Prostate cancer care in Victoria Part 2

Towards optimal care

VICS VICTORIAN INTEGRATED CANCER SERVICES

Cancer Council

VICTORIA State Government

In this presentation…

- Actions since the 2016 Summit
- Survival
- Supportive care
- Unmet needs
- Quality of life after treatment

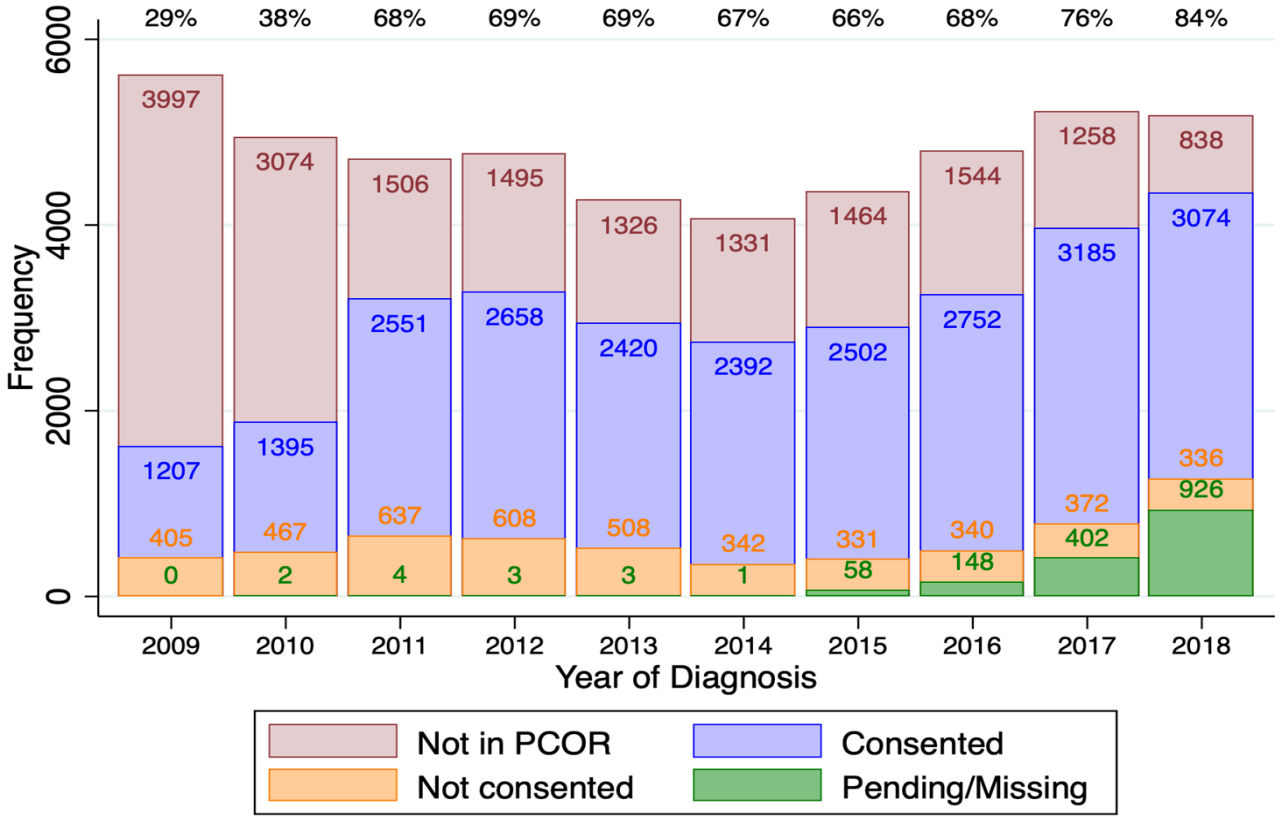
What happened after the 2016 Summit?

Prostate 2016 recommended

- Universal contribution to the prostate cancer outcomes registry and share data with local clinical groups.
- Improve community awareness and GP implementation of the NHMRC PSA testing guidelines for earlier diagnosis and management of localised prostate cancer.
- Address quality of life issues for men with prostate cancer, through a coordinated approach using existing and new integrated models of care.

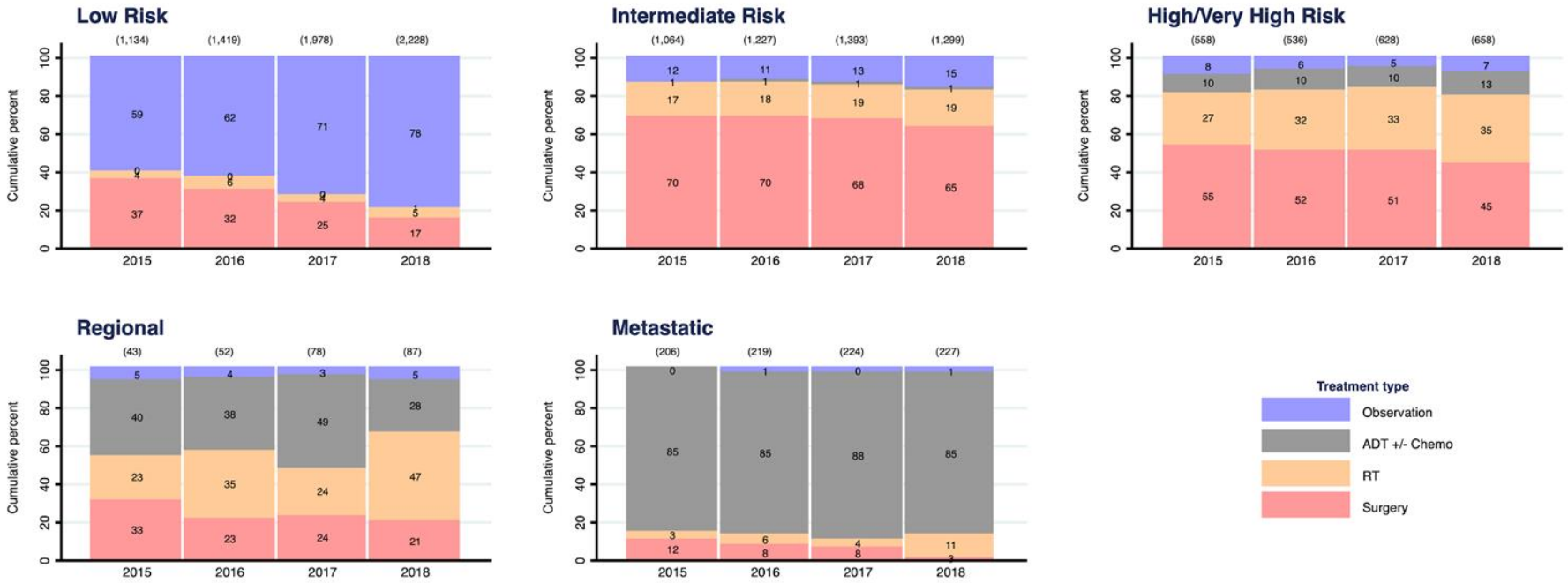
Universal contribution to Prostate Cancer Outcomes Registry

