

Prostate Cancer Foundation of Australia (PCFA) Submission to the Senate Select Committee on Men's Health February 2009

The Prostate Cancer Foundation of Australia (PCFA) is pleased to make a submission to this inquiry, as we are one of a very small number of organisations devoted to work in the prostate cancer area. PCFA appreciates the commitment of the Government to addressing the serious gaps in Men's Health in Australia, in particular the development of a National Men's Health Policy and we look forward to making a further contribution to the inquiry through the public hearing process. This submission aims to:

- Describe the varied nature of prostate cancer
- Highlight the impact of prostate cancer in Australia
- Demonstrate the need for more urgent research and clinical developments
- Present the key consumer recommendations from the inaugural 2008 National Prostate Cancer Conference *Supporting Quality of Life*
- Make recommendations to improve the overall management of prostate cancer in Australia

Prostate Cancer in Australia

Research into prostate cancer has found that:

- Prostate cancer is the most common cancer in Australian men, excluding the non-melanoma skin cancers
- In 2005 more than 2,900 Australian men tragically died from prostate cancer
- In 2006 it is estimated that 18,700 new cases of prostate cancer were diagnosed

(Australian Institute of Health and Welfare and the Australian Association of Cancer Registries, 2007)

Research into breast cancer has found that:

- 2,640 woman die each year from breast cancer
- More than 13,000 new cases were expected in 2006

(Australian Institute of Health and Welfare and National Breast Cancer Centre, 2006)

The Australian community is not aware that the number of men diagnosed with prostate cancer, is much higher than the number of women diagnosed with breast cancer.

The Australian community is also not aware that PCFA receives no core funding from the Australian, State or Territory Governments, as the peak prostate cancer organisation in Australia.

A study into Urban–rural differences in prostate cancer found that:

- Regional and rural Australian men have a 21% higher mortality from prostate cancer than men in capital cities
- Australian men of socio-economic disadvantage have a 21% higher mortality

(Coory & Baade, 2005)

The Australian community is generally not aware of the increased risk of death from prostate cancer in rural and regional Australia and in men of socio-economic disadvantage

Prostate Cancer Foundation of Australia

The Prostate Cancer Foundation of Australia (PCFA) is the peak national body for prostate cancer in Australia. PCFA is dedicated to reducing the impact of prostate cancer on Australian men and their families by:

- Funding research into the cause, diagnosis, treatment and prevention of prostate cancer
- Raising awareness about prostate cancer
- Providing support, information and advocating in partnership with men and families impacted by prostate cancer

PCFA receives limited funding from government and relies on the generosity of corporate partners, individuals and the community for our essential work. In total PCFA has had three projects funded by government since the organisation began in 1996.

Awareness, Information and Support

There are currently 81 Prostate Cancer Support Groups affiliated with PCFA across every state and territory of Australia. There are more than 7000 members of this national network of Prostate Cancer Support Groups. Currently 8 new Prostate Cancer Support Groups are being established with more on a waiting list. Members of the Support Groups create awareness in their local area and beyond, distribute information on prostate cancer and offer peer support to men at all stages of their disease. Men and their partners are welcome at all of the groups.

In addition to these groups, PCFA convened the inaugural National Prostate Cancer Conference, ‘Supporting Quality of Life’ in 2008, which concentrated on involving men with prostate cancer and their partners in developing a formal declaration to be delivered to the Australian Government. More detail about the conference and the declaration is on Page 5.

National PCFA Men's Health Promotion Forums 2007/2008

Melbourne, Perth, Sydney, Adelaide, Hobart, Canberra, Newcastle

- In community partnership with men's health organisations and funded by the corporate sector, PCFA has initiated Men's Health Promotion Forums nationally in every state and territory except the Northern Territory, with more than 2000 members of the general public attending.
- Experts in prostate health, depression, continence health, bowel health, erectile health, cardiovascular health, the prevention of Type 2 diabetes, exercise and nutrition have presented to audiences of between 200 and 350 people. Where possible international presenters in Australia have also participated.
- The PCFA Men's Health Promotion Forums focus on health promotion and prevention of chronic illness.
- Multiple aspects of men's health promotion are presented which has been appraised positively by attendees. Appraisal Reports are available on all PCFA Men's Health Promotion Forums if required.
- Many men and their partners have self selected into a Support Group after attending a PCFA Men's Health Promotion Forum.

