

## Bringing prostate cancer education to regional and rural Australian communities

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### Abstract

Prostate Cancer Foundation of Australia (PCFA) launched its Rural Education Roadshow program in 2013. Funded through the Commonwealth Government, and modelled on the Western Australia Cancer & Palliative Care Network framework, the program brought a structured prostate cancer education program to regional, rural and remote communities across Australia.

The Roadshow aimed to:

- improve local knowledge and skills of local health care providers from all disciplines who come into contact with prostate cancer patients
- deliver education directly to those affected by prostate cancer to engage with them on how to improve quality of life with prostate cancer diagnosis, while addressing issues around survivorship.

The Roadshow provided the opportunity for local health professionals to explore the complexities of treatment and increase expertise in regional areas to support patients through their cancer journey. The Roadshow was delivered by a multidisciplinary team including a urologist, oncologist and a prostate care nurse. Local clinicians or Visiting Medical Officers (VMO) were utilised to ensure content reflected local pathways and promoted interdisciplinary networking.

Two sessions were delivered at each Roadshow event; one targeting health professionals, the other, community members affected by prostate cancer. Content for the health professional session included information on diagnosis, treatment and side effect management of both localised and advanced prostate cancer. The community session focused on coping with treatment and side effects, survivorship and support.

Program evaluation was undertaken to determine if the Roadshow met objectives. Data were collected from multiple sources including surveys and interviews with those participating in the education sessions. Ethics approval was obtained from the Australian Department of Health Ethics Committee.

Key evaluation findings demonstrated a positive impact on health professionals. Overall the majority of health professionals reported an increase in their knowledge of both diagnostics and treatment of prostate cancer. 89% of respondents agreed that sessions increased confidence in supporting and managing patients with prostate cancer, and a high proportion retained this view at least three months post event. Consumers reported an increase in knowledge of effects from treatment and when to seek further help in relation to the effects of their disease and treatment. 86% of consumer attendees agreed that attending the session increased empowerment in managing issues relating to prostate cancer.

The Roadshow has been an effective program for delivering education through an outreach model to both health professionals and community groups with potential to apply this model to other disease types.

### Introduction

Prostate Cancer Foundation of Australia (PCFA) is a broad based community organisation and the peak body for prostate cancer in Australia. PCFA are dedicated to reducing the impact of prostate cancer on Australian men, their partners and families, recognising the diversity of the Australian community, and do this by:

- promoting and funding world leading, innovative research into prostate cancer
- implementing awareness campaigns and education programs for the Australian community, health professionals and Government
- supporting men and their families affected by prostate cancer through evidence based information and resources, support groups and prostate cancer specialist nurses.

Prostate Cancer Foundation of Australia (PCFA) launched its Rural Education Roadshow Program in 2013. The program aimed to improve the knowledge and skills of rural and regional health care providers from all disciplines who may come into contact with prostate cancer patients in the primary or secondary care context; and also improve the knowledge on survivorship issues of those affected by prostate cancer in the community.

The objectives of the Roadshow were to:

- provide the opportunity for local health professionals to explore the complexities of treatment and increase expertise in regional areas to support patients through their cancer journey
- empower men and their families to make more informed decisions and be active participants in managing their individual approach to prostate cancer in the post diagnosis phase.

Health professional development programs are usually delivered through metropolitan service providers, and opportunities for community based health education are also limited in regional and rural areas thus creating disadvantage. The delivery of education at a local rather than metropolitan level reduces costs on local service providers, ensures resources are maintained within the regional setting and increases Health Care Professionals accessibility to education. Consumers benefit from informed decision making, reduced travel costs and accessibility to evidence based practice.

Following implementation, the Rural Education Roadshow Program was evaluated with the aim of measuring both the impact on the health care professionals' confidence and practice with prostate cancer management; and the impact on the consumers' confidence in increasing their knowledge and awareness. The outcomes from these measures will be reported in this paper.

### Prostate cancer in Australia

Prostate cancer is a significant Australian public health issue. More than 20,000 men are diagnosed with prostate cancer in each year making it the most commonly diagnosed non cutaneous male cancer in Australia. It is the fourth leading cause of mortality among Australian males, with 3,294 deaths from prostate cancer in 2011. Prostate cancer does however have higher survival rates in comparison to other cancers, with around 9 in 10 (92%) males diagnosed with prostate cancer surviving 5 years from diagnosis (1). This in turn has an impact on the Australian health care system to provide treatment and supportive care for these men.

