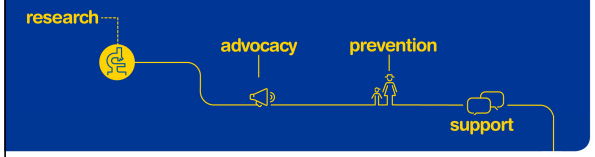
Using PROMS to better understand prostate cancer outcomes:

The NSW Prostate Cancer Care and Outcomes Study

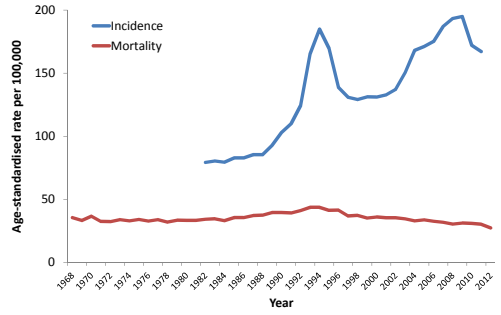


David Smith – Research Fellow
Cancer Research Division

Monash Uni, 26th June 2015

Cancer Council NSW

Trend in prostate cancer incidence and mortality rates in Australia



Australian Institute of Health and Welfare (AIHW) 2015. Australian Cancer Incidence and Mortality (ACIM) books: Prostate cancer. Canberra: AIHW. <http://www.aihw.gov.au/acim-books>.
Standardised to Australian 2001 standard population

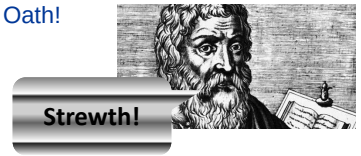
Survival outcomes for men in rural and remote NSW

- 68,686 men diagnosed 1982-2007
- 10-year survival 57% in 1992, 84% in 2007
- Compared to major cities
  - Inner regional men 18% higher risk of death
  - Rural men at 32% higher risk of death

Yu XQ, Luo Q, Smith DP, O'Connell DL, Baade PD. Geographic variation in prostate cancer survival in New South Wales. Med J Aust. 2014 Jun 2;200(10):586-90.

The prostate cancer conundrum

1. High incidence rates v low mortality rate
2. Should men be tested for prostate cancer?
3. Who really needs treatment and when?
4. Hippocratic Oath!



Treatment options for early prostate cancer

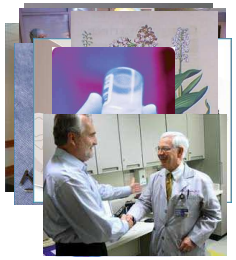
Surgery
- Open prostatectomy
- Robot assisted prostatectomy

Radiotherapy
- External beam radiotherapy
- Low dose rate brachytherapy
- High dose rate brachytherapy

Androgen deprivation therapy
- Orchidectomy
- Hormone manipulation

Active surveillance

Other treatment (cryotherapy, HIFU, proton therapy)



NSW Prostate Cancer Care and Outcomes Study - Aims

To undertake a long term observational study to describe:

1. patterns of care for prostate cancer
2. **quality of life of men with prostate cancer by treatment type**
3. Unmet supportive care needs
4. Coping
5. Men's preferences for management outcomes
6. Health system costs
7. Recurrence and survival

Choice of PROM

- Prostate Cancer Quality of Life scale (PC-QoL)
- Prostate Cancer Specific Quality of Life (PROSQALI)
- **UCLA Prostate Cancer Index (UCLA-PCI)**
- Functional Assessment of Cancer Treatment – Prostate (FACT-P)
- European Organisation for Research into Treatment of Cancer, Quality of Life Questionnaire and prostate cancer module (EORTC-QLQ-C30+PR25)

UCLA-PCI*

Pros
- Validated instrument with clear coding instructions
- Had been used in Australia and internationally
- Captured "function" and "bother"
- Included Rand SF-36 General Quality of Life items
- Appropriate for prostate cancer cases and controls

Cons
- Long – 20 Items +RAND 36-Item Health Survey v2 (SF-36 v2)
- Not validated for telephone administration
- Language: English for the USA
- Inadequate collection of information on urinary function
- Inadequate collection of important outcomes related to hormone treatment
- Recall – "in the past 4 weeks"

Litwin MS, et al. The UCLA Prostate Cancer Index: development, reliability, and validity of a health-related quality of life measure. Med Care. 1998 Jul;36(7):1002-12

Pilot testing of the PROM

Telephone administration (CATI)

- We could insert skips
- Increased response rate
- Less missing data

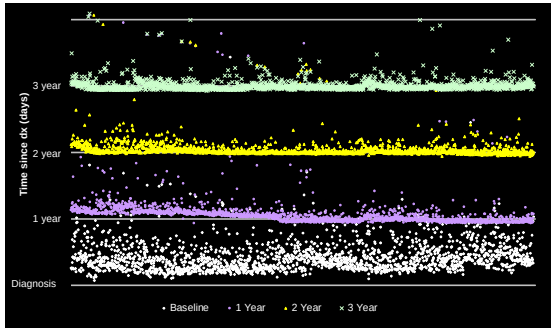
Pre-pilot testing with 5 "consumers"

- Logistics, flow and timing
- Missing information – so we added a new urinary scale
- Developed a prompt sheet