PCFA National Rural Road Shows 2006/2007

VIC, SA, NSW, WA, NT, QLD, ACT, TAS*

- PCFA initiated and event managed PCFA Rural Road Shows funded by a major corporate sponsor. Total national rural attendance >2000
- A guest Urologist attended each road show and presented on Prostatitis, Benign Prostatic Hyperplasia and Prostate Cancer
- A local man with prostate cancer shared his journey with the audience and discussed how important attending a local Support Group was for him
- Men and women attended the evenings
- Questions from the floor were robust and many
- A light supper was always served
- Rural Road Shows were held in the evening so that working men could attend

*In Tasmania, a national magazine and corporate partner also supported a Rural Road Show to raise awareness of prostate cancer in partnership with PCFA. These sessions were held during the day

Australian Government Funded Projects

Current Australian Government Funded PCFA Projects 2008 (2):

- **The 2008-2010 National Men's Health Ambassador Speaker Program**
This program is funded by the Australian Government Department of Health and Ageing as part of the National Men's Continence Awareness Project under the National Continence Management Strategy. PCFA is recruiting 100 National Men's Health Ambassador Speakers presenting on prostate health and continence health and distributing *National Men's Health Links* to all audience members in every state and territory. The National Men's Health Ambassador Speaker Program is targeting 50,000 people by June 2010

- **The 2008-2010 Let's Go Men's Health Program.**
This program is funded by the Australian Government Healthy Active Australian Community and Schools Grant Program. Purpose: To encourage and provide a mechanism for men with a chronic illness to participate in physical exercise. Background: Extensive research clearly demonstrates that exercise improves physical and mental health of men with chronic illnesses. Exercise is also a strong preventative strategy, greatly reducing the risk of developing further chronic disease. However, older men, especially in rural and remote areas find it difficult to initiate and maintain an exercise program. Activities: In partnership with researchers and exercise physiologists PCFA will develop a well planned, accessible, measurable exercise program which appeals to inactive men with a chronic illness, delivered and monitored using Internet technologies. The program will involve aerobic and resistance training individually and in small groups with emphasis on developing communities. Expected outcomes: A sustainable, user-pays program developed in consultation with men for men, in both rural and remote areas of Australia, where such an opportunity currently does not exist

Previous Australian Government Funded PCFA Projects (1)

- **Building and Strengthening Cancer Care**
This grant from the Department of Health and Ageing was used to establish the Queensland Chapter Prostate Cancer Support Group Network 2006-2008. This outstanding model is now being replicated by Prostate Cancer Support Groups in every State and Territory.

The Inaugural 2008 National Prostate Cancer Conference

PCFA held the Inaugural National Prostate Cancer Conference, *Supporting Quality of Life* for men with prostate cancer and their partners, carers and family members in November 2008. More than 500 people attended including men with a diagnosis of prostate cancer from every state and territory, health professionals, medical professionals and research scientists from as far away as Canada and the USA. Consumer consultants were an important driver of this conference and identified and articulated the need to hold such a forum for discussion, peer support and communication with the Australian Government.

At the close of the conference, PCFA Support Group members acclaimed PCFA's mission to reduce the impact of prostate cancer on the Australian community and thanked them for bringing men and their partners to the inaugural National Prostate Cancer Conference. They also presented the PCFA Board and Management with a declaration on patient-centred involvement in policies and research, which they requested PCFA take to the Australian Government. The declaration includes:

- Include translational research, clinical trials and psychosocial research within the scope of PCFA-funded research
- Investigate avenues for improving the quality of life of those with advanced or metastatic disease
- Provide professional submissions to government enquiries and review and planning processes
- Advocate for the establishment of a prostate cancer desk within government administration
- Increase opportunities for consumer participation on internal committees and within external forums
- Embrace the notion of a consumer audit on all programs and publications where consumer consultants have been actively involved
- Support training and development programs for support group members to discharge consumer representation roles with credibility
- Publicise the support group role, services and capacity to complement professional medical advice along the cancer care pathway
- Collaborate with kindred organisations that address complementary aspects of men's health
- Make greater use of technology for the provision of information and resources to the public

The conference proved that there is much to be gained in the overall management of prostate cancer by providing opportunities for active engagement of the consumer and carer base. This can include elements such as information, peer support, self management, prevention of chronic illness and well being frameworks, as well as contributions to policy development and research.