Treatment choice is influenced by a number of factors including disease grade and stage, life expectancy and patient preference. Generally, cancers considered to be potentially curable are treated with radical prostatectomy, external beam radiotherapy or brachytherapy. Increasingly, however, men with early stage, low grade cancers are being offered active surveillance or watchful waiting, which entail no initial treatment but follow-up clinically with periodic Prostate Specific Antigen (PSA) blood tests and, in the case of active surveillance, periodic biopsies. A later decision may be made to treat actively if the cancer appears to be progressing. Androgen deprivation therapy is usually used as an adjunct to radiotherapy or as the only initial treatment for men whose cancer has progressed to a stage at which it is unlikely to be curable by surgery or radiotherapy. Chemotherapy and targeted therapies are reserved for patients with metastatic prostate cancer (2) (3). Treatment of prostate cancer is invariably a cause of anxiety and distress, discomfort and is acknowledged to cause a wide range of adverse side effects:

- urinary incontinence is apparent in many men initially following surgery and persists in some 12-15% of men treated by radical prostatectomy

- loss of sexual potency in men treated by radical prostatectomy, radiotherapy or androgen deprivation therapy
- bowel problems, which are most common after external beam radiotherapy (about 15% after 3 years) (3).

As a result, there is a need for evidence-based education about prostate cancer for both health professionals and consumers to enable informed decision making and subsequently improved pathways of care for those affected by the disease.

### Rural Education Roadshow Program Structure

In order to recruit sites and presenters to the Roadshows, PCFA issued an Expression of Interest (EOI) through Cancer Networks and the Department of Health. Data reported in this evaluation stems from a sample of the 12 sites participating in the program in 2013. The following table shows host sites for the program that participated in the program evaluation;

Table 1 Roadshow host sites included in program evaluation

State	Regional / Rural Sites	ASGC Remoteness Area
NSW	Armidale	Inner Regional
VIC	Bairnsdale	Outer Regional
QLD	Gladstone	Remote
	Emerald	Outer Regional
WA	Albany	Outer Regional
	Bunbury	Inner Regional
SA	Port Pirie	Outer Regional
	Berri	Outer Regional
TAS	Burnie	Outer Regional
NT	Katherine	Remote
	Nhulunbuy (Gove)	Very Remote
ACT	Canberra	Major City

A further 10 Roadshows were delivered in 2014.

For each Roadshow the presenters delivered two sessions, one for health professionals and one for consumers. An Expert Advisory Panel (EAP) together with PCFA developed the core content for the Roadshow based on current Australian clinical practice guidelines (3) (4) (5) and consumer resources. Presenters collaborated with PCFA to refine content and delivery of the presentations. Table 2 presents the core content for the Roadshow which were developed by the EAP.

Table 2 Core content for the Roadshows

Healthcare professional session: "Prostate Cancer: detection, treatment and supporting the local community"	Community session: "Living better with Prostate Cancer"
<ul style="list-style-type: none"> <li>• PSA testing – basics</li> <li>• Biopsy, including:               <ul style="list-style-type: none"> <li>– basic complications</li> <li>– when to refer</li> <li>– results</li> </ul> </li> <li>• Recommending treatments including:               <ul style="list-style-type: none"> <li>– active surveillance</li> <li>– further tests</li> </ul> </li> <li>• Psychological effects of a cancer diagnosis, including:               <ul style="list-style-type: none"> <li>– impact to patient</li> <li>– financial impact</li> </ul> </li> <li>• Localised , locally advanced and advanced prostate cancer, including:               <ul style="list-style-type: none"> <li>– treatment options</li> <li>– side effects.</li> </ul> </li> <li>• Survivorship including:               <ul style="list-style-type: none"> <li>– what are the issues for men?</li> <li>– treating incontinence</li> <li>– treating erectile dysfunction</li> </ul> </li> <li>• Support services including:               <ul style="list-style-type: none"> <li>– peer support (patients)</li> <li>– local support options</li> <li>– national support services</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>• Coping with treatments, including:               <ul style="list-style-type: none"> <li>– selecting treatment</li> <li>– psychosocial impact of decision making</li> <li>– financial implications</li> <li>– preparation for treatment</li> <li>– preparation for recovery.</li> </ul> </li> <li>• Coping with side effects of treatments, including:               <ul style="list-style-type: none"> <li>– what is normal?</li> <li>– what needs further consultation?</li> <li>– financial implications.</li> </ul> </li> <li>• Localised and advanced prostate cancer - basics</li> <li>• Hormone treatments, including               <ul style="list-style-type: none"> <li>– side effects</li> <li>– strategies to reduce</li> </ul> </li> <li>• Psychological effects of a cancer diagnosis               <ul style="list-style-type: none"> <li>– living with a cancer diagnosis</li> <li>– GP support</li> <li>– peer support</li> <li>– local and national support services.</li> </ul> </li> <li>• Survivorship including:               <ul style="list-style-type: none"> <li>– Optimising health following diagnosis and treatment</li> </ul> </li> <li>• Needs of the support person, including:               <ul style="list-style-type: none"> <li>– peer support</li> <li>– financial assistance.</li> </ul> </li> </ul>

An emphasis was placed on educating about Androgen Deprivation Therapy (Hormone therapy) as this treatment is often given for significant periods of time in partnership with primary care practitioners as opposed to being a hospital based treatment.