↑ 68%-84%
2016-2018



Percentages = PCOR coverage

PCOR Data: Treatment by NCCN Risk Group

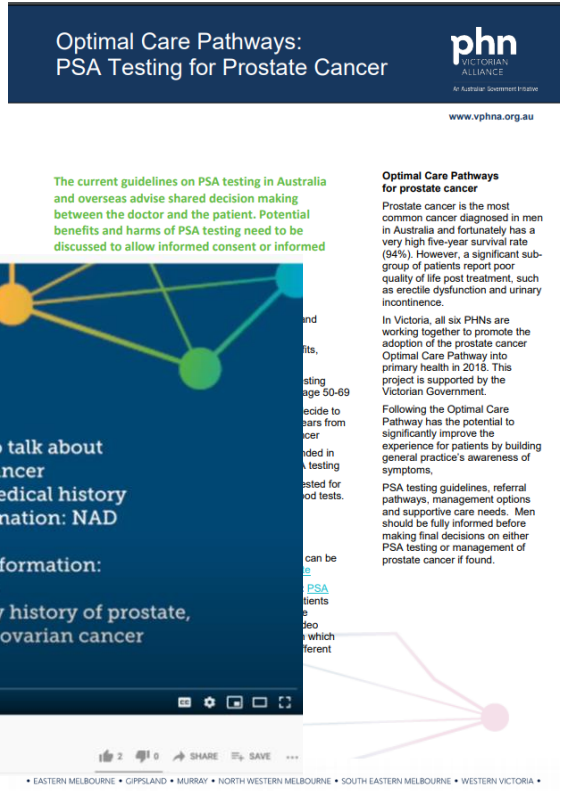


Improve GP and community awareness of PSA testing guidelines

Primary Health Networks produced a range of resources for GPs:

- HealthPathways online GP portal resources
- Education events
- Videos

https://vtphna.org.au/our-work/best-practice-prevention-management-and-support/optimal-care-pathways-prostate-cancer/



I-PACED: Implementing pathways for cancer early diagnosis

Cancer Council Victoria, The University of Melbourne:

- E-learning modules for GPs and health professionals
- Resources highlighting recommendations about prevention, early detection, initial investigation and referral pathways

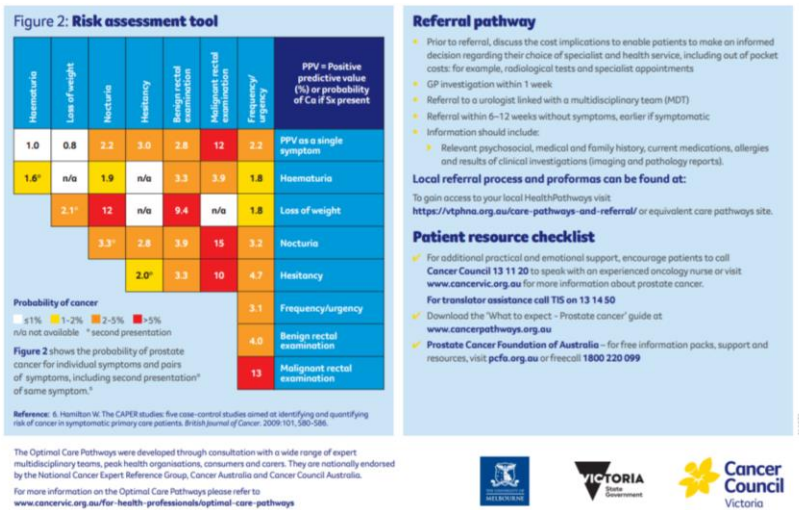


Figure 2: **Risk assessment tool**

Haematuria	Loss of weight	Nocturia	Hesitancy	Benign rectal examination	Malignant rectal examination	Frequency/ urgency	PPV = Positive predictive value (%) or probability of Ca if Sx present
1.0	0.8	2.2	3.0	2.8	12	2.2	PPV as a single symptom
1.6*	n/a	1.9	n/a	3.3	3.9	1.8	Haematuria
	2.1*	12	n/a	9.4	n/a	1.8	Loss of weight
		3.3*	2.8	3.9	15	3.2	Nocturia
			2.0*	3.3	10	4.7	Hesitancy
						3.1	Frequency/urgency
						4.0	Benign rectal examination
						13	Malignant rectal examination

Probability of cancer
≤1% 1-2% 2-5% >5%
n/a not available * second presentation

Figure 2 shows the probability of prostate cancer for individual symptoms and pairs of symptoms, including second presentation* of same symptom.[6]

Reference: 6. Hamilton W. The CAPER studies: five case-control studies aimed at identifying and quantifying risk of cancer in symptomatic primary care patients. *British Journal of Cancer*. 2009:101, 580-586.

Referral pathway

- Prior to referral, discuss the cost implications to enable patients to make an informed decision regarding their choice of specialist and health service, including out of pocket costs: for example, radiological tests and specialist appointments
- GP investigation within 1 week
- Referral to a urologist linked with a multidisciplinary team (MDT)
- Referral within 6–12 weeks without symptoms, earlier if symptomatic
- Information should include:
  - Relevant psychosocial, medical and family history, current medications, allergies and results of clinical investigations (imaging and pathology reports).