The Australian and state governments have an opportunity to promote their respective policy positions by supporting and participating in this conference and funding a range of State-based Support Group networks. This will extend the reach of men's health promotion messages and unmet needs in relation to prevention of chronic illness. The PCFA National Conference is planned to become an international consumer conference and scientific conference by 2011. The next PCFA National Prostate Cancer Conference will take place in International Men's Health Week on the Gold Coast in June 2010.

Information and support and the development of a National Information Pack for men diagnosed with prostate cancer

Research has indicated that men with prostate cancer, and their families, face unique challenges and that information and support in coping with these challenges is far from sufficient in the Australian healthcare system.

One large population based Australian study of 1,067 men diagnosed with prostate cancer between 2000-2001 in NSW surveyed patients between 3 and 12 months after diagnosis (Smith et al., 2007). This study found that 74% of men reported some form of unmet need in relation to their prostate cancer diagnosis. Fifty-four percent of men reporting to their health and the rate rose to 74% in men under the age of 50 years. Men reported a range of areas of unmet support needs. The most commonly reported area of unmet support need was in the psychological support domain where 54% of men expressed that they felt some level of unmet psychological support need (Smith et al., 2007). Sexuality was reported by 47% of men as an area where they had some level of need for assistance or support and more than 20% of men reported a moderate to high need for the “uncertainty for the future” domain.

The authors of this study strongly recommended improved access to the spectrum of supportive care services for prostate cancer patients, including nursing specialists, psychological counselling, peer support groups and consumer information (Smith et al., 2007).

Inadequate patient and spouse knowledge has also been implicated in poor prostate cancer outcomes and increased distress experienced by the patient and spouse. A recent study found that inadequacies in patient and spouse knowledge and awareness of prostate cancer contributed to delayed contact, shock at diagnosis, preferences regarding decision making, health judgements and patient coping (Docherty, Brothwell, Symons, 2007). This study highlighted the common misunderstandings and misinformation about prostate cancer in the wider community. The findings of this study indicated an apparent lack of awareness of treatment options or side-effects and a reliance on general practitioner (GP) assistance, highlighting the need for consistent information and support provision (Docherty et al., 2007).

Currently the information and support provided to men with prostate cancer and their partners lags significantly behind the resources provided to women with breast cancer. The prostate cancer field has a long way to go in support provision. The first step in sufficiently supporting prostate cancer patients is the provision of relevant information resources in a consistent manner. Nationally, men often face the challenges of prostate cancer without sufficient information and men in rural or regional areas are even more disadvantaged. A national approach to the dissemination of information needs to be considered so as to minimise the impact of this disease on quality of life and to equalise equity issues in access to information and support between metropolitan and rural populations.

A national initiative to address the information needs of men with prostate cancer should be considered so as to inform, support, empower and engender hope in this population of Australian men. This type of national initiative could not only educate and support men and

their families, but also facilitate a change in attitude in the general population away from prostate cancer being considered to be an “old mans disease” and the stigma attached to this, particularly for young men faced with this disease.

The Prostate Cancer Foundation of Australia is currently piloting a national information and support initiative across 18 Australian hospitals. This initiative has involved the development of information and resource pack that we hope can be distributed to each man diagnosed with prostate cancer each year in every state and territory Australia wide. The feedback received thus far has been overwhelmingly positive. However, in order for this initiative to be sustained into the future, funding must be sought to support it.

Prostate Cancer Research

For the scale and health impact of prostate cancer and associated disorders in Australia, the research effort into treatments and patient support is minimal. Prostate cancer is under researched in comparison to its importance in the community, and specifically in relation to breast cancer, which has a similar mortality and lower incidence.

There is currently a disparity in National Health and Medical Research Council (NHMRC) funding and publications between breast cancer and prostate cancer. PCFA research committee (see appendix 1) focus on increasing the number of talented prostate cancer scientists (both young investigators and senior investigators) in Australia who, once in the field, will attract government funding and generate the publications and discoveries that will redress the balance.

