

17 February 2017

Budget Policy Division
Department of the Treasury
Langton Crescent
PARKES ACT 2600

Dear Sir/Madam

Pre-Budget submission (2017-2018)

This pre-budget submission (2017-2018) seeks \$5.9 million of funding over three years from 1 July 2017 to expand Prostate Cancer Foundation of Australia's (PCFA's) Prostate Cancer Specialist Nursing service from 28 to 42 nurses.

For many men, their diagnosis is the first time they have given prostate cancer a thought. Most have no understanding of the disease or treatment and that it can and does cause much fear and uncertainty. Friends and families are vital, but specialist nurses have the knowledge and skills to help men at all stages of their complex cancer journey and the significant and varied choices confronting these men in the areas of – diagnosis, treatment and aftercare as recommended by their medical practitioners.

1. Executive Summary

PCFA's Prostate Cancer Specialist Nursing service was established in 2012 with generous financial support from The Movember Foundation and other community organisations. In 2014 the service was expanded by 14 additional nurses through \$6.9 million of Federal Government funding provided through the Department of Health. Today there are 28 Prostate Cancer Specialist Nurses across Australia.

Evaluation of the pilot conducted by a team from Queensland University of Technology Institute of Health and Biomedical Innovation (QUT ihbi) led by Professor Patsy Yates (Head of School of Nursing) has demonstrated the high community value and appreciation of the service, especially in areas of psychosocial care and in addressing disease-specific and treatment-related concerns of men and carers. Prostate Cancer Specialist Nurses are highly trained professionals dealing with a myriad of unique circumstances pertaining to prostate cancer who also play an important role in achieving broader system level and local service improvements in both rural and metropolitan settings.

In December 2016, the Minister for Health gave policy approval to renew the current Department of Health funding. This funding has secured the future of the service over the next three years. However, based on the incidence and estimated prevalence of prostate cancer and case load from the pilot, we estimate there is a demand for some 110 Prostate Cancer Specialist Nurses in total

nationally. This is particularly important in rural Australia where the mortality rate for men suffering this disease is in the order of 34% higher than their metropolitan counterparts. This means that with just 28 Prostate Cancer Specialist Nurses for all of Australia, 3 out of 4 men diagnosed currently do not have access to life-changing expert nursing support. We therefore seek additional funding of \$5.9 million over three years to expand the service by another 14 nurses. This would take the total number of nurses across Australia to 42, still less than half the estimated need but a major step forward in assisting in better managing the health of the men in Australia affected by prostate cancer.

2. The Need

In Australia some 20,000 men are diagnosed with prostate cancer each year making it the second most commonly diagnosed cancer after non-melanoma skin cancer [1]. It is the sixth leading cause of mortality among Australian men, with 3,112 deaths from prostate cancer in 2013 [2]. Prostate cancer does, however, have an improving relative survival rate, due to advances in detection and treatment, in comparison to other cancers with 92% of men diagnosed with prostate cancer surviving five years from diagnosis [3]. With both a rising population and improvements in survival rates, researchers at Cancer Council NSW have estimated that some 200,000 Australian men are currently living post diagnosis and treatment for prostate cancer. In far too many cases these men and their families are living with long-lasting, and in some cases devastating, impacts on physical and mental well-being and often do not seek or find help or support.

Treatment options for prostate cancer are given with the intention of either eradicating the disease or offering palliation from symptoms in the event of disease spread. Individual treatment plans are determined by a number of factors including the grade and stage of disease, age, other comorbidities and patient preference. This often involves a multimodality approach. Significant side effects, including urinary incontinence, sexual dysfunction, bowel problems, and depression, are a common feature for many men who have received prostate cancer treatment and these can persist for many years and require specialist advice and intervention.

The Prostate Cancer Specialist Nurses pro-actively assist men and their families in the following ways

- Providing those affected by prostate cancer with ongoing point of contact and support
- Assisting men access services both in their hospital and in their community during and after treatment
- Providing men with reliable evidence based information about their diagnosis and treatment plan
- Providing men with plain language information on dealing with the effects of treatment and how to get further help to deal with specific problems they may be having or be vulnerable to.
- Coordinating care efficiently wherever a man is in his cancer journey
- Helping men and families access a support group in their local community or via a range of electronic mediums and forums.
- Providing education and training to other health care workers as well as those affected by prostate cancer

- Participating in projects and developments to improve care for those affected by prostate cancer.

3. History of the Service

The role of the nurse in providing specialist supportive and clinical care is widely recognised in published literature and the Australian health care system has for many years made provision for specialist nurses in disease modalities including breast care and other forms of chronic illness [4] [5] [6] [7]. In May 2012, recognising the potential role for a specialist nurse in prostate cancer, PCFA launched its Prostate Cancer Specialist Nursing service with the generous financial support from The Movember Foundation and other community organisations.