In addition to the structured sessions, the forums allowed ideas, information and practical advice to be exchanged so that prostate cancer patients in rural and regional Australia could benefit from better-quality services in their localities and improved referral pathways to specialist services.

### Evaluation methodology

The program was evaluated with the aim of measuring both the impact on the health care professionals' confidence and practice with prostate cancer management; and the impact on the consumers' confidence in increasing their knowledge and awareness. Data were collected from multiple sources:

- surveys of health professionals who attended the sessions distributed immediately after the event
- surveys of all consumers who attended sessions distributed immediately after the event
- re survey via telephone of a sample of health professionals at three months after the event to assess knowledge retention and / or change in practice
- re survey via telephone of a sample of consumers at three months after the event to assess knowledge retention and / or changes in their own self-management.

Ethical approval was obtained from the Australian Department of Health Ethics Committee prior to commencement of the evaluation.

## Evaluation results

### The Roadshow Model

Surveys were distributed to 322 health professional who attended the Roadshows. 229 post-session surveys were received, reflecting a 71% response rate. The majority of health professionals were nurses (46%), followed by GPs (33%) and pharmacists (9%). The model used by PCFA, which involved the inclusion of one visiting clinician (usually the urologist or specialist prostate cancer nurse) in the Roadshow team, was considered valuable by the session attendees. The majority of Roadshow attendees 'strongly agreed' or 'agreed' (93% of health professionals and 92% of consumers) that the Roadshow presenters had sufficient local knowledge.

### Impact of the Roadshow on health professionals

Information was gathered to assess the impact of the Roadshow on health professionals' confidence and practice in prostate cancer management. 92% of all health professionals reported that their knowledge on aspects of prostate cancer had increased immediately post-session and at three months post-Roadshow, 79% reported that they had retained this knowledge. This is shown below in Table 3.

Table 3 Impact of program on health professional's knowledge

Topic	Number of attendees reporting increased knowledge immediately post-Roadshow				Number of attendees retaining knowledge three months post-Roadshow			
	GP	Nurse	Other	All	GP	Nurse	Other	All
When to conduct prostate cancer testing	61	88	37	186	9	16	6	31
When to start talking about prostate cancer	66	97	43	206	10	17	7	34
What happens after referral to specialist	69	104	39	212	10	19	5	34
Biopsy procedure, side effects and complications	73	101	41	215	11	17	6	34
Psychological effects of cancer diagnosis	53	99	38	190	8	16	7	31
Localised prostate cancer	71	103	46	220	10	17	7	34
Locally advanced prostate cancer	73	104	45	222	9	16	8	33
Advanced prostate cancer	75	103	43	221	10	15	8	33
Treatment and management of incontinence	69	98	38	205	9	17	6	32
Treatment and management of erectile dysfunction	68	101	42	211	11	18	6	35
Hormone treatment	72	97	39	208	11	15	6	32
Survivorship and the issues for men	57	95	38	190	9	13	6	28
The range of available support services	64	99	42	205	6	17	6	29

Source: HealthConsult health professional immediately post and three month post Roadshow survey. 'Other' includes allied health professionals.

The majority of health professionals (89%) reported an increase in confidence in various aspects of managing patients with prostate cancer immediately post-session survey, with the majority of these health professionals retaining this confidence (76%) three months post the Roadshow.

Health professionals were asked immediately after the Roadshow whether some of the information presented or provided at the Roadshow was not previously accessible or known to them. A high proportion of health professionals (89%) 'strongly agreed' or 'agreed' that the Roadshow presented information that was either new or not previously accessible to them.

The most useful aspects of the health professional session were:

- treatment options and/or side-effects of treatment
- information on local support services
- information on PSA testing and diagnosis of prostate cancer
- networking with other health professionals.

The least useful aspects of the health professional session were the level of technical information in the chemotherapy and radiotherapy sections and the lack of information on when to undertake PSA testing.

### Impact of the Roadshow on consumers

Information was gathered to assess the impact of the Roadshow on consumers' knowledge of side effects and when to seek help in relation to their prostate cancer. 242 surveys were distributed and 146 post-session surveys were received reflecting a 60% response rate. The largest proportion of responses were received from current or previous prostate cancer patients (43%), followed by friends or relatives of a person with a prostate cancer diagnosis (30%).

Consumers were asked whether the Roadshow had increased their knowledge in a number of aspects presented in the session. A sample of these consumers were also followed up three months after the Roadshow to assess whether they had retained any knowledge. 90% of all consumers reported that their knowledge on aspects of prostate cancer had increased immediately post-session and 67% had retained this knowledge three months after the Roadshow. This is shown below in Table 4.