PCFA Research Grant Categories include:

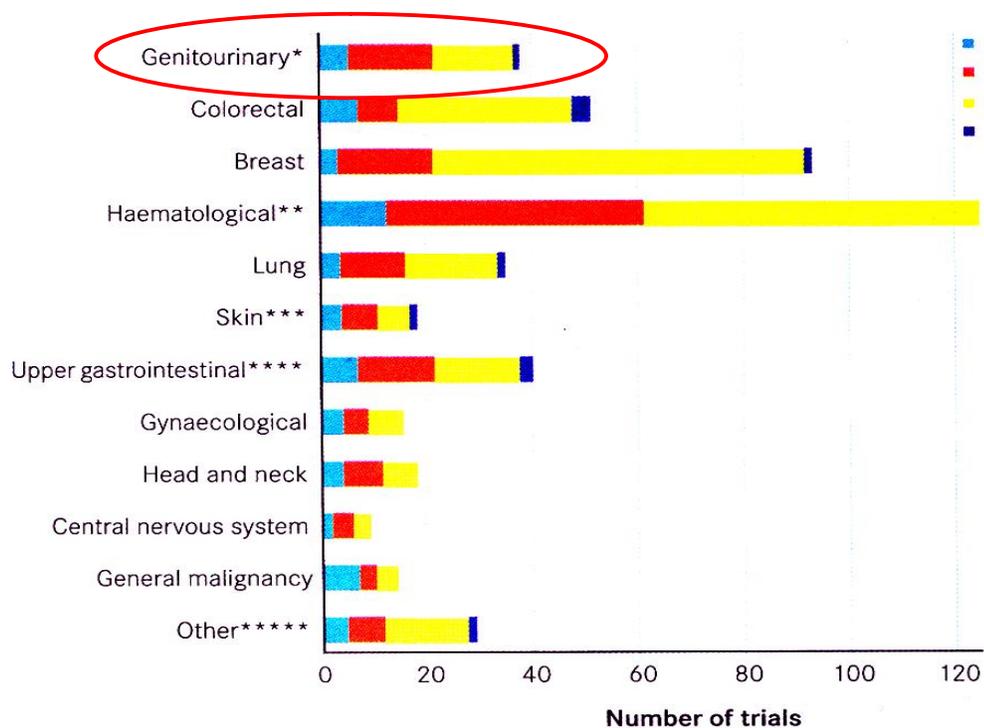
- Young Investigators
- Concept Grants
- Project Grants
- Equipment Grants

The under-funding, and hence the under-investigation of prostate cancer is illustrated by two data sets. The first is clinical trial data from Victoria in 2005, showing that there were far fewer clinical trials for all genitourinary cancers (of which prostate cancer is only a part) than there were for breast or colorectal cancer (Figure 1).

Secondly, the global underfunding of prostate cancer is shown by the relative paucity of publications relating to the disease, in comparison to breast cancer (Figures 2 and 3). Looking at all scientific publications indexed by the US National Library of Medicine in the "Entrez PubMed" database, there were nearly three times as many publications overall for breast cancer than there were for prostate cancer. And if one's PubMed search focused on publications generally reporting ground-breaking research, for example *Science* magazine, the disparity is more like 7-fold.

PCFA is profoundly concerned about this disparity in research, because in contrast to many cancers, including breast cancer, good non-invasive or minimally-invasive tests for prostate cancer are needed. Prostate cancer lacks good markers that will differentiate between "bad" and "good" prostate cancers, and there aren't the kinds of chemotherapy that have cured many other types of cancers, including breast cancer.

Prostate Cancer is Under-Researched



*Includes prostate, bladder, kidney & testis.

Cancer trials in VIC, 2005

Figure 1

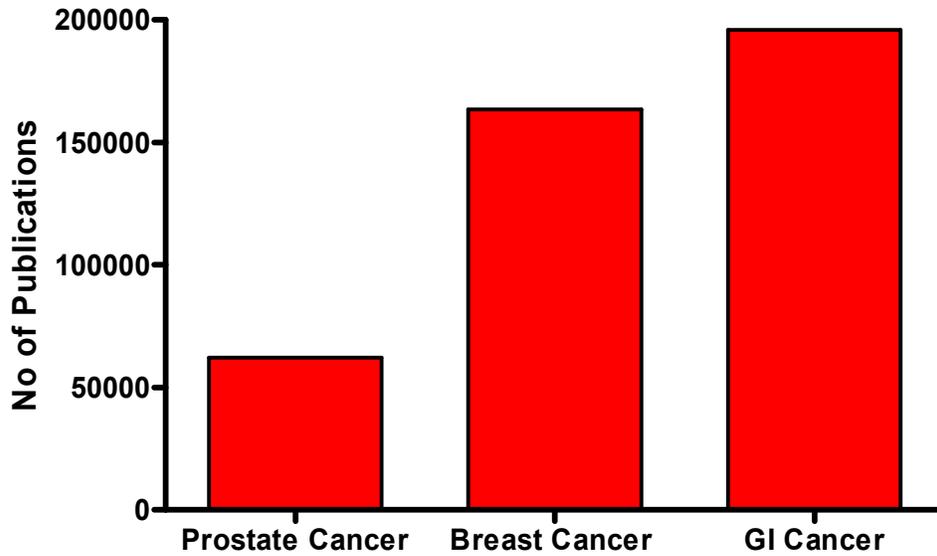


Figure 2

(US National Library of Medicine Entrez PubMed database)