The pilot involved PCFA working in partnership with health care providers across Australia to recruit, train and support 12 Prostate Cancer Specialist Nurses in various locations in metropolitan and regional Australia. Locations were selected by a competitive application process. The pilot trialled a best practice model for providing specialist nursing care to those affected by prostate cancer with a view to creating a sustainable model as part of routine cancer care delivery [8]. In 2014 the service was expanded by a further 14 nurses through \$6.9 million of Federal Government funding provided through the Department of Health. Locations were again selected by competitive application process. Additional community funding has enabled PCFA to support nurses in other locations so that, as of February 2017, there are 28 Prostate Cancer Specialist Nurses across Australia.

In December 2016, the Minister for Health gave policy approval to renew the current Department of Health funding. This funding has secured the future of the service over the next three years.

4. Evaluation of the Pilot

PCFA commissioned an independent team from QUT ihbi led by Professor Patsy Yates to undertake evaluation of the pilot. Data was collected from multiple sources which included

- Descriptive analysis of survey data of men and carers who received the services of nurses during the evaluation period
- Comparison of survey and interview data from the 12 Prostate Cancer Specialist Nurses at the beginning, middle and end of the evaluation period
- Comparison of nurses' monthly activity reports over the evaluation period
- Comparison of nurse manager survey and interview data at the middle and end of the evaluation period
- Comparison of clinician survey data at the middle and end of the evaluation period.

Key findings from the patient and carer surveys include

- The majority of men (76%-90%) either "agreed" or "strongly agreed" that the nurses provided information and general care to them

- More than 90% of men either “agreed” or “strongly agreed” that they could contact the nurse when needed and that the nurse provided helpful answers to questions about their cancer and treatment
- 78% of men were “very satisfied”, 7% “moderately satisfied” and 13% “satisfied” with the level of support provided by the nurse
- The majority of carers either “agreed” or “strongly agreed” that the nurses provided information (85%-92%) and general care (78%-86%) to them
- 90% of carers either “agreed” or “strongly agreed” that they could contact the nurse when needed and that the nurse provided helpful answers to questions about their family member/ friend’s cancer and treatment
- 82% of carers were “very satisfied”, 4% “moderately satisfied” and 11% “satisfied” with the level of support provided by the nurse.

Key findings from nurse surveys and activity reports include

- By the end point, all nurses were participating in multidisciplinary team meetings and 11 out of the 12 had documented referral criteria
- The proportion of referrals from other nurses increased significantly from the beginning to mid-point of the evaluation
- The most frequently delivered interventions were psychosocial assessments and support for men (75%), followed by provision of information (68%), communication with treating teams (57%) and care coordination (56%)
- At the mid- and end-point, the nurses reported having a competent to expert level of expertise in nearly all of the key performance criteria relating to clinical care
- At the mid- and end-point, all nurses reported having a competent to expert level of expertise for all key performance criteria in collaborative and therapeutic practice
- Nurses reported improved competency levels in all professional practice performance criteria over the evaluation. At the end-point, more than 80% reported having a proficient to expert level of expertise in all criteria in this domain.
- Nearly all nurses reported that they were very satisfied or satisfied with their role in assisting patients as a Prostate Cancer Specialist Nurse.

Key findings from manager surveys include

- At the end of evaluation, all managers rated the nurses’ competencies at a competent to expert level in all criteria
- Managers reported Prostate Cancer Specialist Nurses’ competent delivery of a specialist level of care which is not replicated elsewhere in the delivery of medical services for men affected by prostate cancer, through development of patient management plans, development and delivery of patient education sessions, completing comprehensive patient assessments, and case management of post treatment issues related to the care of the prostate cancer patient and their carer. In particular, managers’ comments focused on

their abilities to address specialised and difficult topics such as sexual dysfunction and incontinence in a sensitive manner.

- Managers also reported positively about the structure of the program and how this enabled the delivery of the service at the local level.

Key findings from clinician surveys include

- Clinicians rated that the Prostate Cancer Specialist Nurse's role had significantly more influence on men's outcomes at the end of evaluation than at the beginning in areas including acceptance of appropriate treatment, reduction of duplication of service provision, and reduction of variation in evidence based care
- The proportion of clinicians who reported that the nurses performed the following tasks increased over the evaluation period: providing information and advice on PSA testing ($p = 0.02$), helping men to make decisions about their treatments ($p = 0.03$), providing continence ($p < 0.01$) and sexual function assessment and/or advice ($p < 0.01$).