Local referral process and proformas can be found at:

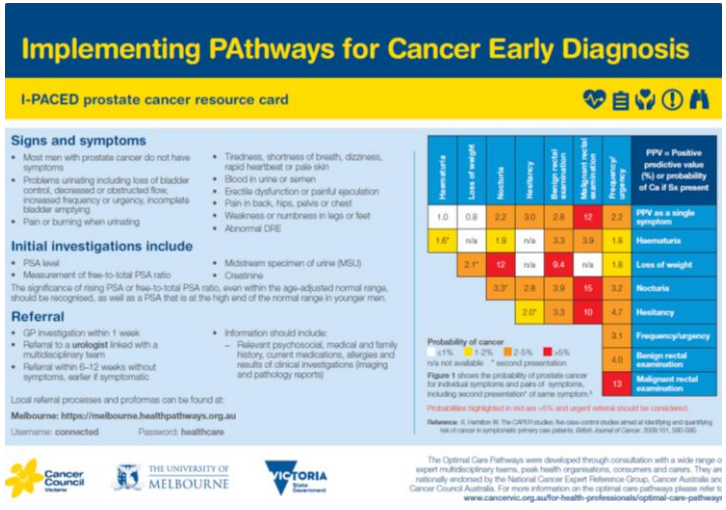
To gain access to your local HealthPathways visit
https://vtphna.org.au/care-pathways-and-referral/ or equivalent care pathways site.

Patient resource checklist

- For additional practical and emotional support, encourage patients to call **Cancer Council 13 11 20** to speak with an experienced oncology nurse or visit **www.cancervic.org.au** for more information about prostate cancer.
  For translator assistance call TIS on 13 14 50
- Download the 'What to expect - Prostate cancer' guide at **www.cancerpathways.org.au**
- **Prostate Cancer Foundation of Australia** – for free information packs, support and resources, visit **pcfa.org.au** or freecall **1800 220 099**

The Optimal Care Pathways were developed through consultation with a wide range of expert multidisciplinary teams, peak health organisations, consumers and carers. They are nationally endorsed by the National Cancer Expert Reference Group, Cancer Australia and Cancer Council Australia.

For more information on the Optimal Care Pathways please refer to
www.cancervic.org.au/for-health-professionals/optimal-care-pathways



Implementing PAthways for Cancer Early Diagnosis

I-PACED prostate cancer resource card

Signs and symptoms

- Most men with prostate cancer do not have symptoms
- Problems urinating including loss of bladder control, decreased or obstructed flow, increased frequency or urgency, incomplete bladder emptying
- Pain or burning when urinating
- Tiredness, shortness of breath, dizziness, rapid heartbeat or pale skin
- Blood in urine or semen
- Erectile dysfunction or painful ejaculation
- Pain in back, hips, pelvis or chest
- Weakness or numbness in legs or feet
- Abnormal DRE

Initial investigations include

- PSA level
- Measurement of free-to-total PSA ratio
- Midstream specimen of urine (MSU)
- Creatinine

The significance of rising PSA or free-to-total PSA ratio, even within the age-adjusted normal range, should be recognised, as well as a PSA that is at the high end of the normal range in younger men.

Referral

- GP investigation within 1 week
- Referral to a **urologist** linked with a multidisciplinary team
- Referral within 6–12 weeks without symptoms, earlier if symptomatic
- Information should include:
  - Relevant psychosocial, medical and family history, current medications, allergies and results of clinical investigations (imaging and pathology reports)

Local referral processes and proformas can be found at:

Melbourne: https://melbourne.healthpathways.org.au

Username: **connected** Password: **healthcare**

Haematuria	Loss of weight	Nocturia	Hesitancy	Benign rectal examination	Malignant rectal examination	Frequency/ urgency	PPV = Positive predictive value (%) or probability of Ca if Sx present
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Probability of cancer
≤1% 1-2% 2-5% >5%
n/a not available * second presentation

Figure 1 shows the probability of prostate cancer for individual symptoms and pairs of symptoms, including second presentation* of same symptom.[6]

Probabilities highlighted in red are >5% and urgent referral should be considered.

Reference: 6. Hamilton W. The CAPER studies: five case-control studies aimed at identifying and quantifying risk of cancer in symptomatic primary care patients. *British Journal of Cancer*. 2009:101, 580-586.

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Improving quality of life

Meeting supportive care needs:

- ICS projects:
  - Sexual health education
  - Support group engagement
  - Local projects
  - Education video
  - Self-management resources
- TrueNTH
- BroSupPORT
- SUNS-SF data collection

Men share strategies for navigating diagnosis and treatment planning, and maintaining wellbeing/ QoL.

Movember TrueNTH

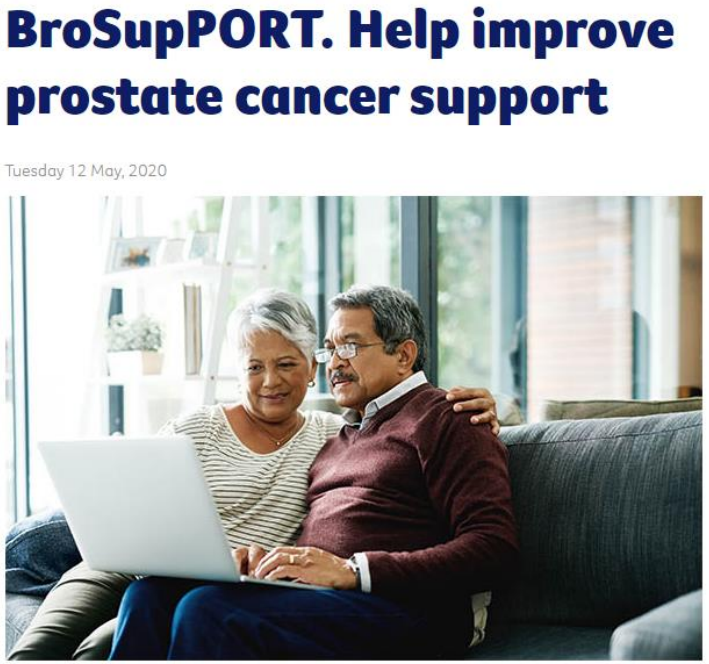
Model of care

- Studied the impact of a Prostate Cancer Nurse Care Coordinator on QoL after prostate cancer
- Enabled access to psychiatry/psychology, exercise physiology, dietitians
- Men in the TrueNTH group were 60 % less likely to report moderate to big problems with their sexual function compared with men in the historical control group.