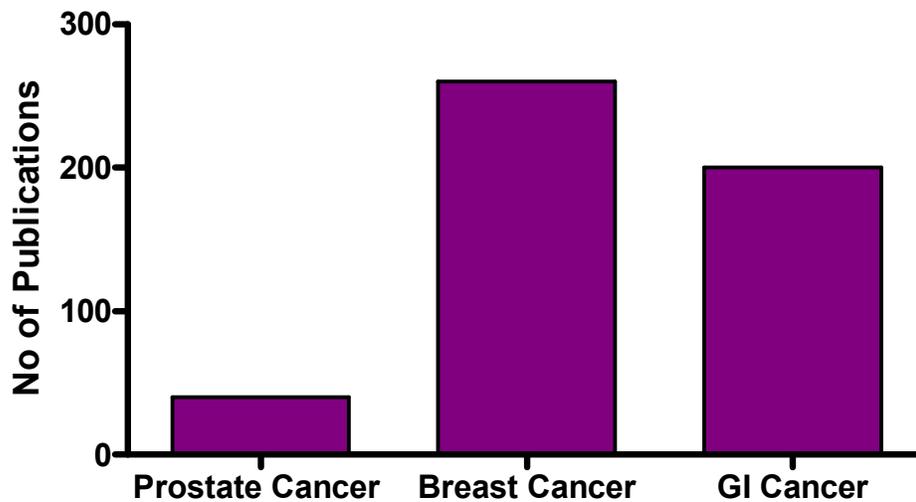


Figure 3

(Science; the Journal of the American Association for the Advancement of Science)

The disparity in research funding is also evident from NHMRC data, which show that there is a significant gap in funding between breast and prostate cancer, in dollar terms as well as in the numbers of projects funded. These relativities have not changed significantly over most of the past decade.

NH&MRC Breast and Prostate Cancer Research Funding

(by dollars allocated or number of grants funded)