Table 4 Impact on consumers' knowledge as a result of attending the consumer Roadshow session

Prostate Cancer Topic	% attendees reporting increased knowledge immediately post-Roadshow	% attendees retaining knowledge three months post-Roadshow	% change in knowledge gain
Members of the treatment team	95%	83%	12%
Side effect of treatment	89%	82%	7%
Which side effects require further consultation	89%	56%	33%
Treatment and management of side effects	90%	67%	23%
When to see a doctor urgently	88%	47%	41%
Things that help me live better	85%	59%	26%
Different types of support services available	90%	81%	9%
Contacts for support information and assistance	96%	73%	23%
Resources available online	85%	58%	27%

Source: HealthConsult immediately post and three month post Roadshow consumer survey

The majority of consumer attendees felt their knowledge had increased across a range of prostate cancer topics immediately post-session. Three months post the Roadshow, 67% of attendees reported still retaining this knowledge. The most useful aspects of the Roadshow session for consumers were information on treatment options, treatments for side effects, question and answer time, information on available support and meeting others in a similar situation. No "least useful" aspects of the Roadshow were suggested.

### Conclusions

One of the aims of the Roadshow was to improve the knowledge and skills of health care providers from all disciplines who may come into contact with prostate cancer patients in the primary or secondary care context in rural and regional Australia. In 2013; 322 health professionals attended the 12 Roadshows held around Australia. About half of the attendees were nurses, a quarter were GPs and the remainder were a mixture of allied health professionals (e.g. pharmacists and physiotherapists) and students (e.g. medical or allied health).

The health professionals' session included content on biopsy, types of prostate cancer, treatment choices, side effects and management of; survivorship, support services and the basics of PSA testing. Majority (92%) of the health professionals 'strongly agreed' or 'agreed' that attending the session increased their knowledge in a number of the topics covered by the session. Importantly a high proportion of those that attended the sessions felt they had retained the knowledge three months post the sessions.

The majority (89%) of the health professionals 'strongly agreed' or 'agreed' that attending the session also increased their confidence in various aspects of supporting and managing patients with prostate cancer. The majority (97%) of health professionals rated the overall Roadshow as 'excellent' or 'good'. A number of Roadshow presenters and health professionals felt the content could have been made more relevant with a stronger focus on PSA testing, implications of positive tests and the role of the GP.

The other aim of the Roadshow was to deliver education to those affected by prostate cancer directly to engage them on how to live better with prostate cancer through providing information on better self-care and the issues around survivorship. 242 consumers attended the 12 Roadshows held around Australia. Consumer attendees were a mixture of current or previous prostate cancer patients, friends or relatives of someone with a prostate cancer diagnosis or members of the general community interested in raising their awareness of prostate cancer.

The consumer Roadshow sessions included content on coping with treatments and side effects, types of prostate cancer, psychological effects of a cancer diagnosis, survivorship and support services. The majority (90%) of consumers 'strongly agreed' or 'agreed' that attending the session increased their knowledge in a number of the topics covered in the session. At three months post the Roadshow, 67% of those interviewed claimed they had retained the knowledge they learnt.

The majority (86%) of the consumer attendees who were current or previous prostate cancer 'strongly agreed or agreed' that attending the session increased their empowerment in various aspects of prostate cancer. At three months post the Roadshow 43% of consumers reported they still felt empowered in managing their care as a result of attending the Roadshow.

Almost half of the consumers (49%) reported that they would not have attended the session had it only been available in a metropolitan area while a further 23% said they would only be 'slightly' likely to attend in a metropolitan area.

The Roadshow has been an effective program for delivering education through an outreach model to both health professionals and community groups with potential to apply this model to other disease types.

## Disclosure

Funding for the PCFA Rural Education Program was through the Commonwealth Government Chronic Disease Prevention and Service Improvement Fund.

## Presenter

**Julie Sykes** is the Director of Health and Education Programs at the Prostate Cancer Foundation of Australia. Julie is a registered nurse with a special interest in prostate cancer and has worked in both the UK and Australia in senior nursing positions in cancer care service development and delivery. Julie is responsible for the strategic development and implementation of PCFA's education programs and services. Julie was the project manager for PCFA Rural Education Roadshow, a program which took prostate cancer experts to regional and rural Australia to deliver structured education to health professionals and those affected by prostate cancer. Julie is also responsible for the production of PCFA consumer information materials in both online and print format and PCFA advocacy programs in partnership with key stake holders. Julie has an extensive publication and presentation profile on prostate cancer nursing and was responsible for the development and implementation of the PCFA Prostate Cancer Specialist Nursing Service. This national structured program currently funds 27 Prostate Cancer Specialist Nurses hosted in hospitals in all States and Territories across Australia providing care to men and families affected by prostate cancer. Julie is also President of the Australia and New Zealand Urological Nursing Society.