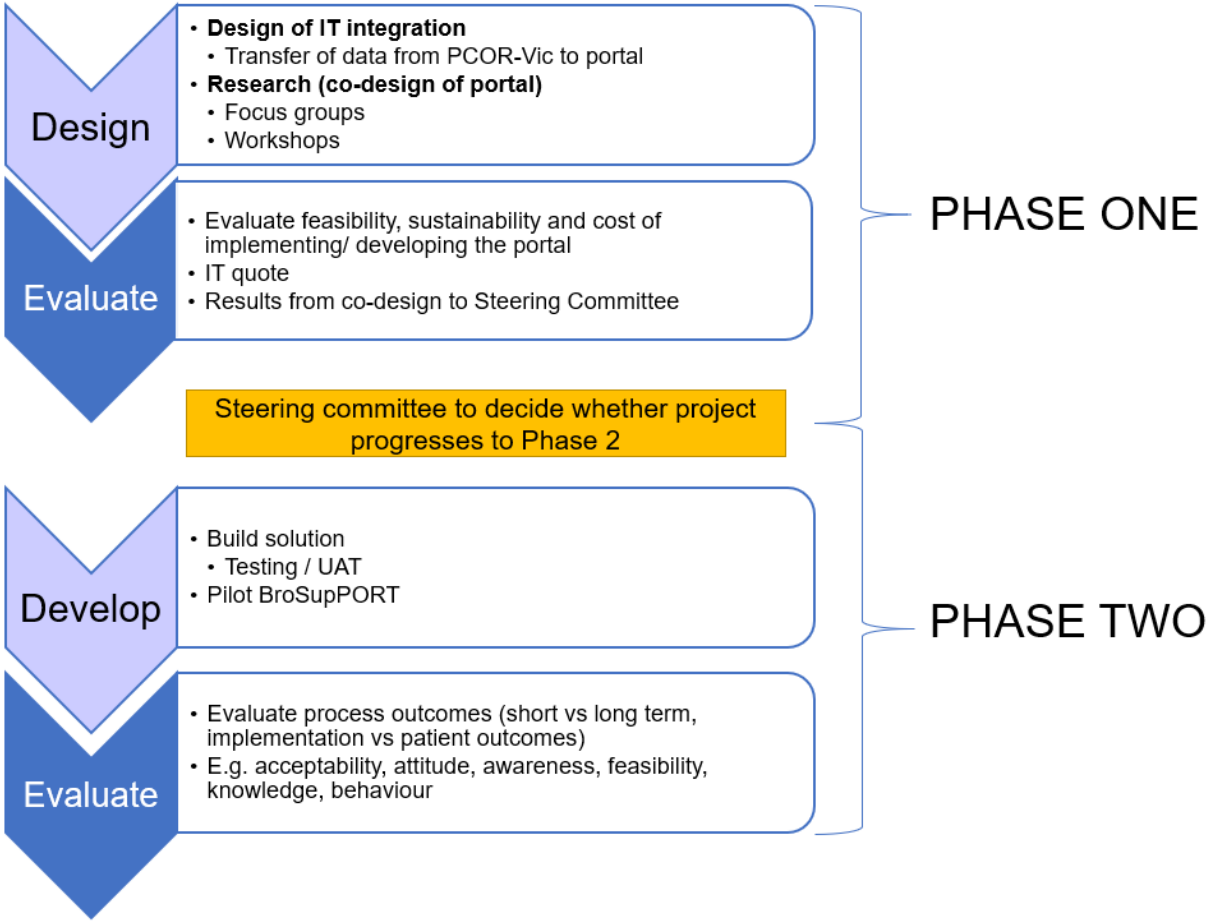
Sue Evans, Lead Gippsland Pilot

BroSupPORT

- PCOR/Monash Pilot project funded by VHA-Movember
- Aims to provide a scalable solution for men with difficulties after diagnosis
- Supportive care website developed directly from men's experiences



Progress & plans



Health Professionals

4 Focus groups

39 Participants

10 Advisory Group Meetings

Consumers

7 Workshops

33 Participants

Data context

About data sources

	Linked data set (prostate cancer)			PCOR Vic
	VCR	**VAED**	**VRMDS**	
Coverage	100% of Vic	All Vic health services except Albury	All Vic radiotherapy centres	VCR through participating health services (6 in 2008, now ~90% pop. coverage)
Years	2008-2018	2008-2019	2011-2018	2008 – 2019
Number	54,000 patients	703,000 hospital admissions	18,000	25,981 patients consented
Purpose	Monitoring cancer population outcomes	Reimbursement of hospital activity	Reimbursement of hospital activity	Patterns of disease, management and patient-reported outcomes for quality improvement and research

Demographic and tumour characteristics

	Linked dataset (VCR, VAED) Diagnosed 2014-2018 N = 23,395		Prostate Cancer Outcomes Registry-Victoria Diagnosed 2008-2019 N = 25,981	
Variable	**Level**	**Median [IQR] or N (%)**	**Level**	**Median [IQR] or N (%)**
Age	Years	68 [62 - 74]	Years	66.8 (60.9 - 72.5)
Socio-economic status (address at diagnosis)	Disadvantaged (Q1) Middle (Q2-Q4) Affluent (Q5)	4141 (18%) 13736 (59%) 5514 (24%)	Disadvantaged (Q1) Middle (Q2-Q4) Affluent (Q5)	16% 57% 27%
Stage at diagnosis	1 - VCR derived 2 - VCR derived 3 - VCR derived 4 - VCR derived Unknown - VCR derived	3095 (13%) 8124 (35%) 8320 (36%) 1983 (8%) 1873 (8%)	NCCN Low risk NCCN Int risk NCCN High risk cN1, but not cM1 cM1	19% 49% 24% 4% 4%
PSA		NA	ng/ml	7 (4.9 - 11)
Grade	ISUP1 ISUP2 ISUP3 ISUP4 ISUP5 Metastatic Unknown	6881 (29%) 6288 (27%) 3220 (14%) 1713 (7%) 2077 (9%) 1917 (8%) 1299 (6%)	ISUP1 ISUP2 ISUP3 ISUP4 ISUP5	30% 31% 17% 10% 12%
	Death Certificate Only (DCO) patients excluded (n = 315)			