On the basis of evaluation data, we draw the following conclusions

- Men with prostate cancer have a diverse range of needs, highlighting the need for the Prostate Cancer Specialist Nurse role, especially in areas of psychosocial care and in addressing disease-specific and treatment-related concerns
- Men and their carers perceived that Prostate Cancer Specialist Nurses played an important role in supporting their experience, and that the timing and methods of contact with the nurses were appropriate
- Prostate Cancer Specialist Nurses became well integrated into the multidisciplinary team
- Prostate Cancer Specialist Nurses have broad role functions across various clinical and strategic activities. As the nurses developed their practice, their involvement in more strategic activities increased.
- The Prostate Cancer Specialist Nursing service pilot reached men across all stages of their cancer journey, and over time, Prostate Cancer Specialist Nurses were more likely to reach men earlier in their cancer journey
- Differences between rural and metropolitan settings indicate that access issues can be addressed by using flexible approaches to service delivery
- Prostate Cancer Specialist Nurses play an important and significant role in achieving broader system level and local service improvements
- The broad range of competencies required of the Prostate Cancer Specialist Nurse reflects the advanced and specialised role of these practitioners. The identified priority professional development areas reflect a need to maintain a skill set in activities relating to core clinical and supportive care functions of the role.

Factors which supported the implementation of the program included leadership, guidance, frameworks, tools and resources provided by PCFA. These are likely to be critical factors influencing the success of the service going forward.

5. Senior Constable Steve Lindsay's Story

Whilst the formal evaluation demonstrates the high value of the Prostate Cancer Specialist Nursing service, the testimony of men like Senior Constable Steve Lindsay brings home the critical importance of the service to men and their families

"In all my 28 years of policing, 17 years as a solo officer, police dog handler, I have never run from a fight. Yet it only took 4 small words to bring me to my knees... "you have prostate cancer"....I just wanted to run.

I'm not embarrassed to admit I was scared to even read the documentation the doctor gave me. Weeks went by and I couldn't read the information...it terrified me just seeing the word "cancer".

My family are very close, we look out for each other. My mum was so supportive, she had been through it before with my dad. My daughter even quit her job to be with me. It was wonderful to have them all rally around me but I was still terrified.

I was just 24 when my dad passed away with prostate cancer. My own kids were just a bit younger when I was diagnosed. I didn't want them to go through what I went through, losing my dad so young. I was also worried about my son's future, given the family history.

I remember waiting for all my family to leave the house. I dialled the number and got Chris (Chris McNamara, Prostate Cancer Specialist Nurse). I spoke to Chris for over an hour and he explained everything and immediately put all my fears to rest, I wish I had rung him weeks earlier.

There are 2 days that I will never forget on my cancer journey - the day I received my prostate cancer diagnosis and the day I met my Prostate Cancer Specialist Nurse Chris. Chris does a brilliant job. His credibility in my eyes was unshakeable. It was really good to have him in my corner."

6. Funding Requested

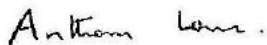
Based on incidence and estimated prevalence of prostate cancer and case load from the pilot, we estimate there is a current need for some 110 Prostate Cancer Specialist Nurses nationally. This means that with just 28 Prostate Cancer Specialist Nurses for all of Australia, only 1 out of 4 men diagnosed currently has access to life-changing expert nursing support. We therefore seek additional funding of \$5.9 million over three years to expand the service by another 14 nurses (approximately \$140,000 per nurse per year including professional development, tools and resources). This would take the total number of nurses across Australia to 42, still less than half the estimated need.

Priority areas of need include

- Tasmania (part time to full time)
- Hunter/ New England
- Wollongong
- Adelaide
- Latrobe Valley
- Western Sydney
- Gosford
- Albury Wodonga
- Dubbo
- Bairnsdale.

We trust that this submission meets with Australian Government approval. We would be happy at any time to provide additional material and would be pleased to meet to discuss or amplify any aspect of this submission where further clarity may be helpful.

Yours sincerely



Associate Professor Anthony Lowe
Chief Executive Officer#

7. References

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- [4] Yates, P. (2008) Cancer Care Coordinators: realising the potential for improving the patient journey. Cancer Forum, Vol. 28, pp. 128 - 132.
- [5] Eley, & Rogers - Clark, C. (2012). Consumer perceptions of a breast care nurse in providing coordinated care to women with breast cancer in Queensland Australia. 3, s.l.: Australian Journal of Advanced Nursing, Vol. 12.
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- [8] Sykes, J. (2013). Practice Framework and Competency Standards for the Prostate Cancer Specialist Nurse. Sydney : Prostate Cancer Foundation of Australia.