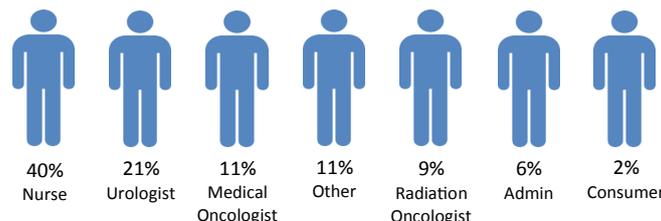
Are we delivering effective and integrated models care for men with prostate cancer?

Since the summit we have been talking to multidisciplinary clinicians and health administrators across Victoria about their models of care. To date, we conducted 12 interviews, one focus group and collected 53 responses to a survey.



Forty-four (83%) respondents to the survey were clinicians working across regional/rural settings with 22 (42%) working only in metro settings.

Survey respondents by role



Different models of care

Three distinct models of care were noted, organised around the type of setting; acute, community and acute / primary care interface. All examples of integrated and effective models of care featured a specialist nurse. The value of nurses was clear.

“ If used wisely, a well- trained nurse practitioner acts as a prostate cancer nurse, a social worker, a psychologist, a registrar. The nurse practitioner has time to take calls, discuss issues and side effects of treatment. This frees up time to see other patients.

Oncologist

Most models of care evolved from the needs of local clinical teams combined with opportunities to secure start-up funding for example: Prostate Cancer Foundation Australia (PCFA) funding rounds, Movember funding or survivorship research grants.

Specialist nurses in prostate cancer

Interviews with urology nurse practitioners and candidates and prostate cancer specialist nurses in Victoria highlighted a number of enablers and barriers to creating and sustaining these roles.

Enablers

Preparing a strong business case was viewed as integral to securing sustainable funding and ongoing organisational support.

“ One of the best things we did was map our region to build a business case. This provided us with a clear direction and enabled us to develop a concise role description and gain management support

- Nurse Specialist

Having clear policies, guidelines and role expectations provides a successful framework for integrating these roles into existing multidisciplinary teams. Securing support from teams especially urologists was seen as crucial to creating an integrated model of care. Enablers specifically for nurse practitioner candidates were access to scholarships and appropriate remuneration once accredited.

Barriers

Key barriers to specialist nursing roles included skill and commitment to preparing a business case, access to ongoing funding and access to referral services to address identified quality of life needs. Remuneration for study including backfill and lack of ongoing sustainable funding affected job security. Nurses highlighted limitations in access to services in the community to support sexual health issues of men leaving gaps in the quality of care they provide.

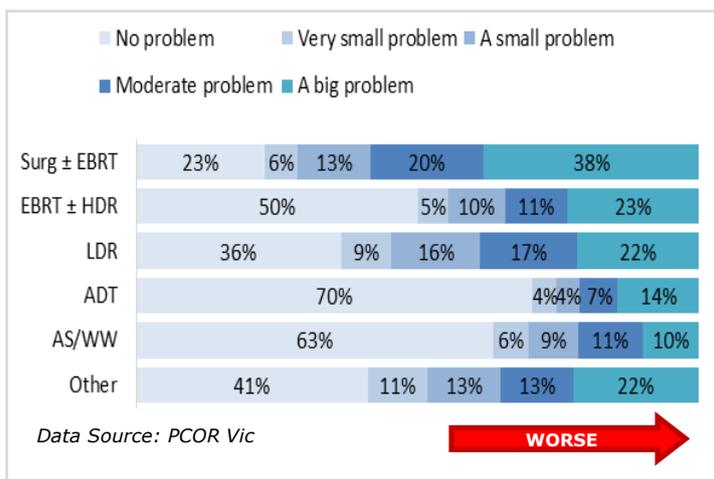
“ Referral pathways between acute and primary care is still very ad hoc. To be able to provide men with an effective model of care we must do this better to ensure that men's survivorship issues are adequately followed up.

- Nurse Specialist

The most reported quality of life need is the most challenging to address

In Victoria sexual dysfunction is still reported as a concern for men two years post prostatectomy or radiotherapy treatment.⁶ Men with prostate cancer are reluctant to access psychological or psychosexual support.⁷

Sexual bother (EPIC-26), (2009-2014) N=7,558



In our inquiry many clinicians reported a gap in access to sexual health counseling and interventions for erectile dysfunction.

“ I think the most rewarding part is that our roles allow us to really identify men's issues, but sometimes when it comes to sexual health issues I just don't have anyone to refer to. The lack of resources is really frustrating

- Nurse Specialist

Clinicians also identified resources or programs that provide information or sexual health support including [Andrology Australia](#), [Family Planning Centre](#), [Prostate Cancer Foundation of Australia](#), [Cancer Council](#) and [Movember](#).

Other useful information

Prostate Cancer Foundation of Australia funds the placement of prostate cancer specialist nurses in a variety of Australian health care settings in partnership with health service providers.

For more information about the program contact: [Ann Marie Alexander](#)

The [Department of Health and Human Services Nursing and Midwifery Workforce](#) offers scholarships and funding for the development of Nurse Practitioner models of care.

For more information about the program and funding submission contact: [Dan Schiftan](#)

We are preparing a detailed report documenting findings of our inquiry into integrated models of care for prostate cancer. For any questions please contact: [Melinda Williams](#)

- 1 Victorian Cancer Registry <http://vcrdata.cancervic.org.au/vs/>
- 2 Smith DP, King MT, Egger S, et al. Quality of life three years after diagnosis of localised prostate cancer: population based cohort study. *BMJ*; 2009
- 3 Carlsson S, Sandin F, Fall K, et al. Risk of suicide in men with low-risk prostate cancer. *Eur J Cancer*. 2013; 49(7):1588-99.
- 4 Agency for clinical innovation W Government 2015
- 5 Department of Health, Clinical Services Framework 2005-2015, Perth, Western Australia, Department of Health WA; 2005
- 6 Sampurno F and Evans SM (eds) for the Victorian Prostate Cancer Clinical Registry Steering Committee. *Victorian Prostate Cancer Clinical Registry - Five Year Report [Internet]* Melbourne, Victoria. Monash University; 2015.
- 7 Chambers S, Dunn J, Lazenby M, et al. *ProCare: A psychological care model for men with prostate cancer*. Sydney, Australia: Prostate Cancer Foundation of Australia; 2013.