Slightly older

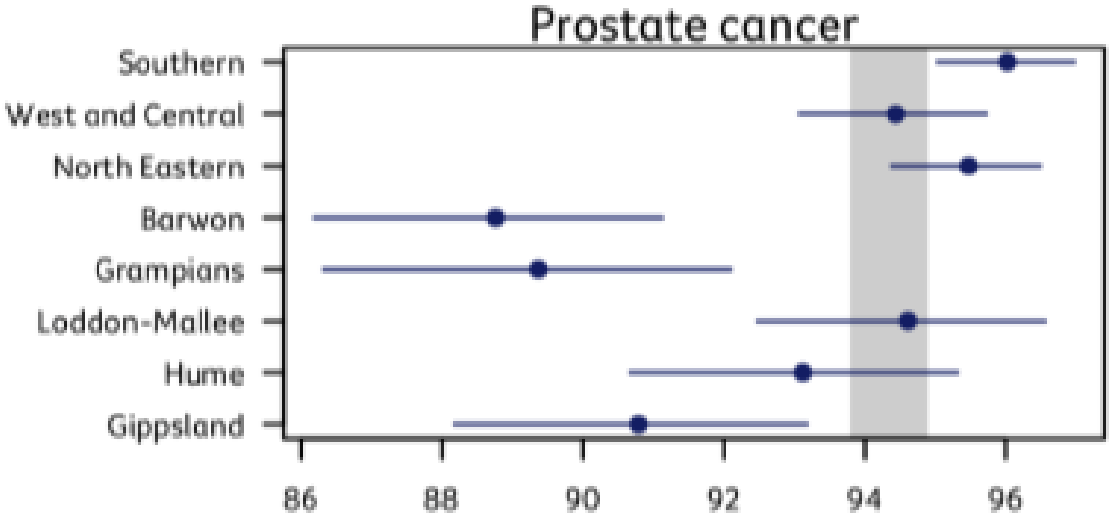
Slightly higher SES

PCOR includes stage, PSA & grade

Might reflect accrual at earlier period

Survival

Variation in five-year relative survival by ICS of residence 2014-2018



Relative 5 year survival does vary with Metro ICS or Regional ICS as a class

Note scale from 86-96, so magnify differences

Data Source: VCR
Grey are indicates the Victorian 95% survival confidence intervals

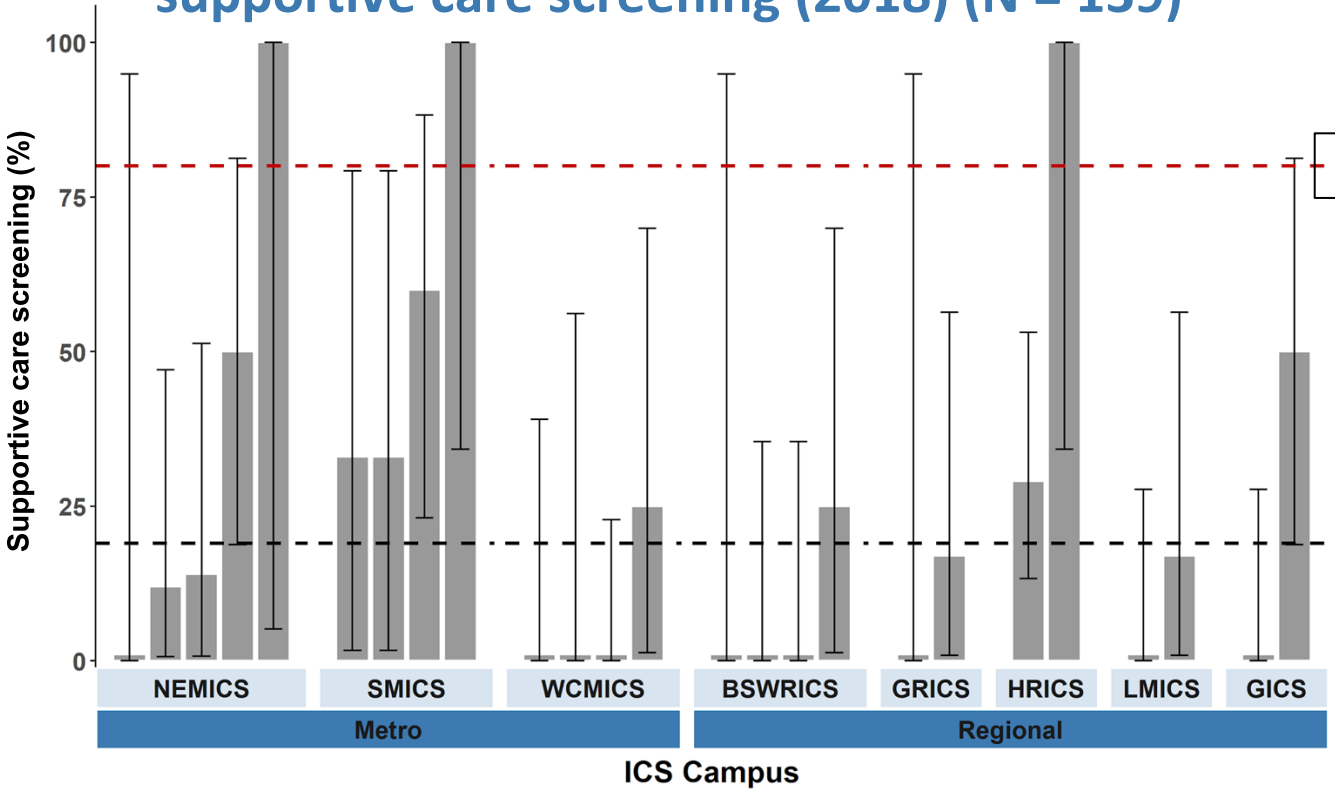
Proportion of prostate cancer patients in each ISUP group, by ICS of residence (2014-2018) (N=23,380)

ICS of residence	ISUP group (% row)						
	1	2	3	4	5	Metastatic	Unknown
NEMICS (n=5772)	30%	28%	14%	7%	8%	7%	5%
SMICS (n=6761)	32%	29%	13%	6%	7%	7%	4%
WCMICS (n=3748)	31%	26%	13%	7%	8%	9%	6%
BSWRICS (n=1601)	25%	22%	11%	10%	11%	10%	10%
GRICS (n=1360)	24%	26%	14%	8%	11%	10%	7%
HRICS (n=1359)	27%	26%	13%	10%	10%	8%	6%
LMICS (n=1756)	29%	24%	15%	7%	11%	9%	5%
GICS (n=1023)	21%	19%	18%	9%	15%	11%	6%
Victoria (n=23380)	*29%*	*27%*	*14%*	*7%*	*9%*	*8%*	*6%*

Data Source: VCR, VAED.