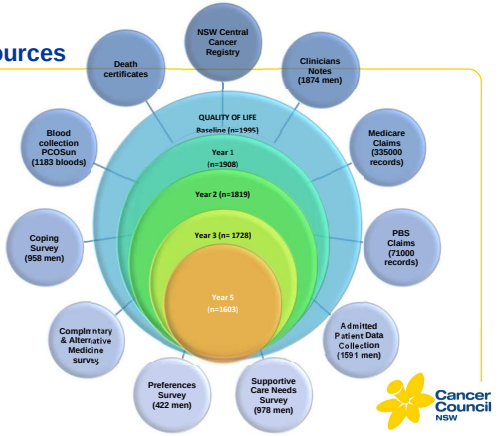
Pilot testing with 40 cases and 20 controls

- Average time = 37 mins (range 10 to 60) – 10% said it was too long
- 24% felt that important areas were not covered
- 91% comfortable with male or female interviewers
- 25% expressed issues with recall bias
- Refuse to answer - 2.9% household income, 1.2% firmness of erections

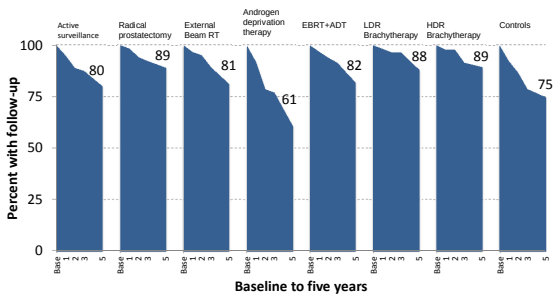
Timing of case interviews



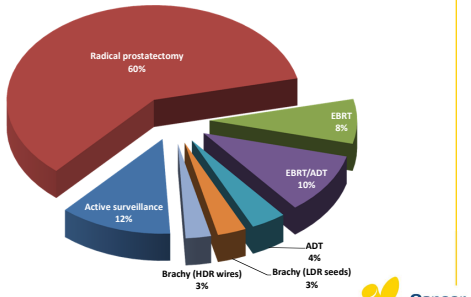
PCOS Data sources



Five year follow up by treatment group



Initial therapy for men with localised prostate cancer in PCOS (n=1,642)



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Five year quality of life outcomes in NSW men with localised cancer by initial treatment

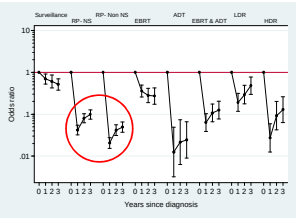
Treatment group	Incontinent*	Bowel problems#	Impotent^
Radical prostatectomy	12%	4%	75%
External Beam RT	2%	9%	66%
Combined EBRT/ADT	3%	10%	77%
Brachy (LDR seeds)	2%	2%	43%
Brachy (HDR wires)	5%	12%	74%
Androgen Deprivation Therapy	5%	5%	95%
Active surveillance	8%	11%	58%

* Needing to wear one or more pads per day
\# Moderate or big problem with bowels
^ Unable to obtain an erection sufficient for intercourse

Source: updated from Smith et al BMJ 2009

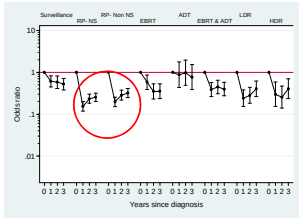
Sexual function and bother

Sexual Function



adjusted for baseline sexual function score, age, income, ARIA and co-morbidity

Sexual Bother



adjusted for baseline sexual bother score, age, marital status and co-morbidity

Source: Smith et al BMJ 2009

PROMs translation to practice

PSA Testing and Early Management of Test- Detected Prostate Cancer

- *"For men informed of the benefits and harms of screening who wish to undergo regular testing,* ***offer PSA testing every two years from age 50*** *to age 69, and offer further investigation if the PSA is greater than 3.0 ng/mL."*

- **Review of Brachytherapy use in NSW**
- **Patient information**

Source:
http://wiki.cancer.org.au/australiawiki/img_auth.php/d/d5/20141125_Draft_Clinical_Practice_Guidelines_PSA_Testing.pdf

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U.S. Preventive Services Task Force

The U.S. Preventive Services Task Force (USPSTF) recommends against prostate-specific antigen (PSA)-based screening for prostate cancer (D recommendation).

Key Question 4: What Are the Harms of Treatment of Early-Stage or Screening-Detected Prostate Cancer?

- NSW PCOS study results were referenced 18 times in this document
- Our study was one of only three cohort studies to be rated "good"
- In some cases was the only study to report specific comparisons

eg: *"One good-quality cohort study reported a 7.0% rate of urinary incontinence after high-dose brachytherapy (n=47), 5.4% after low-dose brachytherapy (n=58), and 2.7% after EBRT (n=123) (56)."*

Ref: Roger Chou et al Screening for Prostate Cancer A Review of the Evidence for the U.S. Preventive Services Task Force. October 2011

Summary

- **PROMs have altered the way prostate cancer is managed and communicated**
- **Choice of the right instrument, methods of administration and analysis are vital**
- **Movember prostate cancer registry will be vital in the future**

Working together to beat cancer

Cancer Council NSW