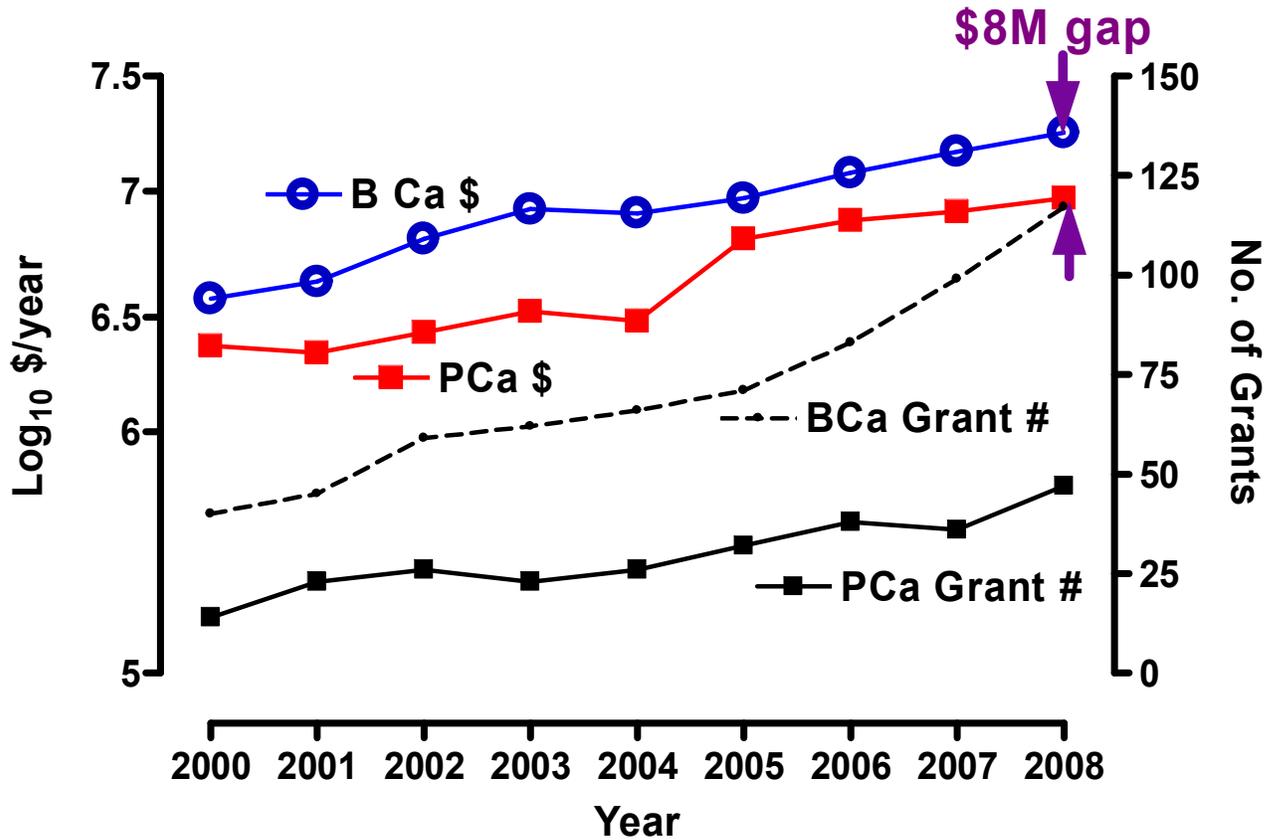


Figure 4

The National Men's Health Alliance

In January 2008 Prostate Cancer Foundation of Australia initiated a meeting with other national men's health organisations to discuss the viability of officially developing a collaborative community partnership in the interest of:

- Inclusion and accessible men's health promotion across Australia.
- Developing a multi-organisational approach to work with State, Territory and Federal Governments
- To identify the core business of each of the national organisations and discuss the complimentary nature of their work
- To work collectively towards promoting the strengths of each organisation and reducing replication of products and programs

By November 2008, the following national men's health organisations have agreed to form the National Men's Health Alliance:

- Andrology Australia
- *beyondblue: the national depression initiative*
- Continenace Foundation of Australia
- Crisis Support Services
- Foundation 49
- The Pharmacy Guild
- Prostate Cancer Foundation of Australia

Recommendations:

1. The Australian Government consider supporting PCFA in partnership to achieve the items requested in the National Network of Prostate Cancer Support Groups declaration made at the inaugural National Prostate Cancer Conference *Supporting Quality of Life* November 2008:

- Include translational research, clinical trials and psychosocial research within the scope of PCFA funded, Australian Government funded, State and Territory funded prostate cancer research
- Investigate avenues for improving the quality of life of those with advanced or metastatic disease
- Provide professional submissions to government enquiries, reviews and planning processes
- Advocate for the establishment of a prostate cancer desk within government administration
- Increase opportunities for consumer participation on internal committees and within external forums
- Embrace the notion of a consumer audit on all programs and publications where consumer consultants have been actively involved
- Support training and development programs for Support Group members to discharge consumer representation roles with credibility
- Publicise the Support Group role, services and capacity to complement professional medical advice along the cancer care pathway
- Collaborate with kindred organisations that address complementary aspects of men's health
- Make greater use of technology for the provision of information and resources to the public

2. The establishment of a jointly funded Prostate Cancer Research Program

The PCFA has identified a need to establish a strategic research program to be jointly funded by State, Territory and the Australian Government with PCFA, to govern prostate cancer research in Australia. Research priorities needing to be addressed through such a program include:

- The health inequity of regional, rural and remote Australian men and their partners/carers
- The health inequity of Australian men of socio-economic disadvantage and their partners/carers
- The health inequity of Australian men from Culturally and Linguistically Diverse (CALD) backgrounds and their partners/carers
- The health inequity of Indigenous and Torres Strait Islander men and their partners/carers
- The health inequality of men of all abilities and their partners/carers
- The health inequality of gay men and their partners/carers
- The health inequality of men who are socially isolated
- The health inequality of all Australian men and their partners/carers

3. National Prostate Cancer Support Services

There is a clear need to fund a range of support services for people living with prostate cancer and their carers. This includes:

- The development of a peer support model of Prostate Cancer Support Groups in regional and rural Australia
- To establish evening support groups in metropolitan, regional and rural areas
- To establish formal teleconferencing and on line support groups to link together men with advanced prostate cancer who request peer support
- To establish formal teleconferencing and on line support groups for young men under 50 and under 40 with prostate cancer who request peer support
- The development of carer support services for partners and family members caring for men with advanced prostate cancer. Awareness of the current support for carers, including respite care, is not well known by partners and family members of men with prostate cancer

4. Government funded National Rural Men's Health Promotion Road Shows

To complement existing Australian Government Initiatives in men's health (including the National Men's Health Ambassador Speaker Program), a dedicated road show program covering prostate health and male sexual reproductive health and the major men's health issues in urban and regional areas, would be beneficial. Issues covered would include:

- Heart Health
- Suicide Prevention and emotional and mental health
- Lung Health
- Road Safety
- Bowel Health
- Sexual Reproductive Health including Prostate Health, Testicular Health, Continence Health, Erectile Health and Awareness of Sexually Transmitted Infections
- Exercise and nutrition to reduce obesity and assist with prevention of Type 2 Diabetes

Such a program would greatly assist in achieving positive change in health self management by men by creating awareness. They should have a health promotion focus and prevention of chronic illness approach, and in particular prevention of multiple chronic medical conditions in ageing Australian men.

5. National Men's Health Promotion Forums

The inclusion of targeted forums as a permanent feature of the community health system in Australia would build on interest created by the Road Shows and PCFA National Men's Health Promotion Forums and promote men's health interests in the sector. These would need to be established in metropolitan, regional and rural Australia designed with consumer consultation, resourcing and referral as core functions.

6. Men's Health organisations working together

The Australian Government to encourage men's health organisations to work together in partnership.

The Australian Government to fund the secretariat, management and delivery of programs initiated by collaborative men's health partnerships. A result of this would be a diverse range of organisations and Australian men benefiting from these partnerships.

7. Prostate Cancer Nurses in Regional and Rural Australia

With reference to a press release from the Minister for Health The Hon Nicola Roxon MP, on 9 September 2008 announcing \$43 million to support women with breast cancer by delivering new breast cancer nurses to rural and regional areas and providing a subsidy for breast prosthesis through Medicare. Please see appendix 2. No one questions the value of this support for regional and rural women with breast cancer; it was a most popular announcement.

PCFA makes the recommendation for consideration that large cancer specific or gender specific cancer grants, be considered across gender. For example if newly trained breast cancer nurses could also be trained prostate cancer nurses, the regional and rural communities and individuals may be better served.

8. Prostate Cancer Foundation of Australia

The Australian Government to initiate core funding to PCFA as the peak national organisation for prostate cancer supporting men with prostate cancer and their families, creating awareness and funding and encouraging high quality prostate cancer research. PCFA has invested approximately \$11 million dollars into Prostate Cancer Research in Australia in 2007 and 2008. The 2009 Prostate Cancer Research Grants open in May 2009.

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US National Library of Medicine Entrez PubMed database

Appendix I

PCFA National Research Committee

National PCFA Research Committee Chair:

Professor John Mills: Professor of Medicine, Microbiology and Epidemiology, Faculty of Health Sciences, Monash University; Adjunct Professor of Medicine, University of California, San Francisco; Consulting Physician, the Alfred Hospital, Melbourne.

PCFA Research Committee Members:

Professor Chris Sweeney: Medical Oncologist and Director of Clinical Trials at the Royal Adelaide Hospital Cancer Centre

Professor Frank Gardiner: Reader in Urology University of Queensland;
Conjoint Professor at the Queensland University of Technology

Clinical Associate Professor Howard Gurney: Western Clinical School, Westmead Hospital, the University of Sydney

Associate Professor Sue Henshall: Senior Research Fellow, Cancer Research Program, Garvan Institute of Medical Research; Associate Professor, Faculty of Medicine, University of NSW

Professor Robert Newton: Foundation Professor Exercise and Sports Science, Edith Cowan University, WA

Appendix 2

Rudd Government Improves Help for Women with Breast Cancer

The Rudd Government is investing \$43 million to support women with breast cancer – delivering new breast cancer nurses to rural and regional areas and providing a subsidy of up to \$400 for breast prostheses through Medicare Australia.

To view the full media release, click on the link below:

<http://www.health.gov.au/internet/ministers/publishing.nsf/Content/mr-yr08-nr-nr119.htm>