Supportive care and unmet needs

19% of prostate cancer patients had documented evidence of supportive care screening (2018) (N = 139)



Sample size small by hospital as suggested by error bars, so unreliable estimates

Data source: CSPI medical record audit 2018; Bars represent 95% CI
Data limitation: patients were audited from 21 public hospitals and 4 private hospitals *HRICS data limitation

Victorian Healthcare Experience Survey (VHES) Results

- 2019 survey of patients treated in 2018 in Victorian public hospitals
- Data can be analysed by cancer type and treatment types
- Findings indicated areas for improvement and areas where prostate cancer care was rated more highly than care provided for all/most other cancer types

Treatment type/s received	%
Surgery	39.83%
Radiotherapy	24.25%
Chemotherapy or targeted therapies	10.66%
Hormonal therapy	25.27%
Responses	681

Acknowledgements: Victorian Agency for Healthcare Improvement and DHHS

Victorian Healthcare Experience Survey satisfaction with care

Prostate cancer care	% positive responses	No. of responses
Surgery	96.85%	305
Radiotherapy	98.46%	183
Chemotherapy	98.51%	78
Overall care	97.49%	463

Areas rated highly compared with other cancer types

	% Positive responses
Informed about how to manage ongoing symptoms or side-effects after treatment	81.3%
GP had a good understanding of follow-up care needs e.g. symptom management support	81.3%
Communication with health professionals	85.6%
Felt able to ask health professionals any questions	86.6%
Informed about the impact of treatment on ability to perform work/other activities	79.9%
Given information about things to do to stay healthy e.g. exercise, diet, stopping smoking	77.9%

Areas for potential improvement

- Respondents with prostate cancer were the **most likely to report that they had bills to pay** when compared with all other tumour types. (`19%)

- Depending on treatment type between ~ 10% and 15% of men **wanted information about financial support** but did not receive it.

- ~ 1 in 2 men were not **asked about information / support needs of family/friends**

Survivors Unmet Needs Survey

VICS funded PCOR VIC Unmet Needs Project

- **Aim**: ascertain the unmet needs of men diagnosed with prostate cancer at 12 months after treatment.
- **Eligibility**: men treated in Victorian public hospitals who are enrolled in the Registry.
- **PCOR Victoria** administered the EPIC-26 and ‘Survey of Survivor Unmet Needs’ by email/post at 12 months after treatment.
- **Data collection**: March 2019-December 2020 -currently ongoing

Survivor Unmet Needs Survey-Short Form (SUNS-SF) Domains

- The 30 item SF-SUNS includes 4 domains of unmet needs:
  - Information needs
  - Work and financial needs
  - Access and continuity of care needs
  - Coping, sharing and emotional needs

SUNS-SF

EXAMPLE

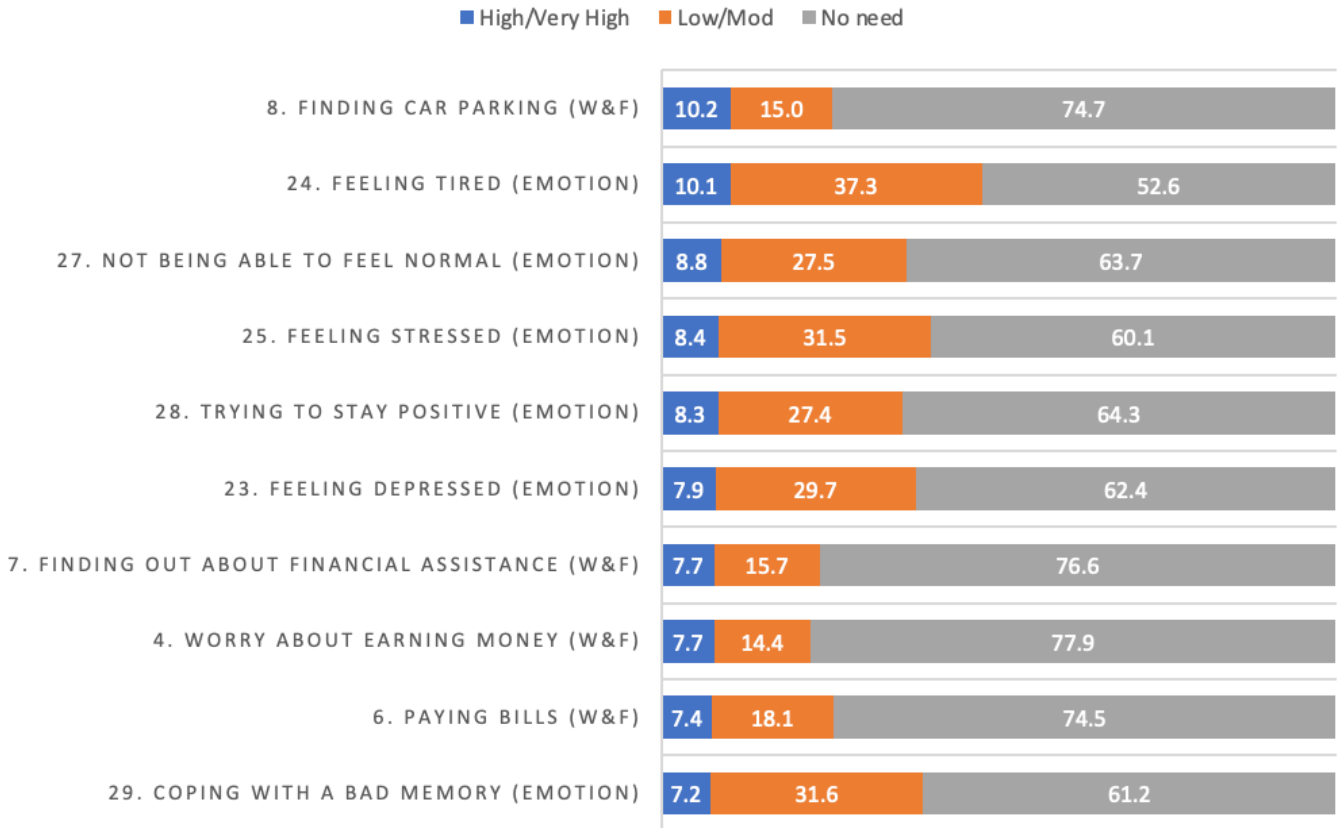
For each statement, circle the choice that best describes your level of unmet need.	No Unmet Need	Low Unmet Need	Moderate Unmet Need	High Unmet Need	Very High Unmet Need
Finding information about complementary or alternative therapies	0	1	(2)	3	4

If you circled #2, it means that IN THE LAST MONTH, you had a moderate need to know about complementary or alternative therapies but you were not able to get that information or help with your concerns.

Circle the choice that best describes your level of unmet need.					
Knowing how much time I would need away from work	(0)	1	2	3	4

If you circled 0, it means that, IN THE LAST MONTH, knowing how much time you needed away from work was not a problem for you.

TOP UNMET NEEDS FOR MEN WHO REPORTED HIGH/VERY UNMET NEEDS (N=1000)



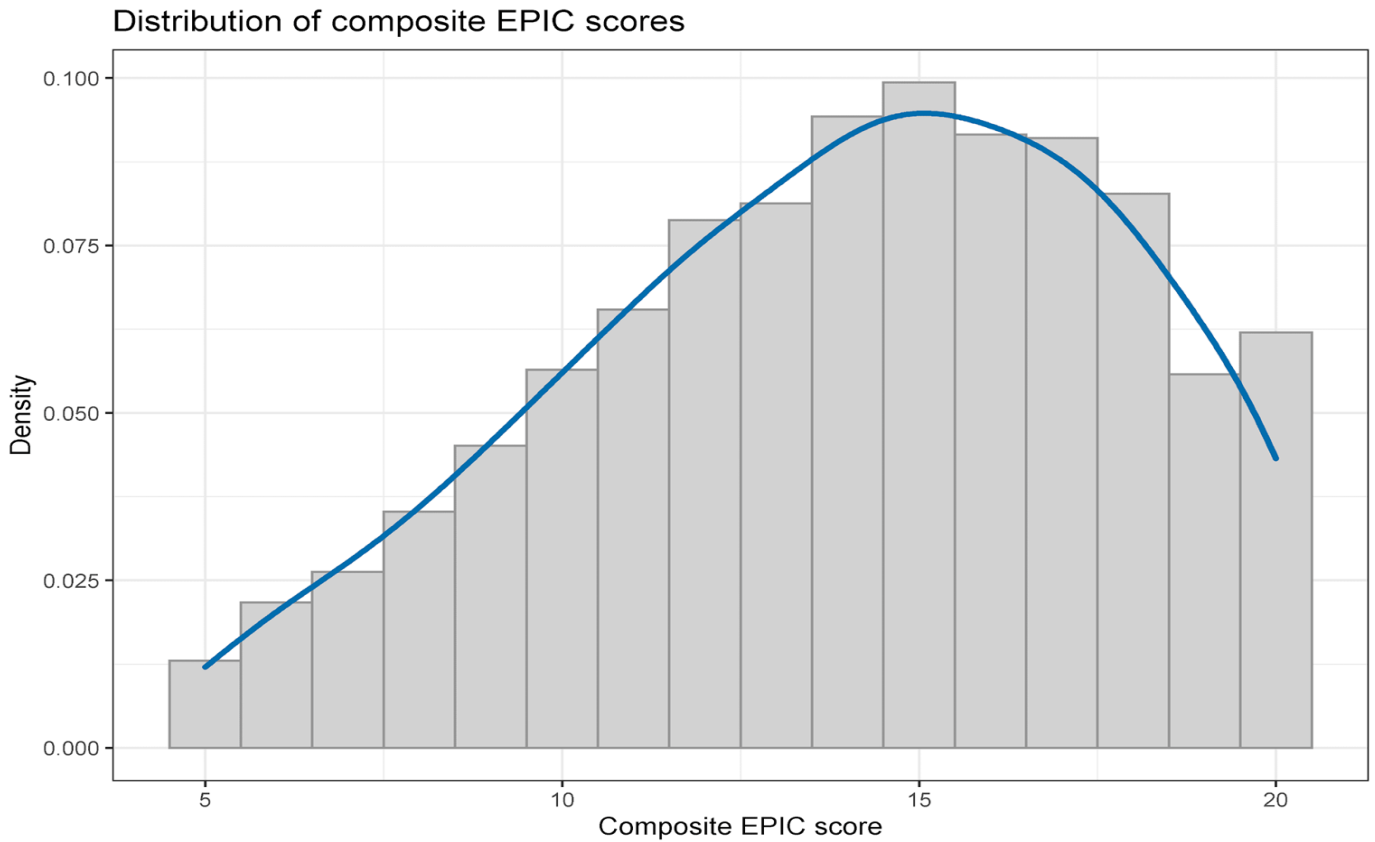
Quality of life 12 months after treatment

Health-related quality of life EPIC 26

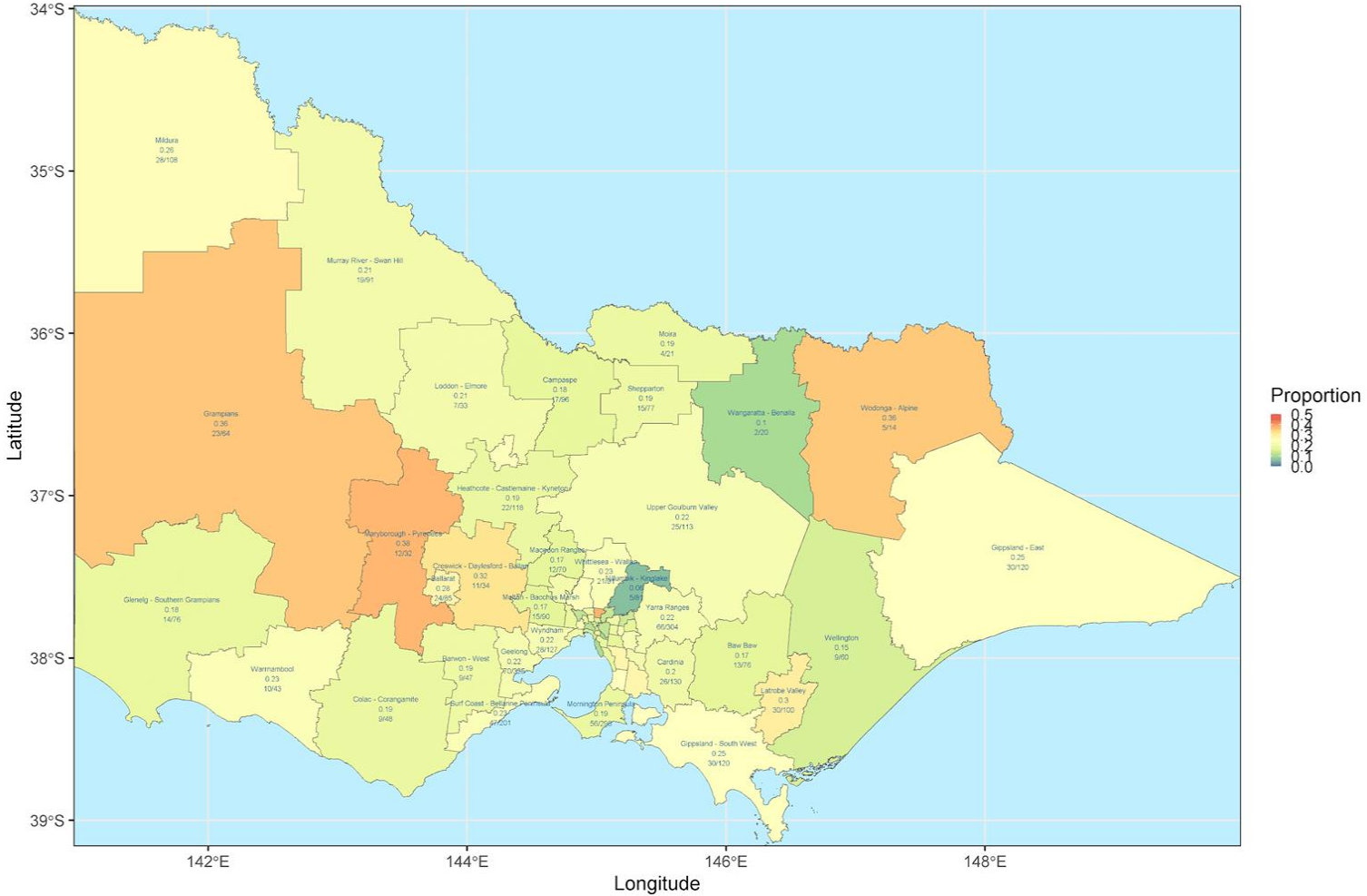
- 5 symptom domains:
  - Urinary incontinence
  - Urinary irritation
  - Sexual function
  - Bowel function
  - Hormonal function

- Scored from 0 (worst) to 100 (best)
- Enables understanding of symptom burden, function and the impact of side effect management strategies

Composite EPIC 26 Scores Oct 14-Dec 18

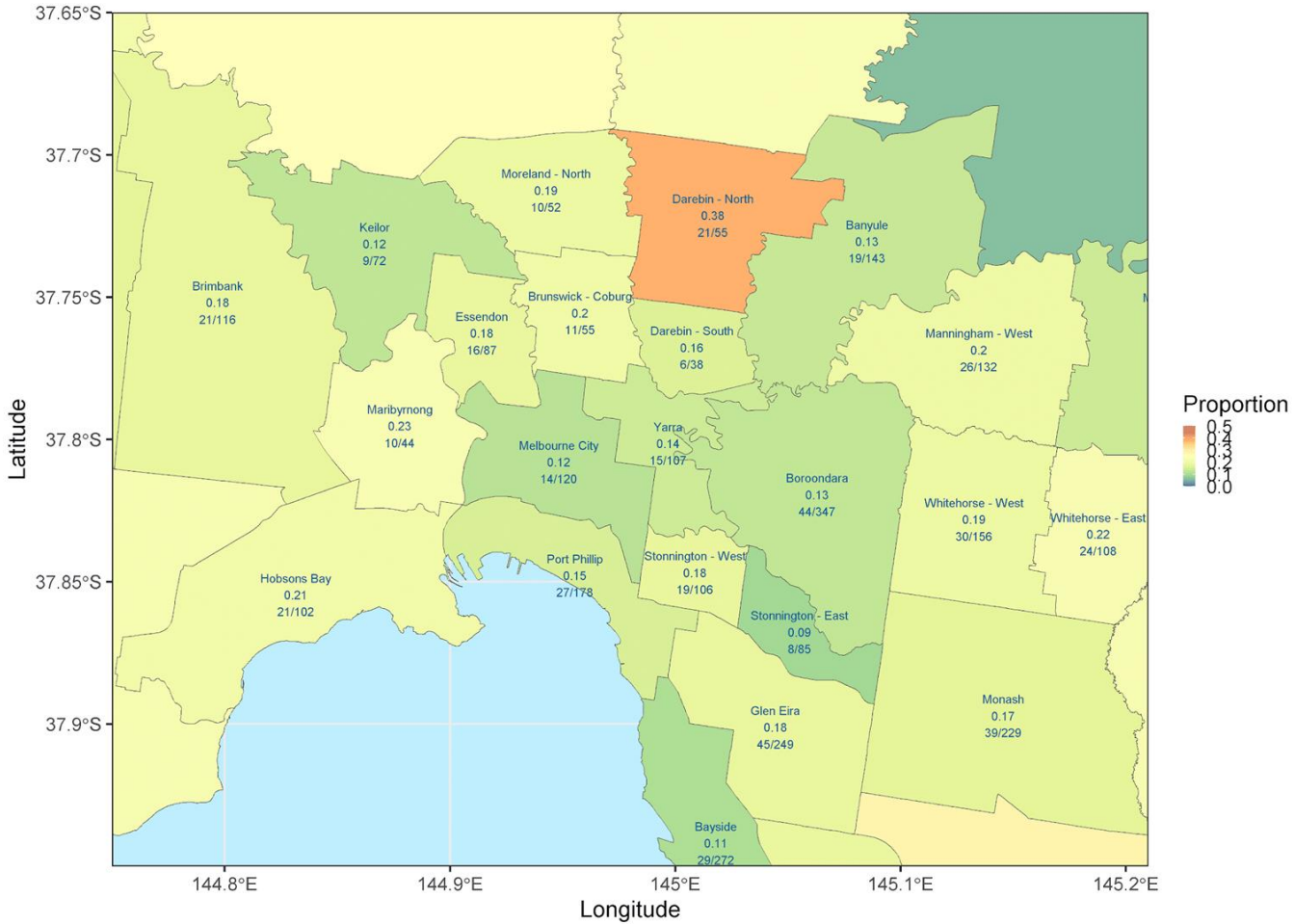


Acknowledgements to PCOR & The Australian Cancer Survivorship Centre for data



Proportion composite score

≤10



Proportion composite score

≤10

Variations

- In survival across ICS regions, but also variation by ICS in stage and grade at diagnosis that might account for this
- In identifying and addressing needs of men with prostate cancer (especially emotional, financial and fatigue management needs)
- In quality of life at 12 months after treatment across Victoria

Part 1 & 2 Summit Variations

- In access to prostatectomy by SEIFA status & geography
- In hospital surgical volumes
- In access to RT (incl brachytherapy) and unexplained disparity between surgery and RT
- In access to MDM/MDT discussion
- In survival across ICS regions, but also variation by ICS in stage and grade at diagnosis that might account for this
- In information & support at diagnosis and treatment planning
- In identifying and addressing needs of men with prostate cancer (especially emotional, financial and fatigue management needs)
- In quality of life at 12 months after treatment across Victoria

Acknowledgements

Chairs

Prof. Jeremy Millar

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